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**Out of the Darkness:  
A History of Huntington's Disease in Australia**

by

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of  
Philosophy

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I declare that the research presented here is my own original work and has not been submitted to any other institution for the award of a degree.

Signed: Th. A. H.

Date: 14-8-15

## **Abstract**

Huntington's disease (HD) is a genetic neurological condition which has a profound influence on the families it affects. The symptoms of the disease are challenging – in addition, social forces strongly influence the way the disease is experienced. It has been a deeply stigmatised condition, and its presence was often kept secret. In this dissertation, I have explored both social and medical aspects of the history of HD, primarily in Australia, building on the work of two scholars, Peter Harper (UK) and Alice Wexler (US). By tracing the histories of HD families, I discovered that HD has been part of the fabric of life in Australia since the convict era, and that some families with the disease were well-respected in their communities, in contrast to narratives which have presented the stigma as inevitable. Wexler has previously shown that in the US, the degree of stigma faced by HD families has varied over time, and my research found this to be also true of the disease in Australia. The earliest descriptions of the disease in the US were mostly made by physicians familiar with HD families. My research revealed a similar story - two physicians who published on HD both grew up in an area of Tasmania with relatively high rates of the disease. The impact of eugenic thinking in the stigmatization of HD in the US, Germany and the UK was noted more than 20 years ago, though its impact in other countries has remained unexplored. Eugenics as a formal movement was not successful in Australia, however eugenic ideas formed part of the social discourse. I show through medical journal articles, items in the popular press and educational organisations how those with hereditary diseases were labeled as “unfit”, promoting stigma which contributed to HD being hidden. Finally I describe how the disease began to emerge from “the closet” in the early 1970s, with families and researchers forging a new collaboration to search for treatments, support families and reduce stigma.

## Acknowledgments

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## Chapter 1 Introduction

*Huntington's Disease has ... made a profound contribution in our perception of how patients with a serious brain disorder interact with society more generally.*<sup>1</sup> Peter Harper, 2014.

Huntington's Disease (HD) has a deep and lasting effect on the families it touches – it is a genetic condition that generally comes on in middle age, changing the way the affected person moves, talks, thinks, feels and behaves. It is a fatal, though slowly progressive disease. Several thousand Australians are either at risk of developing it or already have symptoms of the disease. The primary features were described by a young American physician, George Huntington (1850-1916), in 1872. This and other aspects of the origins and history of the disease have been studied in some detail, especially regarding the unfolding of the HD story in the US. Other aspects have been less well explored - while its biological features remain much as Huntington described almost 150 years ago, the experience of the families living with this disease has varied enormously. In this dissertation, I will chart how living with this challenging disease has changed over the past two centuries, exploring both medical and social aspects of its history, with the primary emphasis on the unfolding of the HD story in Australia.

### 1.1 Primary features of Huntington's disease

Today, HD is understood as a genetic disorder with neurological, psychiatric and cognitive symptoms, which also involves personality and behavioural changes. The mutation in the gene on Chromosome 4 causing this disease was discovered in 1993 by a multidisciplinary

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<sup>1</sup> Peter Harper, "Huntington's Disease in a Historical Context," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New, York:Oxford University Press, 2014), 3-24.

team of researchers,<sup>2</sup> one of whom is at risk of developing the disease.<sup>3</sup> The disease occurs when there is an expansion of a protein sequence, CAG (cytosine, adenine and guanine). Each child of a person who carries the abnormal, expanded HD gene is at 50/50 risk of inheriting it – a pattern of transmission known as autosomal dominance. If a person carries the expanded gene, they will develop the disease (unless they die earlier of other causes), a phenomenon known as full penetrance. After a period of normal development, the symptoms come on gradually, most commonly appearing between the ages of 30 and 50, though with onsets ranging from two to 80.<sup>4</sup> Males and females are equally affected. The disease is fatal, usually 15-20 years after the first onset of symptoms.<sup>5</sup> There is a juvenile version of the disease, defined as an onset younger than 20.<sup>6</sup> At the other end of the spectrum many do not develop symptoms until their 60s, and there have even been cases with onset in the 80s - the disease usually has a more benign course with a later onset.<sup>7</sup> Currently, there is no treatment which will alter the progression of the disease, although some symptoms can be alleviated. There is an extensive, co-ordinated international effort working towards treatments for the disease, with study sites in many countries testing potential medications and other forms of treatment.

The symptoms are both physical and mental. The physical symptoms begin with fidgety, uncontrolled movements called chorea. Although chorea, coming from the Greek word to

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<sup>2</sup> Huntington's Disease Collaborative Research Group, "A Novel Gene Containing a Trinucleotide Repeat That Is Expanded and Unstable on Huntington's Disease Chromosomes," *Cell* 72, no. 6 (1993): 971-83.

<sup>3</sup> Adele Glimm, *Gene Hunter: The Story of Neuropsychologist Nancy Wexler, Women's Adventures in Science* (New York: Franklin Watts, 2005).

<sup>4</sup> R. M. Bonelli and M. F. Beal, "Huntington's Disease," in *Handbook of Clinical Neurology*, ed. T. E. Schlaepfer and C. B. Nemeroff, (Amsterdam: Elsevier, 2012), 507-26.

<sup>5</sup> Ibid.

<sup>6</sup> Oliver Quarrell, "Juvenile Huntington's " in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 66-85.

<sup>7</sup> R. H. Myers, "Huntington's Disease Genetics," *NeuroRx: The Journal of the American Society for Experimental Neurotherapeutics* 1 (2004): 255-62.

dance, is the main motor symptom, there are other movement disorders present including hypokinesia (slowing and decrease in movements), dystonia (where unusual postures are adopted) and tics.<sup>8</sup> In the early stages the movements can seem like clumsiness and be partially disguised as intentional, but they gradually become more pronounced and uncontrollable. Purposeful movements become more difficult. Walking is affected, with people losing normal bodily rhythms, which has been interpreted as the person being drunk by people unfamiliar with the disease. The whole body is involved, with involuntary movements of the arms, legs, head and the face. Chorea later gives way to rigidity, and eventually the person becomes unable to control any movements and is confined to bed. Speech is often affected, mostly with dysarthria (slurring of speech) and difficulties with swallowing also emerge.<sup>9</sup>

The mental symptoms involve changes in cognition, mood and personality, and sometimes psychiatric features such as psychosis are present.<sup>10</sup> The cognitive changes are subtle at first, involving difficulties with concentration and memory, and in the later stages sometimes develop into a more severe dementia. Recent research has found the onset of cognitive impairments may be some years before a definite diagnosis is made.<sup>11</sup> Personality and behavioural changes include lessened self-control, diminished judgment and reasoning, less empathy and interest in others and apathy and a lack of motivation.<sup>12</sup> Mood disorders are

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<sup>8</sup> Raymond Roos, "Clinical Neurology," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 25-35.

<sup>9</sup> Ibid.

<sup>10</sup> David Craufurd and Julie Snowden, "Neuropsychiatry and Neuropsychology," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 36-65.

<sup>11</sup> Sarah J. Tabrizi et al., "Biological and Clinical Changes in Premanifest and Early Stage Huntington's Disease in the Track-HD Study: The 12-Month Longitudinal Analysis," *The Lancet Neurology* 10, no. 1 (2011): 31-42.

<sup>12</sup> Craufurd and Snowden, "Neuropsychiatry and Neuropsychology," 36-65.

common, particularly depression,<sup>13</sup> and while individual studies provide different rates, in general the suicide rate is higher than in the rest of the population.<sup>14</sup> Irritability and angry outbursts are common<sup>15</sup> – these changes put major stresses on family life and those in caring roles. A small proportion of people develop florid, schizophrenia-like hallucinations and delusions, which are often treatable with anti-psychotic medications.<sup>16</sup> In a small number of individuals, HD can occur in the absence of a family history. One reason is that new mutations can occur, and the mechanism by which this happens is now better understood.<sup>17</sup>

Another of the challenging features of the disease is that the individuals affected are often unaware of the physical and mental changes which are obvious to others.<sup>18</sup> This “lack of insight” into their cognitive and physical limitations can pose serious problems for family members and carers, as families negotiate the delicate balance of enabling the HD-affected person to maintain as much independence and autonomy as practicable, while ensuring their safety and well-being, and the safety of others. For example the person with inadequate control over their movements and difficulties with concentration may think they are capable of driving when they are no longer safe to do so, or they may no longer be able to manage their finances, but resist allowing others to assist in managing these activities.

Since 1993, people with a family history of this complex and disabling disease can take a simple blood test which will tell them whether or not they have an expanded version of the

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<sup>13</sup> Ibid.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

<sup>16</sup> Christopher A. Ross and Sarah J. Tabrizi, "Huntington's Disease: From Molecular Pathogenesis to Clinical Treatment," *The Lancet Neurology* 10, no. 1 (2011): 83-98.

<sup>17</sup> Cecile Cazeneuve and Alexandra Durr, "Genetic and Molecular Studies," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 109-30.

<sup>18</sup> Craufurd and Snowden, "Neuropsychiatry and Neuropsychology," 36-65.

gene.<sup>19</sup> The results of this test will have dramatic repercussions for these individuals and those close to them. They can find out whether they will develop a disease which will gradually alter the way their bodies move, impair their speech and their ability to think, and affect their mood and personality. As the disease progresses, they will become increasingly dependent on others, eventually requiring high levels of care. Any children they may have without intervention would have a 50/50 chance of developing HD, though there are options now available to parents to prevent transmission of the expanded gene. Parents can utilise pre-natal screening techniques such as chorionic villus sampling to test for the presence of the abnormal gene. Another option is a technology called Pre-implantation Genetic Diagnosis, which allows couples to use IVF technology to choose only embryos without the expanded HD gene.<sup>20</sup>

The disease is neither exceedingly rare nor common. The prevalence rates vary considerably: in most countries with a majority of people of West European descent, the rates have been cited as between five and ten per 100,000,<sup>21</sup> though more recent scholarship has provided a higher figure, at least in Great Britain.<sup>22</sup> The disease is as common as the better-known condition motor neurone disease,<sup>23</sup> but much lower than the rate of Parkinson's Disease – a

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<sup>19</sup> Rhona Macleod and Aad Tibben, "Genetic Counselling and Testing," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 165-81.

<sup>20</sup> Ibid.

<sup>21</sup> John C. Hedreen and Raymund A. C. Roos, "Huntington's Disease," in *Neurodegeneration: The Molecular Pathology of Dementia and Movement Disorders*, ed. Dennis Dickson and Roy O. Weller, (Hoboken: Wiley-Blackwell, 2011), 258-72.

<sup>22</sup> Stephen J. W. Evans et al., "Prevalence of Adult Huntington's Disease in the UK Based on Diagnoses Recorded in General Practice Records," *Journal of Neurology, Neurosurgery & Psychiatry* 84, no. 10 (2013): 1156-60.

<sup>23</sup> Mark H. B. Huisman et al., "Population Based Epidemiology of Amyotrophic Lateral Sclerosis Using Capture-Recapture Methodology," *Journal of Neurology, Neurosurgery & Psychiatry* 82 no. 10 (2011): 1165-70.

recent study found rates of 41 per 100,000 for 40-49 year olds.<sup>24</sup> The most recent prevalence study in Australia was based on the 1996 census in the state of NSW and found a figure of 6.3 per 100,000.<sup>25</sup> This group has recently conducted an updated prevalence study in the same state, and although not yet published, there are indications that this figure is now higher.<sup>26</sup> Many thousands of Australians have symptoms of HD or are at risk of developing it, while others have tested positive for the expanded HD gene. The availability of genetic technologies has created more choices for affected families, but has also opened up a swathe of psychological, ethical and practical dilemmas for those families which have to deal with this complex disease.

HD is an extremely burdensome disease, with caring responsibilities for family members extending over decades.<sup>27</sup> However, in developed countries, the situation is now much improved compared with just a few decades ago. Today, families have access to a range of specialist services, and there is more information than one could ever hope to read about the disease. Technology exists to allow children to be born free of the disease, even when the parent carries the expanded gene. There are international groups of scientists and physicians, aided by willing volunteers from HD families, searching for treatments and ultimately a cure.

While the repercussions of this genetic mutation reach into the future, the disease has its roots in the often well-hidden past. The condition has been highly stigmatised in the past

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<sup>24</sup> Tamara Pringsheim et al., "The Prevalence of Parkinson's Disease: A Systematic Review and Meta-Analysis," *Movement Disorders* 29 (2014): 1583-90.

<sup>25</sup> E. A. McCusker et al., "Prevalence of Huntington Disease in New South Wales in 1996," *Medical Journal of Australia* 173 (2000): 187-90.

<sup>26</sup> Clement Loy, A Lownie, and E McCusker, "Huntington's Disease," *The Lancet* 376 (2010): 1463.

<sup>27</sup> Aimee Victoria Aubeeluck, Heather Buchanan, and Edward J. N. Stupple, "'All the Burden on All the Carers:' Exploring Quality of Life with Family Caregivers of Huntington's Disease Patients," *Quality of Life Research* 21 (2012): 1425-35.

century, though in recent decades, the secrecy and shame surrounding the disease has diminished. While the biological symptoms remain the same, the experience of living with the disease in the current era is a stark contrast to the situation which existed for much of the twentieth century.

## **1.2 Social Aspects of the Disease**

As a neuropsychologist, I met my first person with HD over twenty years ago, and, like many who encounter this disease, the challenges faced by HD families in the present day made a deep impression on me. Later, I began to learn about the history of the disease, and the stigma and secrecy which has surrounded it. In the course of conducting this research many people have told me about their experiences of the disease.<sup>28</sup> Many of the stories were frankly shocking. One woman, Sandra, (not her real name) told me how in the 1980s she had made an appointment with her local GP to discuss concerns she had about her husband.<sup>29</sup> The following account is her recollection of this event. The GP saw the couple briefly, and casually told them “I think it could be Huntington’s disease.” With that, he saw them out of his office into the waiting room, handed her a medical book and told her to read it. Sandra said: “The further I got into it, in words that were very technical and words that I didn’t even understand ... it was all about ... the amount of time the person would have before they died, and about suicide. ... Halfway through I couldn’t read it any more. I had to stop reading it. ... I started to cry and people were looking at us. The secretary was a little embarrassed.” They went back in to the doctor’s rooms, where he told them his diagnosis once again. When Sandra asked: “What can we do about it?” he replied “Nothing.” At this

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<sup>28</sup> Ethics approval for this research was granted on 18 October, 2007 by the University of Sydney Human Research Ethics Committee, reference #10372.

<sup>29</sup> Interview conducted with HD family member. 25 November 2012.



stage she was overwhelmed – the couple had five children and grandchildren. The GP did not mention the existence of any support, though fortunately they were later told of the lay support group, the Huntington’s Disease Association, by another unrelated professional. Some time later, still in shock, they sought another opinion. Although their GP refused to give a referral for this, they managed to arrange an appointment with a specialist in the capital city who knew of HD, who also had access to counselling, and the experience was entirely different – they were listened to, had a chance to talk and were provided information about the disease. In addition to the neglect of the needs of families, other physicians have felt they had the right, and even duty, to tell HD families not to have children. One woman told me how she was berated by a heart specialist in the 1980s for having had children when her husband was at risk of developing the disease<sup>30</sup> (he was later tested and did not carry the expanded HD gene<sup>31</sup>).

Another woman who contacted me was in her 60s when she first learnt she was at risk of the disease. Looking forward to her retirement, her life was turned upside down with the diagnosis of her elderly mother, with dramatic repercussions for her children and grandchildren.<sup>32</sup> I was repeatedly told by people that they had no idea that this disease was in the family until some crucial event brought the long-held secrets out into the open. In the current social climate, where young people in particular reveal so much personal information through social media to strangers as well friends and families, many people who have either tested positive for the mutated gene or know they are at risk choose to broadcast their

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<sup>30</sup> Interview conducted with HD family member 26 November, 2013.

<sup>31</sup> Technically, all of us carry a copy of the “HD gene” though different versions of it. The more correct term would be “the expanded or expanded or mutated HD gene” but for simplicity’s sake it will be referred to in this dissertation as the “HD gene.”

<sup>32</sup> Interview conducted with HD family member, 12 December, 2008.

genetic status to the world. People announce their fundraising efforts on social media platforms. Young people with HD in their families have set up HD youth organisations, using their real names.<sup>33</sup> HD researchers have disclosed the fact that they themselves are at risk of the disease.<sup>34</sup> Two unrelated prominent British journalists have recently revealed that they are gene positive,<sup>35</sup> one of them now spending much of his time campaigning for greater recognition of the disease.<sup>36</sup>

This openness about the disease would have been unimaginable to HD families in the 1970s. For much of the twentieth century, in addition to the biological symptoms, families had to contend with the fact that HD was a deeply stigmatised disease, surrounded by secrecy and shame. Few families were open about its presence, hiding the disease from spouses, children, in-laws and their doctors. The consequences of this secrecy were often devastating, especially once the disease was diagnosed and its implications understood. Some knew that there was “Something in the Family”, the name given to ABC and BBC documentaries about the disease which screened in the 1970s, but the information families had was sketchy and often inaccurate. Many others simply had no idea the disease was in their midst. With the exception of a few specialists, medical interest in the disease was minimal, physicians often knew little themselves, and misinformation abounded. The possible existence of a hereditary disease involving a movement disorder and mental illness was seen as a source of great shame.

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<sup>33</sup> The most recent example is the group HDYO, Huntington’s Disease Youth Organisation. <http://en.HDYO.org>. Accessed 20 December, 2014.

<sup>34</sup> Glimm, *Gene Hunter: The Story of Neuropsychologist Nancy Wexler*.

<sup>35</sup> [www.feministtimes.com/my-feminist-times-journey/](http://www.feministtimes.com/my-feminist-times-journey/) Charlotte Raven. Dated July 2014. Accessed 2 Jul, 2015.

<sup>36</sup> [Ucneuroscience.com/hope-stories/charles-sabine-huntingtons-disease](http://ucneuroscience.com/hope-stories/charles-sabine-huntingtons-disease). Charles Sabine. Dated 28 May 2014. Accessed 2 Jul 2015.

As noted in the examples given above, the repercussions of the attitudes towards the disease during the last century are still unfolding today. While most people now know about HD when it is in their family, there are still new people finding out that they are at risk. From the 1970s, many people have asked questions about the secrecy, shame and stigma which permeated this disease. With such enormous consequences at stake, why did husbands not tell their wives? Why did parents not tell their children? Why was the disease hinted at but not spoken about directly? We might expect that an examination of the history of the disease might provide some answers to those questions.

### **1.3 History of the Disease**

Certain aspects of the history of HD have been explored extensively, but until recently, the published history in medical journals covers the same well-worn, often-repeated and rarely scrutinised subjects. The social history of the disease is relatively unexplored territory. Only two scholars have studied the social forces which have impacted on HD families, and investigated the experience of HD in the past. British geneticist Peter Harper and North American historian Alice Wexler have taken the history of the disease in a different direction, examining social aspects of HD in the US and, to a lesser extent, the UK and Germany.

The constellation of features we now call HD have probably existed for centuries, but it was not until 1872 that they were most fully described by Dr George Huntington, a young physician in the US. While the term “hereditary chorea” was previously used in the medical literature, it was Huntington’s description which excited medical interest over the coming decades, and this new disease entity began to be recognised by medical professionals around

the world. Initially called Huntington's chorea, historical aspects of the disease have been a central concern of writers and researchers, from the first attempts to identify this new condition in the early twentieth century to the present day. During the nineteenth century the catch-all term "chorea" referred to a wide range of conditions. Referring to this terminological free-for-all, the influential Canadian physician William Osler (1849-1919) famously described chorea as an "olla podrida"<sup>37</sup> or hodge-podge.

Into this confusing state of affairs came the famous description of Huntington, a young country family doctor. The orthodoxy in the nineteenth century, supported by neurological greats of the day in Europe, such as the French "the father of neurology" Jean-Martin Charcot (1825-1893), pre-supposed that a wide range of conditions, including chorea, had a hereditary component. The possible existence of a form of hereditary chorea different from other types was of little import. Into this climate, Huntington's careful description of the symptoms of HD, and specifically his description of a novel mode of transmission of inherited disease, entered medical history. Harper stated: "The description by George Huntington in 1872 of the disease that has subsequently borne his name is one of the most remarkable in the history of medicine."<sup>38</sup> Huntington's observations were confirmed in the early twentieth century; consequently, HD became known as one of the first conditions with mental symptoms to have an autosomal dominant mode of transmission. Just how the young Huntington became the first to describe this important new disease entity has been an ongoing topic of interest to those writing about the disease. As we will see in the literature review, this and many other aspects of the history of HD have been well-researched, however there are many other areas of potential investigation which remain unexplored.

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<sup>37</sup> William Osler, *On Chorea and Choreiform Affections* (London: H.K. Lewis, 1894).

<sup>38</sup> Harper, "Huntington's Disease in a Historical Context," 3-24.

The circumstances of HD's discovery, its method of transmission and its prominence as an early example of a human hereditary disease with physical and mental symptoms have been the subject of much academic attention. It has been linked to dramatic historical eras – the dancing manias and plagues of the Middle Ages and witchcraft accusations. However, until recently, very little has been written about the experience of people living with HD, and the way the disease has been portrayed. From the first full description of the disease in 1872, it went on to become a highly stigmatised and hidden disease for much of the twentieth century. Now, though stigma still exists, the disease is much more out in the open, and the stigma has certainly lessened. By labelling those with hereditary diseases as “the unfit,” one particular social movement, eugenics, has had a profound influence on the way the disease was experienced in the twentieth century. Eugenics was a movement which sought to improve the human race by encouraging the “fit” to breed more, and the “unfit” to breed less. The linkage between eugenics and HD has been explored by only two researchers, British geneticist Peter Harper and North American historian Alice Wexler.

In this dissertation, I delve deeper into the experience of the disease in the past, and explore some of the reasons for the secrecy and stigma which have played such a prominent role in the lives of HD families, in addition to considering medical responses to the disease. More traditional medical aspects of the history will also be explored, such as when people with the disease first came to Australia, the backgrounds of the physicians who wrote about the disease and its existence in indigenous communities.

## 1.4 Thesis Overview

In chapter 2, the literature review, I will outline the main themes and different approaches to the history of HD, from the earliest years after Huntington's description through to the present day. Once HD was established as a distinct disease entity in the first decade of the twentieth century, physicians began exploring Huntington's life and legacy. The search was also on for earlier descriptions of the disease, and several precursors were identified.

Beginning in the 1930s, in attempting to trace the origins of HD in the US, several physicians connected the disease with the infamous period when accusations of witchcraft were commonplace. The claim that people with HD were accused of witchcraft persists to the present day. Others writing on the history of the disease connected it with the dancing manias of the Middle Ages, a time when people gathered in the streets and engaged in wild, prolonged dancing. This phenomenon came to be called St Vitus Dance, a name then given to a range of movement disorders – indeed many HD families themselves used the term to describe the disease. The connections between HD and witchcraft have been subjected to closer examination and found wanting, but they nevertheless live on in the medical literature even though these links were highly speculative. Claims that people with HD were involved in the dancing manias are presented without supporting evidence, only conjecture.

The dramatic features of HD often seem to evoke strong feelings in those writing about the disease, and rather intemperate language has seeped into usually staid academic publications. The linkage of HD with these emotionally charged eras has resulted in the disease itself being linked with devils, persecution and the supernatural, using the imagery of wild, uncontrolled bodies. Some of these authors have simultaneously characterised HD families of the past as criminals and outsiders. Narratives which cast HD as an inevitably and

unchangingly stigmatised disease became the main prism through which the disease was viewed. Many advocates of the eugenics movement were interested in HD, and, in turn, those writing on the disease were influenced by eugenic thinking. Eugenics divided the world into the fit and the unfit – those with a condition such as HD, with its physical and mental symptoms, and most importantly its now-known method of transmission, were without doubt amongst the “unfit” in the eyes of most eugenicists.

These alarmist depictions of HD omitted alternative narratives from the published history – that is, subjects usually considered under the rubric of “social history.” While authors have repeatedly commented on the stigmatisation of the disease, few explored the reasons for it – it was almost as though the notion was self-evident, given the stories of outcasts shunned by their community. Harper and Wexler have begun to fill in some of these gaps. Their work on the influence of the eugenics movement, the specific targeting of HD by Nazi physicians and politicians in the 1930s, and the changes which began to occur in the 1970s for HD families in the US will be explored. Wexler has studied the lives of HD families in the nineteenth century and found that sufferers were not uniformly stigmatised at that time. While the literature review shows that aspects of the history of the disease have been studied extensively, much remains to be explored.

In Chapter 3, I will describe the early history of HD in Australia, with particular reference to aspects of the social history of families in the nineteenth and early twentieth centuries. It has been reported that the first instances of the disease in Australia were a family who migrated to Tasmania in the 1840s, and that there was no evidence of HD in the transported convicts who made up a high proportion of early European settlers to Australia. This claim will be

tested against genealogical evidence I collected from a range of sources acquired through novel historical techniques. Using information gained from HD families themselves and medical publications on the disease in Australia, I will describe families who can be traced to the early years of European settlement. The majority of the chapter reports on the results of extensive investigations into three separate kindreds in the nineteenth and early twentieth centuries. Using newspaper reports, local and family histories and obituaries, I present evidence that at least some families with HD in this era were well-respected in their communities. The evidence I gathered found many parallels with the situation in the US described by Wexler, with indications of social integration rather than social exclusion. Next, information regarding the different ethnic origins of HD in Australia will be presented, and the existence of the disease in Aboriginal populations will be described.

In addition to exploring the social dimensions of the disease in Australia, I will explore the changing relationship between HD families and the medical profession over time. Families with HD inevitably came into contact with various medical professionals, and these relationships will be explored in Chapter 4. Given that the disease was not recognised as a clinical entity until the twentieth century, I explore what physicians made of the condition before it was classified as HD. I have been able to do this by tracing the family histories of individuals who have been diagnosed with HD, and examining medical and other historical records of their ancestors. I will then present the results of an investigation of people who were admitted to institutional care for the disease, particularly in reference to the reasons their families could no longer care for them, and the ongoing involvement of some family members with asylum life. The fact that the disease has been so hidden required the use of



innovative historical techniques, such as using physicians' papers to explore asylum records and interviewing family members who had traced the roots of HD in their own families.

Little is known about the history of the disease in Australia, apart from the fact that a large kindred with the disease existed in Tasmania, a state which had and continues to have a very high prevalence rate. In chapter 4 I will examine aspects of the life of Charles Brothers (1905-1963), who researched this Tasmanian kindred for over a decade from 1937. I will also describe the background of Charles Hogg (1870-1951), the physician who provided the first description of the disease in the Australian medical literature in 1902. With both of these men, there were surprising parallels with George Huntington. All three grew up in areas with higher than average proportions of Huntington's families, with Hogg and Huntington having physician relatives. I will also summarise the medical publications on the disease and the contribution of researchers in the states of Queensland, where two large-scale surveys were conducted, and South Australia, where researchers identified an Aboriginal community affected by the disease.

The stigma, secrecy and shame which surrounded the disease in the early twentieth century, and is still too large a part of life for many HD families, has been frequently mentioned but not well explored. In Chapter 5, I will expand on Harper and Wexler's exploration of the role of the eugenics movement in influencing the lives of HD families. I begin with the recognition that there are biological features of the disease which make it prone to stigma, such as the movement disorder, cognitive decline and its hereditary nature. I then go on to argue, with reference to the writings of early eugenicists, that the stigmatisation of people with disabilities was not only one of eugenics' primary goals, but also one of its unspoken

“successes.” Despite it not being a common disease, once HD was identified as an example of an autosomal dominant disease with “mental” features, early eugenicists displayed a disproportionate interest in HD. In turn, physicians working with HD families were influenced by the eugenic concerns of the day. Research into the role of eugenics in HD has primarily focused on the UK, US and Germany, and in particular of the eugenicist Charles B. Davenport (1866-1944). In this chapter, I will explore the role of eugenics in the stigmatisation of the disease in Australia, a country not known for the success of the eugenics enterprise. In addition to discussing the medical response to eugenics in Australia more broadly, I will outline the relationship the main HD researchers in the country had with eugenics and the medical literature referring to both HD and eugenics. Finally, in order to understand the exposure of the general population, including HD families, to eugenic thinking, I will examine the role of newspapers, magazines and educational institutions in disseminating the topic of eugenics to the general public.

In chapter 6, after describing the characterisation of people with HD as “problem families,” I trace the beginnings of a brighter time, which began in the US. Eugenic-inspired thinking was challenged from a range of angles. After outlining developments in the US, in this chapter I will describe the Melbourne clinic where the voices of HD families were finally listened to. Prior to this, in publications on the disease, their many problems were certainly recognised, though no suggestions for managing these problems were offered, and “therapeutic nihilism” was a common response, alongside telling the families not to have children. In the early 1970s, a research project was the catalyst for the development of a service to help these families. These researchers also brought families together and after just a couple of years the first Australian HD Association was formed. This then spread to other

states, and the Tasmanian branch of the HD Association called a booklet about the beginnings of their organisation **“Out of the Darkness,”** the title chosen for this dissertation. Finally in this chapter, I will consider the activism engaged in by these family members and health professionals in comparison to other critical social and intellectual movements, the anti-psychiatry movement and the field of enquiry known as “Disability Studies.” Two contrasting models in particular will be examined for their relevance to the history of HD.

While the following chapters will reveal aspects of the history of a rather uncommon hereditary disease, these themes have a wider significance. Although it had many extremist proponents, eugenics also had widespread support in the twentieth century – in this dissertation, I will outline how the divisive aspects of the eugenic programme, such as the creation of stigma towards the unfit, had profound effects on people’s everyday lives. It is a cautionary tale against simplistic philosophies which seek to solve the complex problems of the world by an appeal to the creation of an “out” group. Taken to an extreme, there are terrible consequences when people’s shared humanity is ignored. On a more prosaic level, I show how despite being hidden from view, HD has played its part in the broader history of Australia, and people have been living with this disease in this country since the first decades of European settlement. Another broader theme is the changing role of health professionals, whose responses to disease, even when there are no effective treatments, can still play a crucial role in improving or worsening people’s experience of disease. HD is one of the most challenging of human diseases, but society’s reaction too, can make things more or less bearable. When we shine a torch into HD’s history, there are lessons for all of us, no matter what version of the gene on the short arm of the fourth chromosome we inherited.

## Chapter 2 Literature Review

*"Like many such scourges, the chorea, or dance, has given rise to a series of legends and superstitions as its fateful saraband has twisted and turned through the ages."*<sup>1</sup> Maltzberger, 1961

*"Huntington's chorea became the example par excellence in the medical literature and in medical texts to illustrate dominant inheritance with complete penetrance."*<sup>2</sup> Myrianthopoulos, 1966

The history of Huntington's disease (HD) has proved a compelling subject to those who encountered this complex condition, especially considering its hereditary nature. Since George Huntington's 1872 description, aspects of its history have been the subject of considerable academic attention, with the majority of the papers being written by physicians with a professional involvement with HD. These scholars have concentrated primarily on traditional medical concerns, such as the first identification of the disease. A common approach within medical history focuses on the advances, or in the case of HD, the lack of advances, in respect to medical treatments and cures. With the exception of two scholars, those studying HD's history have trodden a set of well-worn historical paths. In this chapter, the current state of knowledge and varying approaches to the history of the disease will be outlined and analysed, in order to provide the background for this dissertation.

Almost all accounts begin with descriptions of hereditary chorea in the nineteenth century, with the most attention focusing on Huntington himself - these scholars have analysed the pivotal contribution of Huntington to the initial identification of the disease. A second topic commonly appearing in the medical literature deals with accounts of hereditary chorea which preceded those of Huntington. Many histories have included details of the personal

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<sup>1</sup> John Terry Maltzberger, "Even Unto the Twelfth Generation - Huntington's Chorea," *Journal of the History of Medicine and Allied Sciences* 16 (1961): 1-17.

<sup>2</sup> Myrianthopoulos, "Huntington's Chorea," *Journal of Medical Genetics* 3 (1966): 298-314.

backgrounds of these nineteenth century physicians. This approach sets these physicians firmly in their social milieu, and allows for a consideration of non-biomedical influences which have contributed to the way the disease has been described. In the case of Huntington himself, researching his family history elucidated some of the reasons why he identified the disease well before the neurological greats of the day.

Those writing on the history of the disease usually link it to two dramatic historical epochs. The first concerns the dancing manias of the Middle Ages, where the term St Vitus' Dance has its origins. Later, in the nineteenth and early twentieth centuries, the term was used to describe a wide range of movement disorders, and indeed HD was sometimes referred to as St Vitus Dance. A casual reading of the history has led some to state with certainty that people with HD were amongst those who participated in the dancing manias, though these claims are based on conjecture rather than evidence.

The second historical era involves the alleged association of "witchcraft" with the disease. In the 1930s, it was claimed that people from HD families had been accused of witchcraft in the US in the seventeenth century. Although these connections have been challenged by scholars who have re-examined the original claims, they have been remarkably resilient. Both of these tenuous links have provided potent metaphors and filters for thinking about the disease in the past. Historical depictions of the dancing manias described transgressive individuals with out-of-control bodies breaking social norms, and linked the disease with notions of demonic possession. Witchcraft accusations linked the disease to the devil, and gave the impression that people with HD were necessarily persecuted minorities and

outcasts. These characterisations, with demonic and supernatural twists, proved to be an enticing framework through which to imagine HD's past.

Two other aspects of the disease have been the subject of historical enquiries. The first concerns the genetic discoveries of 1983 and 1993. The next concerns the period around the early 1970s when HD families connected with researchers – especially important was an international conference in 1972 which sparked new interest in the study of the disease. From George Huntington's description in 1872 to the genetic discoveries of the 1980s and 1990s, there were few medical advances in understanding or treating the disease. But the experience of individuals affected by the disease has varied dramatically over different historical periods. In particular, the stigma surrounding the disease was intense throughout much of the twentieth century. Medical history which focuses only on biomedical aspects of disease precludes the possibility of investigating the social forces which have influenced the way the disease was actually experienced.

Although accounts of dancing manias and witchcraft accusations were often referred to as “social history” or “social aspects” of the disease, this was the history of fantastic times, not the real life struggles of HD families. The experiences of the “patient” have been omitted from the historical narrative by many historians of HD. Another kind of “social history” examines the wider social forces which affect the way we think about disease, and places greater attention on the experience of the disease of those affected by it, not just the physicians treating it. Only two HD historians have considered these social forces and their influences. Peter Harper, a British geneticist who has worked for decades with HD families, also has a strong interest in medical history and has written on aspects of the social history

of the disease. In a warning about the potential abuses of genetic knowledge in the future, he was the first author to draw attention to historic abuses of the past. He was the first to describe how people with HD had been targeted on eugenic grounds, especially in Nazi Germany, where the condition was specifically singled out as part of the state-sponsored programmes to reduce disease and disability through “Rassenhygiene” policies.

Historian Alice Wexler has taken the history of HD in novel directions. Beginning in the 1990s, her research has broken entirely new ground and has shone light on hidden aspects of HD’s history in the USA. The variety of theoretical frameworks, the novel use of source material and the sheer volume of her work sets her apart from other writers on the history of the disease. She brings a range and depth of knowledge about the disease due to her own family history. Her mother died from the disease in 1978 and her family has immersed itself in the world of HD. Her sister Nancy Wexler was influential in the discovery of the gene for HD, and both Nancy and Alice are at risk themselves. Their father Milton Wexler founded the Hereditary Disease Foundation, which played an important role in the identification of the mutated gene and whose aim is to fund research into treatments for HD. As a historian with HD in her family, her position as both “insider” and “outsider” has led her to approach the history of the disease from unique angles.

The overlapping but different contributions of these authors, Harper and Wexler, will be further examined in this chapter. Both have begun to investigate the stigma surrounding the disease which was such a prominent part of living with HD throughout the twentieth century. In doing so, they have described the influence of American eugenicist Charles Davenport (1866-1944) who published the first large scale study of HD families in 1916.

Both have described the Nazi eugenic policies which singled out HD. Wexler has also drawn attention to the stigmatising language contained in many medical publications on the disease in the twentieth century, noting its highly emotional and often vilifying tone. She has questioned previous characterisations of the disease as universally stigmatised over time, by investigating the lives of some HD family members in the North East of the USA in the nineteenth century. She has also challenged previous assertions regarding the witchcraft accusations – drawing on the work of others who had questioned the claims and her own research. Both Harper and Wexler have also described the events which led to a change in attitudes for HD families beginning in the late 1960s.

## 2.1 George Huntington

Huntington's 1872 seminal publication "On Chorea"<sup>3</sup> is the centrepiece of almost all histories of HD. It has been ubiquitously cited and over the last century many have seen fit to reprint the entire text, from Osler in 1894,<sup>4</sup> to Browning in 1908,<sup>5</sup> to Barbeau in 1973,<sup>6</sup> Harper and Morris in 1996<sup>7</sup> and as recently as Harper in 2014.<sup>8</sup> Others have quoted liberally from the paper.<sup>9</sup> Huntington initially presented the information in a talk to a meeting of a local medical society, the Meigs and Mason Academy of Medicine at Middleport, Ohio, on

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<sup>3</sup> George Huntington, "On Chorea," *The Medical and Surgical Reporter* 26, no. 15 (1872): 317-20.

<sup>4</sup> William Osler, *On Chorea and Choreiform Affections* (London: H.K. Lewis, 1894).

<sup>5</sup> George Huntington, "Huntington's Original Description of This Form of Chorea (from the 1872 Print)," *Neurographs* 1, no. 2 (1908): 95-98.

<sup>6</sup> Andre Barbeau, Thomas N Chase, and George W Paulson, *Huntington's Chorea, 1872-1972, Advances in Neurology; V. 1.* (New York: Raven Press, 1973) 33-35.

<sup>7</sup> Peter Harper and Michael Morris, "Introduction: A Historical Background to Huntington's Disease," in *Huntington's Disease*, ed. Peter Harper, (London: W.B. Saunders, 1996), 1-29.

<sup>8</sup> Peter Harper, "Huntington's Disease in a Historical Context," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 3-24.

<sup>9</sup> Michael . Okun, "Huntington's Disease: What We Learned from the Original Essay," *The Neurologist* 9 (2003): 175-9.



15th February, 1872. A written version was published in *The Medical and Surgical Reporter*<sup>10</sup> two months later, on 13<sup>th</sup> April, 1872, four days after Huntington's 22<sup>nd</sup> birthday. This article, just short of five pages, devoted the first three and a half pages to a description of the chorea which was most familiar to a medical audience, the chorea of childhood. The last page described a condition which Huntington believed was only found in the east end of Long Island, and at the end of his report, he stated that he did not expect it to be of any great interest, presenting the material "merely as a medical curiosity." (p 321)

After describing the main features of what he called "hereditary chorea," Huntington summarised his own contribution by reference to three main features: its hereditary nature, the tendency to insanity, and onset in adult life. This summary is often taken to reflect the paper as a whole. In fact, Huntington clearly outlined other important aspects of the disease which would set his description apart from previous works. In particular, he described a specific type of heredity which was later identified as autosomal dominance, outlined the personality changes which accompany the disease, and referred to the fact that "hereditary chorea" was fatal and incurable. It was clear from Huntington's description that he had a close knowledge of the disease - he also described how symptoms varied considerably from person to person. While some inaccuracies existed in the original paper, such as his claim that juveniles were never affected, and that men were affected more often than women, the primary features of his description have been confirmed by later researchers.

A substantial portion of Huntington's paper was spent in explaining the unusual form of heredity, and it clearly struck him that this aspect of the disease was worth noting.

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<sup>10</sup> Huntington, "On Chorea," 317-320.

Contrasting it with more common hereditary diseases which might skip a generation, he emphasised that “if by any chance these children go through life without it, the thread is broken and the grandchildren and great-grandchildren of the original shakers may rest assured that they are free from the disease.” (p 320) The importance he gave to this statement is seen in his re-statement of his observations: “it never skips a generation to again manifest itself in another; once having yielded its claims, it never regains them.” (p 320) Huntington was aware that this represented an alternative to previous notions of heredity when he stated: “This you will perceive differs from the general laws of so-called hereditary diseases.” (p 320) Huntington must also have been aware of what this meant for the families themselves. Those whose parents were free from the disease could “rest assured” that they would not develop it themselves, even if one of the grandparents was affected.

Despite claims that this was his only publication,<sup>11 12</sup> three more articles appearing in medical journals list Huntington as the author. In 1895, the *Brooklyn Medical Journal* published a transcript of a speech he had given to the Kings County Medical Society,<sup>13</sup> which was followed by another brief paper in 1903.<sup>14</sup> While some scholars would later cast HD as an “American Disease,”<sup>15</sup> in these later papers Huntington himself clearly noted that the disease existed in many European countries. Once again highlighting his recognition that descriptions of the mode of transmission represented a new way of thinking about heredity,

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<sup>11</sup> Russell DeJong, "The History of Huntington's Chorea in the United States of America," in *Huntington's Chorea 1872-1972. Advances in Neurology V. 1.*, ed. Andre Barbeau, Thomas N. Chase, and George W. Paulson, (New York: Raven Press, 1973), 19-27.

<sup>12</sup> Roy Porter, "Chorea and Huntington's Disease," in *A History of Clinical Psychiatry: The Origin and History of Psychiatric Disorders*, ed. German E Berrios and Roy Porter, (London: The Athlone Press, 1995), 138-46.

<sup>13</sup> George Huntington, "Huntington's Chorea," *Brooklyn Medical Journal* 9 (1895): 173-74.

<sup>14</sup> George Huntington, "Chronic Progressive Hereditary or Huntington's Chorea," *Transactions of the Tri-State Medical Association* (1903): 180-85.

<sup>15</sup> Macdonald Critchley, "Huntington's Chorea and East Anglia," *Journal of State Medicine* 42 (1934): 575-87.

he stated in his 1903 paper: “This peculiarity [not skipping generations] is markedly different from what we generally understand as true concerning most so-called hereditary diseases.”<sup>16</sup> (p 182)

Whereas these two papers have been ignored by most scholars, more attention has been paid to Huntington’s final paper, published in 1910.<sup>17</sup> This publication was also based on a talk first given to a medical society - the New York Neurological Society. Although the title is given as “Recollections of Huntington’s Chorea as I saw it at East Hampton, Long Island, During My Boyhood” with the author George Huntington, it is clear from the text that it was written by an unacknowledged editor. The paper includes a long quote from Huntington, in addition to other contributors. This section is frequently cited, and, like his 1872 paper, has often been reprinted in its entirety, and with good reason.

The now 60-year-old Huntington reflected on the origins of his interest in the disease. He recounted his experience as a 10-year-old boy, when one day he was out with his father, accompanying him on his medical rounds. He described meeting two women walking down the street who displayed significant choreic movements. He noted his father’s rather matter-of-fact reaction to them, and then reported his own: “It made a most enduring impression on my boyish mind ... I stared in wonderment, almost in fear.”<sup>18</sup> (p 255) In addition to revealing how the disease had captured his imagination and excited his interest, he paid tribute to his father and grandfather, stating that without their knowledge of the families, he would never have been able to make the observation that brought him such a prominent

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<sup>16</sup> Huntington, "Chronic Progressive Hereditary or Huntington's Chorea," 180-185.

<sup>17</sup> George Huntington, "New York Neurological Society," *Journal of Nervous and Mental Diseases* 37 (1910): 255-57.

<sup>18</sup> Ibid.

place in medical history. The papers which have emphasised Huntington's contribution to medical history are too numerous to review separately, but it is instructive to note the lasting attention paid to him over time, as can be seen in the following table. (GH=George Huntington, HC=Huntington's chorea)

YEAR	TITLE	AUTHOR	OCCUPATION
1893	Remarks on the varieties of chronic chorea...	Osler	Physician
1894	On chorea and choreiform affectations	Osler	Physician
1908	Editorial	Browning	Physician
1908	Historical note on hereditary chorea	Osler	Physician
1908	A biographical sketch of GH	Winfield	Physician
1932	On the transmission of HC for 300 years	Vessie	Physician
1934	Treasury of Human Inheritance	Bell	Geneticist
1934	A biography of George Huntington	Stevenson	Physician
1937	GH and his relationship to earlier descriptions of chronic hereditary chorea	De Jong	Neurologist
1953	George Sumner Huntington	De Jong	Neurologist
1958	The understanding of involuntary movements: an historical approach	Barbeau	Neurologist
1961	Even unto the twelfth generation	Maltsberger	Psychiatrist
1966	Huntington's chorea	Myrianthopoulos	Neurologist
1967	Huntington's chorea	Brody	Neurologist
1968	Huntington's chorea: historical, clinical and laboratory synopsis	Bruyn	Neurologist
1972	The history of Huntington's chorea	Stevens	Neurologist
1973	HC: A centenary review	Heathfield	Neurologist
1973	The history of HC in the USA	De Jong	Neurologist
1983	Reflections on the history of HC	Hayden	Geneticist
1989	George Huntington and George Sumner Huntington	van der Weiden	Physician
1993	GH: the man behind the eponym	Durbach/Hayden	Geneticist
1995	Mapping fate: a memoir of family, risk and genetic research	Wexler	Historian
1995	Chorea and Huntington's disease	Porter	Historian
1995	Chorea and Huntington's disease	Schiller	Neurologist
1996	A historical background of HD	Harper	Geneticist
2000	History of chorea	Goetz et al	Neurologist
2000	GH and hereditary chorea	Lanska	Neurologist
2001	Huntington disease	Siemers	Neurologist
2002	Chorea and community in a C19th town	Wexler	Historian
2003	Neurodegenerative disorders. GH's description of hereditary chorea	Neylan	Psychiatrist
2003	HD: What we learned from the original essay	Okun	Neurologist
2003	Huntington's chorea	Pearce	Neurologist
2005	The molecular genetics of Huntington disease – a history	Bates	Neuro-geneticist
2005	Dr GH and the disease bearing his name	Conomy	Neurologist
2008	Before Mendel	Harper	Geneticist
2008	The woman who walked into the sea	Wexler	Historian
2010	The history of movement disorders	Lanska	Neurologist
2012	Witchcraft and Huntington's disease: a salutary history of societal and medical stigmatization	Loi and Chiu	Psychiatrists
2014	Huntington's disease in a historical context	Harper	Geneticist

Table 1. List of publications with prominent references to George Huntington.<sup>19</sup>

<sup>19</sup> Full details of these references can be found in the bibliography.

In considering Huntington's legacy, the most obvious question is how this unaccomplished 22-year-old recent medical graduate, unattached to any academic institution, ended up being credited as the first person to describe this important new disease entity. Several papers in the 1908 journal *Neurographs* set out to answer this question,<sup>20</sup> and these articles contain much of the information relied on by researchers over the subsequent century, often without acknowledgement. The editor of the journal, physician William Browning, referred to the "world-wide interest that has been shown in the subject of hereditary degenerative chorea."<sup>21</sup> (p 85) He considered the history of the disease to be of great importance – eight out of 13 articles explored aspects of the history of HD, covering three main themes in relation to his discovery: the process by which Huntington's paper reached a wider audience; biographical details of Huntington's life; and the intellectual climate of the time which allowed identification of new diseases more broadly.

In what was to become a recurring theme, physician James Winfield stated poetically that writing about Huntington "becomes a fascinating search for the reasons and causes which made it possible for him to read where others had all unwittingly thumbed the leaves."<sup>22</sup> (p 89) This early biographer was the first to publish the Huntington family lineage, and in particular noted how George's father George Lee Huntington and grandfather Abel Huntington had both been physicians in the town of East Hampton where "among them existed a peculiar nervous disease."<sup>23</sup> (p 93) Both men were well aware of the condition, and the fact that George Huntington's father had corrected his manuscript "On Choreia" was

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<sup>20</sup> W. Browning, "The Huntington Number," *Neurographs: A Series of Neurological Studies, Cases and Notes* 1, no. 2 (1908): 84-163.

<sup>21</sup> William Browning, "Editorial," *Neurographs* 1, no. 2 (1908): 85-88.

<sup>22</sup> James Macfarlane Winfield, "A Biographical Sketch of George Huntington, MD," *Neurographs* 1, no. 2 (1908): 89-95.

<sup>23</sup> Ibid.

first mentioned by Winfield. In one of the early derogatory descriptions of the disease, the Huntingtons' family background of "gentle English stock" (p 89) was contrasted with "this hopeless disease with its hideous and grotesque symptoms" (p 93) by Winfield. The next major biography of Huntington was published in 1934 by Charles Stevenson.<sup>24</sup> This reproduced large sections of Winfield's text (without citations) adding some additional details he had gained from interviewing members of the family. The Huntington family provided further biographical details to Nadja Durbach and Michael Hayden for their 1993 sketch<sup>25</sup> and to Alice Wexler for her book published in 2008.<sup>26</sup>

Most authors point to these family connections as being crucial to Huntington's identification of the main features of the condition. Wexler expanded the list of potential influences, including a widely educated, worldly Scottish relative who boarded with the family for some time and George Huntington's aunt Cornelia, who wrote poetry and a novel about the town, and lived in the family home.<sup>27</sup> Harper and Morris provided an additional emphasis, noting Huntington's own extended contact with families who had the disease. In their words, "a description of this nature could only be have been written by one whose observations were based on direct and continued contact with affected patients."<sup>28</sup>(p 5)

In answer to the question of what allowed Huntington to make such accurate observations, several authors have gone beyond his family background and have commented on his

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<sup>24</sup> Charles S Stevenson, "A Biography of George Huntington, M.D.," *Bulletin of the Institute of the History of Medicine* April, no. 2 (1934): 53-76.

<sup>25</sup> Nadja Durbach and Michael Hayden, "George Huntington: The Man Behind the Eponym," *Journal of Medical Genetics* 30 (1993): 406-09.

<sup>26</sup> Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven: Yale University Press, 2008).

<sup>27</sup> Ibid.

<sup>28</sup> Harper and Morris, "Introduction: A Historical Background to Huntington's Disease," 1-29.

individual characteristics. Foremost amongst these is the concept that Huntington had his “eyes open.” Winfield noted his keen interest in nature (he was a member of the Audubon society, a birding organisation) and emphasised his propensity for sketching. This has also been a prominent theme in recent scholarship – Okun’s 2003 essay drew heavily on this analogy.<sup>29</sup> Wexler, too, refers to his “aesthetic sense” as a potential contributor to his astute observations.<sup>30</sup>

Huntington’s early exposure to the disease also allowed him to gain insights into the experience of patients and families. He reported on the responses of family members to the disease. He noted how it was often spoken of with a kind of dread, and if referred to was called “that disorder.” He also revealed aspects of his own reactions, using language not customarily found in the medical literature. For example, he described the disease progressing until “the hapless sufferer is but a quivering wreck of his former self.”<sup>31</sup> (p 320) He then described the impression left by two “flirting men” who were displaying symptoms of chorea: “The effect is ridiculous in the extreme.” (p 321) In describing the choreic movements he stated that “the poor patient presents a spectacle which is anything but pleasing to witness.” (p 321) In his 1903 paper he referred to “general ludicrous movements.”<sup>32</sup> (p 185) These emotive responses would continue to be a feature of many articles on the disease over the next century. Despite these graphic descriptions revealing some of his personal reactions, Huntington did not then go on to vilify the families as a group, which later came to be a prominent response to the disease.

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<sup>29</sup> Okun, “Huntington’s Disease: What We Learned from the Original Essay,” 175-179.

<sup>30</sup> Wexler, *The Woman Who Walked into the Sea: Huntington’s and the Making of a Genetic Disease*.

<sup>31</sup> Huntington, “On Chorea,” 317-320.

<sup>32</sup> Huntington, “Chronic Progressive Hereditary or Huntington’s Chorea,” 180-185.

Despite the ready availability of information about Huntington through his many biographies, many eminent researchers have confused two different George Huntingtons. Several refer to George Sumner Huntington (1861-1927), who was in fact an American anatomist. This error has been made so regularly that an entire article was published to rectify the misunderstanding in 1989.<sup>33</sup> However the two continue to be confused, even in recent scholarly articles.<sup>34 35 36 37 38 39</sup> Wexler corrected the most recent misidentification by Ben Harper.<sup>40</sup> This minor error is of no great significance in itself, but faith in other assertions are questionable, when the authors have not done sufficient research to identify the correct name of their subject, or to be aware that the misidentification has been rectified in the literature. In what was to become a prominent theme in HD's history, much scholarship simply repeats previous claims.

The fact that HD was a distinct clinical entity, separable from other forms of chorea, which now seems so obviously visible and identifiable, had remained obscured by preconceptions of the nature of heredity. Entrenched beliefs by eminent European physicians and specialists of the day, like the French “the father of neurology” Jean-Martin Charcot (1825-1893) and prominent British neurologist William Gowers (1845-1915), who must have encountered many people with HD in their clinics, resulted in their failure to see the patterns before them. Charcot was particularly intransigent, and in 1888, even after most of the rest of the

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<sup>33</sup> R. M. Van der Weiden, "George Huntington and George Sumner Huntington. A Tale of Two Doctors," *History Philosophy Life Sciences* 11, no. 2 (1989): 297-304.

<sup>34</sup> B. Harper, "Huntington Disease," *J R Soc Med* 98, no. 12 (2005): 550.

<sup>35</sup> John M.S. Pearce, "Huntington's Chorea," in *Fragments of Neurological History*, ed. John M.S. Pearce, (London: Imperial College Press, 2003), 119-22.

<sup>36</sup> Harold L. Klawans, *Toscanini's Fumble* (Bodley Head, 1989).

<sup>37</sup> Porter, "Chorea and Huntington's Disease," 138-146.

<sup>38</sup> Francis Schiller, "Chorea and Huntington's Disease," in *A History of Clinical Psychiatry: The Origin and History of Psychiatric Disorders*, ed. German E Berrios and Roy Porter, (1995), 123-37.

<sup>39</sup> Eric Siemers, "Huntington Disease," *Arch Neurol* 58, no. 2 (2001): 308-10.

<sup>40</sup> A. Wexler, "Huntington Disease," *J R Soc Med* 99, no. 2 (2006): 53.



world accepted that Huntington's or hereditary chorea was a disease distinct from other forms of chorea, Charcot insisted that:

Huntington's chorea does not represent a distinct, well-delineated or specific pathological entity to be definitively set apart from a condition like ordinary chorea. It is only an aspect or single form in the larger sphere of chorea.<sup>41</sup> (cited by Goetz p 406)

In summarising the literature by and about Huntington, a range of personal and social factors enabled him to make his contribution to medical history. First, he was born in a town with a significant population of people with Huntington's disease. Not only did he come across HD families in his everyday life from a young age, but his father and grandfather had also served as physicians in this community; their combined observations provided insight into the hereditary nature and main features of the disease. As a recent graduate, Huntington had his eyes open to the world around him. He was able to synthesize his observations into a succinct, readable summary, and his observations were re-published in Europe and championed by William Osler, one of the most influential figures of the day. Huntington's description of the families was compassionate but he also portrayed some features of HD in emotional language. His personal reaction to the symptoms of the disease informed his depiction, which was also to become a prominent feature of later descriptions.

The hereditary nature of the disease was best revealed when physicians knew members of different generations of families, which would not be the case in the asylums or clinics where the neurological specialists worked. Personal exposure to the actual lived experience of HD

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<sup>41</sup> C. G. Goetz, "William Osler: On Chorea: On Charcot," *Ann Neurol* 47, no. 3 (2000): 404-7.

allowed physicians to identify the most important features of the disease, including this new form of inheritance.

## 2.2 Descriptions of hereditary chorea before 1872

Huntington's 1872 description of HD has long been credited as the first to capture the most salient features of this previously undefined disease entity. However, as is often the case with historical "firsts," earlier descriptions of hereditary chorea with adult onset were later identified. Initial attention was centred on American precursors: Charles Waters (1841), Charles Gorman (1846) and Irving Lyon (1863).<sup>42</sup> The Norwegian Johan Christian Lund was claimed by fellow Norwegian Orbeck in 1959 to be the first physician to provide a reasonably complete description in 1862,<sup>43</sup> and in 1972 David Stevens claimed that the Briton John Elliotson had mentioned hereditary chorea as early as 1832.<sup>44</sup>

As with Huntington himself, personal and professional details of the life and the circumstances of the physicians identifying hereditary chorea were thought to provide insights into their observations, and were explored as early as 1908. In Browning's words, better knowledge of their background was "of both historical and scientific importance,"<sup>45</sup> (p 87) and he published biographical sketches of all three American doctors – Waters,<sup>46</sup> Gorman<sup>47</sup> and Lyon.<sup>48</sup> Browning lamented the fact that they had previously "remained more

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<sup>42</sup>Browning, "The Huntington Number," 84-163.

<sup>43</sup> Alf L Orbeck, "An Early Description of Huntington's Chorea," *Medical History* 3 (1959): 165-68.

<sup>44</sup> D. L. Stevens, "The History of Huntington's Chorea," *Journal of the Royal College of Physicians London* 6 (1972): 271-82.

<sup>45</sup> Browning, "Editorial," 85-88.

<sup>46</sup> William Browning, "Sketch of Rev. C.O. Waters, MD," *Neurographs* 1, no. 2 (1908): 137-44.

<sup>47</sup> William Browning, "Sketch of C.R Gorman, M.D.," *Neurographs* 1, no. 2 (1908): 144-47.

<sup>48</sup> William Browning, "Sketch of I. W. Lyon, M.D.," *Neurographs* 1, no. 2 (1908): 147-49.

obscure than the pre-Columbian discovers of America” (p 87) and set out to rescue them from this historical invisibility. Browning was successful in this endeavour. Over the next century, most researchers who have made substantial studies of HD’s history have referred to these prior nineteenth century descriptions of a form of hereditary chorea.<sup>49 50 51 52</sup> One common feature of the three American doctors is that they were all young and had recently graduated from medical school; as was the case with Huntington himself. They were not specialists in university clinics. A recurring element in the biographies of these physicians is that they had open minds and a broad knowledge of the families which they studied, giving them a greater opportunity to recognise the unique features of the disease.

These nineteenth century descriptions of hereditary chorea in the US commented on social aspects of the condition as well as strictly scientific and medical information, presenting contrasting impressions of the social position of HD families. In 1937, neurologist Russell De Jong drew attention to these earlier writers and reprinted the original sources. He reported that, in 1841, a letter from Waters was printed in Robley Dunglison’s textbook *The Practice of Medicine*.<sup>53</sup> It stated that the disease he was describing “is markedly hereditary, and is most common among the lower classes, though cases of it are not infrequently found among those, who by industry and temperance have raised themselves to a respectable rank in society.”<sup>54</sup> (p 203) A later edition of Dunglison’s textbook (1846) contained another letter,

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<sup>49</sup> Andre Barbeau, "The Understanding of Involuntary Movements: An Historical Approach," *The journal of nervous and mental disease* 127, no. 6 (1958): 469-89.

<sup>50</sup> G. W. Bruyn, "Huntington's Chorea: Historical, Clinical and Laboratory Synopsis," in *Handbook of Clinical Neurology*, ed. P.J Vinken and G. W. Bruyn, (Amsterdam: North-Holland Publishing Company, 1968), 298-378.

<sup>51</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

<sup>52</sup> Harper, "Huntington's Disease in a Historical Context," 3-24.

<sup>53</sup> Russell N DeJong, "George Huntington and His Relationship to the Earlier Descriptions of Chronic Hereditary Chorea," *Annals of Medical History* IX (1937): 201-10.

<sup>54</sup> Ibid.

this time from Charles Gorman, another newly graduated physician presenting his inaugural dissertation. Duglison, paraphrasing Gorman's thesis (which has never been located) stated that the families were well integrated into their communities - they "are intimately connected in their social and business relations."<sup>55</sup> (p 205)

Lyons' portrayal of the families painted a different picture. He stated that people "have repeatedly been known to interdict marriage alliances between their children and those believed to be tainted with the migrim diathesis, under the severe penalties of disinheritance and social ostracism. It is however, regarded by many as a disgraceful disease."<sup>56</sup> (p 206)

Over the coming century, this latter view was more often emphasised, portraying individuals with HD as inevitably stigmatised. The impression of social inclusion described by Gorman, including the possibility that people with the disease were accepted in their communities, was often absent from later historical analysis.

These early studies of hereditary chorea were only recognised after Huntington's contribution had been accepted by the medical community and indeed remained in obscurity until the twentieth century - their absence of recognition was in stark contrast to the widespread fame and recognition accorded to Huntington. The question of why these earlier descriptions were never recognised as representing a new disease entity is an obvious one. In reply, most refer to Huntington's predecessors' brief and vague references to heredity, the lack of completeness of the descriptions and the absence of details about the families' location which might have allowed for further examination of their claims, and contrast the limitations of the earlier papers with the brief but influential description by Huntington.

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<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

### 2.3 HD as Movement Disorder: Chorea and St Vitus Dance

Throughout most of its history, HD was primarily classified as a movement disorder, reflected in its earlier name Huntington's chorea. This neurological interpretation dominated until the 1970s, when it was recognised that the cognitive, personality and behavioural features of the disease often have more significant effects than the motor symptoms. From the early 1970s, most scholars use the term Huntington's disease, which is now the most commonly used term, though recently others have preferred the term Huntington (without the possessive "s") disease.

Until the 1980s, those writing on the *history* of the disease echoed this emphasis by focusing on it as a movement disorder. For example, George Bruyn in 1968 bluntly stated that "the history of Huntington's chorea is the history of involuntary movements 'tout court.'"<sup>57</sup> Andre Barbeau's history of the disease in 1958 came under the rubric "The Understanding of Involuntary Movements: An Historical Approach."<sup>58</sup> Many articles commonly begin with the history of the term "chorea." From William Osler in 1894<sup>59</sup> to Michael Okun in 2003,<sup>60</sup> the history of HD is viewed through this prism, typically beginning with a reference to the phenomenon of the dancing manias, linked with the term "Chorea Sancti Viti," better known as St Vitus Dance.

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<sup>57</sup> Bruyn, "Huntington's Chorea: Historical, Clinical and Laboratory Synopsis," 298-378.

<sup>58</sup> Barbeau, "The Understanding of Involuntary Movements: An Historical Approach," 469-89.

<sup>59</sup> Osler, *On Chorea and Choreiform Affections*.

<sup>60</sup> Okun, "Huntington's Disease: What We Learned from the Original Essay," 175-79.

The interweaving stories of the mediaeval dancing manias, chorea, the plagues of the Middle Ages, St Vitus Dance, and HD are complicated and confusing – the meanings of the terms change over time, and there is no definitive text which satisfactorily examines the relationship between these disparate phenomena. This is of relevance for three main reasons. First, many families called the disease St Vitus Dance, demonstrating a genuine link between the disease and this earlier nomenclature. Second, physicians who linked the history of the disease to the dancing manias often used the kind of florid, emotional language which added to the sensationalisation and stigmatisation of the disease. Finally, in publications on the history of the disease, it is sometimes stated unequivocally that people with HD were amongst those with the dancing manias, whereas this is more a matter of speculation.

The following brief exposition of these inter-related phenomena is a small step in sorting the mythology from the better-researched information. A range of explanations has been put forward to account for the “Dancing manias,” from medical to sociological. The term mostly refers to a time in the Middle Ages when unruly groups of people gathered together and danced - just why they engaged in this activity has been hotly debated. There were several manifestations of this phenomenon in different locations in different times, for example tarantism was a form of dancing mania in what is now Italy.

Regarding the origins of the term St Vitus’ Dance, St Veit or Vitus was allegedly a Sicilian-born Christian martyr whose relics were taken to various chapels in Europe.<sup>61</sup> In 1418, according to the *Strasbourg Chronicles*, a chief magistrate ordered people suffering from the so-called dancing manias to travel to the shrine of St Vitus in Zabern, and they were

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<sup>61</sup> A. C. Eftychiadis and T. S. N. Chen, "Saint Vitus and His Dance," *Journal of Neurology Neurosurgery and Psychiatry* 70, no. 1 (2001): 14.

“miraculously cured.”<sup>62</sup> From this time on, St Vitus was considered to be the patron saint of the “dancing manias,” which also came to be known as St Vitus Dance. Another term for the “dancing manias” was “choreomania,” the word chorea coming from the Latin, meaning “to dance,” via the Greek (Χορεία), meaning either chorus or dance. The meaning of the word chorea changed from “dance” to “disease,” and St Vitus Dance, or Chorea Sancti Viti, came to refer to a wide range of movement disorders over the coming centuries. Wexler has noted how the term referred both to a disease state and also the cure for the disease.<sup>63</sup> In all likelihood, people participated in the dancing for a range of reasons, and no single explanation is likely to explain the phenomenon.

In the nineteenth century, Victorian Britons were by the dancing manias. A medical organisation, the Sydenham Society, arranged a translation of an 1832 German work called “The Epidemics of the Middle Ages” by the German physician and medical historian Justus Hecker.<sup>64</sup> As can be gleaned from the title, Hecker described the dancing manias in a work primarily devoted to the contemporaneous plagues, and it is in this context that he refers to the “epidemics” of “the dancing Plague.”<sup>65</sup> The stories of the dancing manias appealed to a broader audience, particularly in Britain, and excerpts of the translation were published in popular magazines such as *Blackwood's* and *The Penny Magazine*.<sup>66</sup> In linking the story of St Vitus Dance to the history of HD, two prominent texts which have been much cited employed dramatic and emotional terminology in otherwise scholarly works. Barbeau wrote

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<sup>62</sup> R. H. Park and M. P. Park, “Saint Vitus' Dance: Vital Misconceptions by Sydenham and Bruegel,” *Journal of the Royal Society of Medicine* 83 (1990): 512-5.

<sup>63</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>64</sup> Justus Friedrich Carl Hecker, Benjamin Guy Babington, and Robert Humphrey Cooke, *The Epidemics of the Middle Ages* (London, 1859).

<sup>65</sup> Ibid.

<sup>66</sup> Molly Engelhardt, “Seeds of Discontent: Dancing Manias and Medical Inquiry in Nineteenth Century British Literature and Culture,” *Victorian Literature and Culture* 35, no. 01 (2007): 135-56.

a highly influential paper on the history of the disease in 1958. Employing colourful language, he employed phrases such as “the darkest hours of the Middle Ages,” “a period of blind cruelty” and the dancing manias themselves as “the strangest of maladies.”<sup>67</sup> In the other major study of the disease in the next decade, Bruyn referred to the “epidemic dance psychosis” and the “wild, religious, mass psychotic St John’s dance,”<sup>68</sup> (p 300) (“St John’s dance” was another term used to describe dancing manias).

Although not a common claim, authors occasionally state without reservation that amongst the “dancers” there were some people with HD. A recent book claimed that: “Such behaviour during their frenzied dances became a hallmark of dancing manias and of later conditions such as Huntington’s chorea.”<sup>69</sup> (p 16) A 2008 PhD thesis on genetic discrimination in HD opened with the sentence: “Huntington disease (HD), the “Dancing Mania” of the Middle Ages, has always been a particular target of social stigma and discrimination.”<sup>70</sup> The claim has also been repeated in popular accounts of the phenomenon. Although not published in the academic literature, a website offers an account of the history of HD which presents speculation as historical fact:

Huntington’s chorea can be recognised as the “dancing mania” which occurred on the Continent of Europe in the Middle Ages. Religious persecution following revocation of the Edict of Nantes gave impetus to emigration from the Low Countries and the condition spread to Britain. Thereafter it reached North America and the

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<sup>67</sup> Barbeau, "The Understanding of Involuntary Movements: An Historical Approach," 469-489.

<sup>68</sup> Bruyn, "Huntington's Chorea: Historical, Clinical and Laboratory Synopsis," 298-378.

<sup>69</sup> David M. Lawrence, *Huntington's Disease* (New York: Chelsea House Publications, 2009).

<sup>70</sup> Yvonne Bombard, "The Nature and Extent of Genetic Discrimination among Persons at Risk for Huntington Disease" (2008). PhD Diss., University of British Columbia, 2008. Accessed online 10 January, 2015.



Commonwealth and it is now widely distributed throughout the world.<sup>71</sup>

In his paper purporting to examine the social history of HD, the prominent medical historian Roy Porter (1946-2002) chided previous writers on the history of the disease for “monotonously” referring to the “dancing sicknesses” of the mediaeval period in relation to HD.<sup>72</sup> He reflected on the fact that “modern disorders, through association with a fantastic past, are endowed with a historical pedigree and a voyeuristic fascination.” (p 143) To this, it can be added that HD evokes strong reactions in those who come across it, which often seep into even academic writing on the disease, a theme which will be discussed in more detail in Chapter 4 on medical responses to the disease.

As noted in the previous quotation, a simplistic narrative traced the spread of HD from the plagues of the Middle Ages to the US and other Commonwealth countries via Britain. The impression was of a stigmatised minority fleeing persecution. A similar, related claim is that HD was present in persecuted Huguenots seeking refuge in Britain.<sup>73 74</sup> This narrative had these persecuted minorities then fleeing witchcraft accusations in the UK, and heading to the New World. This fable is now refuted by the fact that we know the disease has multiple genetic origins, and exists in almost every country.<sup>75</sup> The rates of the disease vary enormously in different regions, but nevertheless there is no evidence to support the idea that the disease stemmed from a single source. Details of another potent HD myth will now follow.

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<sup>71</sup> [www.whonamedit.com/doctor.cfm/966.html](http://www.whonamedit.com/doctor.cfm/966.html). Accessed 27 September, 2014.

<sup>72</sup> Porter, "Chorea and Huntington's Disease," 138-146.

<sup>73</sup> P. R. Vessie, "On the Transmission of Huntington's Chorea for 300 Years. The Bures Family Group," *Journal of Nervous and Mental Disorders* 76 (1932): 553-73.

<sup>74</sup> Myrianthopoulos, "Huntington's Chorea," 298-314.

<sup>75</sup> Chris Kay, Emily Fisher, and Michael R. Hayden, "Epidemiology," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 131-64.

## 2.4 Huntington's Chorea and Witchcraft

Once again linking HD with a dramatic historical epoch, physicians writing on the history of the disease have frequently reported that, in colonial America, accusations of witchcraft were made against individuals with HD. I will provide a brief overview of the genesis and development of these claims, followed by a summary of the research debunking them - most comprehensively by Wexler in 2006<sup>76</sup> and 2008.<sup>77</sup> Despite the careful scholarship which has gone into investigating these claims and which has shown them to be unfounded, the link continues to be made, as recently as 2012.<sup>78</sup> In linking HD with witchcraft, the original authors also used the opportunity to make highly derogatory comments about HD families, using stigmatising language which painted them as social outcasts. Their descriptions tarnished the people allegedly accused of witchcraft, and HD families more broadly, often drawing eugenic lessons from these allegations. As with the dancing manias, the language used to link the two tended towards the dramatic and gothic, which is unusual in traditionally staid medical publications describing other diseases.

Wexler has made an examination of these claims, and also drew attention to the accompanying vilifying narratives.<sup>79</sup> In 1932, in the prestigious *Journal of Nervous and Mental Diseases*, a psychiatrist, Dr Percy Vessie, outlined his claims that he had traced the origins of

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<sup>76</sup> Alice Wexler, "Inventing the History of a Genetic Disorder: The Case of Huntington's Disease," in *The Nature of Difference : Science, Society, and Human Biology*, ed. George T. H. Ellison and Alan H. Goodman, (Boca Raton: Taylor & Francis, 2006), 81-98.

<sup>77</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>78</sup> Samantha Loi and Edmond Chiu, "Witchcraft and Huntington's Disease: A Salutory History of Societal and Medical Stigmatisation," *Australasian Psychiatry* 20, no. 5 (2012): 438-41.

<sup>79</sup> Wexler, "Inventing the History of a Genetic Disorder: The Case of Huntington's Disease," 81-98.

HD in the US to a small number of individuals from Suffolk in the UK.<sup>80</sup> In his introduction, he stated that they “played the important part in a true American tragedy, and our disclosures of their social problems and court trials will show why the choreic affliction was reputed disgraceful and viewed with terror in succeeding generations.” (p 556) Vessie claimed that three men from a town called Bures, who arrived in 1630, were the primary sources of HD in the US. He reported on their alleged criminality and claimed that several of their descendants were accused of witchcraft, some being put to death. He then described several members of later generations of the same family who had HD. In highly inflammatory language, he also damned these present-day descendants of these families. In just one example, he stated that they had “mean, despicable natures.” (p 565) Vessie thus not only linked HD to the potent historical narratives of witchcraft and sorcery, he also vilified the families living with HD in the 1930s. As an ardent eugenicist, he concluded: “Such persistent stupidity of inbreeding and propagation of a degenerate evolution have contributed to the dooming of many of their descendants.”<sup>81</sup> (p 565)

Vessie’s 1939 paper expanded on his earlier themes, including the frequent use of emotional and vilifying language: “Huntington never dreamed of absolute priority so it is certainty [sic] not his fault that his family name is now identified with this horrible American tragedy.”<sup>82</sup> (p 596) Vessie’s two papers “stirred a lively interest on both sides of the North Atlantic”<sup>83</sup> (p 169), according to Wexler. She also noted that the British journal *The Lancet* abstracted Vessie’s article, the editor congratulating Britain on the fact that it had rid itself of the three

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<sup>80</sup> Vessie, "On the Transmission of Huntington's Chorea for 300 Years. The Bures Family Group," 553-573.

<sup>81</sup> Ibid.

<sup>82</sup> P. R. Vessie, "Hereditary Chorea: St Anthony's Dance and Witchcraft in Colonial Connecticut," *Journal of the Connecticut State Medical Society* 3 (1939): 596-600.

<sup>83</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

alleged men who brought HD to the US, as they were “undesirable characters” who belonged to the “social problem group.” (p 169) Wexler also noted the importance of two other prominent physicians who were most responsible for perpetuating Vessie’s initial claims and the subsequent embellishment of the witchcraft story.

In 1961 the psychiatrist John Terry Maltzberger wrote an article in the *Journal of the History of Medicine and Allied Sciences* with the dramatic title “Even unto the twelfth generation.” This article reinforced the association between HD and witchcraft and was much cited. Despite admitting that Vessie “has not found incontestable evidence that any of the alleged witches had Huntington’s chorea themselves,”<sup>84</sup> (p 6) Maltzberger nevertheless reinforced this connection. He ostensibly wrote a general paper on the history of the disease; however 10 of the 16 pages were devoted to aspects of witchcraft in colonial US society. Once again, highly dramatic language was used, possibly even more than in Vessie’s account. Much of the text contains frankly bizarre descriptions, going into great detail about beliefs surrounding witchcraft in colonial Connecticut and Massachusetts. He detailed witches’ pacts with the devil, “signed in blood,” and outlined the claim that witches grew special nipples to feed the offspring of sex with the devil: “These monsters attach themselves to her body, usually hanging from the breasts and genitals.” (p 6) The reasons for the inclusion of such detailed information about witchcraft beliefs of the 1600s in a work on the medical history of HD are not provided, though the last paragraph continues the dramatic language this disease often evoked: “The dance continues unabated. Medicine offers little more respite to its victims now that it did 88 years ago. For the families concerned it remains a curse, devilish if you will, reaching unto the twelfth generation, and even beyond.” (p 16) Once

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<sup>84</sup> Maltzberger, "Even Unto the Twelfth Generation - Huntington's Chorea," 1-17.

again, HD was guilty of trial by association with an alleged fantastic past, one of devils and curses, outsiders beyond the bounds of acceptable societal norms.

Although Maltzberger's paper has been frequently cited, the person who has probably had the most influence in the spreading of the witchcraft/HD link is the prominent British neurologist Macdonald Critchley (1900-1997). His interest in the history of HD spanned half a century – his first publication on the history of the disease was in 1934,<sup>85</sup> the last in 1984,<sup>86</sup> with one other work in 1964.<sup>87</sup> Like Vessie, Critchley painted a denigrating portrait of HD families in the present and the alleged past. The opening lines of his initial paper stated that the “story of Huntington's chorea” is “sinister.” He described family members as bearing “the marks of a grossly psychopathic taint, and the story of feeble-mindedness, insanity, suicide, criminality, alcoholism and drug addiction, becomes unfolded over and over again”<sup>88</sup> (p 575). He then goes on to attempt to trace the English forebears of the three men from the town of Bures in Suffolk which Vessie had described. Critchley reiterated Vessie's claims that these men were responsible for a large number of cases of HD in the US. As Wexler pointed out, these claims were made at the height of influence of the eugenics movement in both the US and UK, which greatly added to the stigmatisation of HD. Critchley used emotive language in describing the woman he initially dubbed Mary H., who he claimed was likely the mother of at least two of the men who allegedly took the disease to the US. She was “that local light o' love” with “tainted germ plasm” who was the “villainess of the

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<sup>85</sup> Critchley, "Huntington's Chorea and East Anglia," 575-587.

<sup>86</sup> Macdonald Critchley, "The History of Huntington's Chorea," *Psychological Medicine* 14 (1984): 725-27.

<sup>87</sup> Macdonald Critchley, "Huntington's Chorea: Historical and Geographical Considerations," in *The Black Hole and Other Essays*, ed. Macdonald Critchley, (London: Pitman Medical Publishing Company, 1964), 210-19.

<sup>88</sup> *Ibid.*,

piece.”<sup>89</sup> (p 579) Whilst admitting that he had no evidence to support this proposition, Critchley nevertheless raised the possibility that “Mary H.” herself had been accused of witchcraft. He reiterated a theme common in eugenic discourse, ending his article with an account of the financial cost the US had to bear, in supporting those with HD on account of “that gay lady of Bures.” (p 587)

Critchley’s 1964 paper repeated these claims, once again using language which painted the families as not only involved in witchcraft accusations, but also as outsiders.<sup>90</sup> The descendants of Vessie’s three young men are described as “undesirables and ne’er-do-wells.”<sup>91</sup> (p 214) Despite that, another is criticised for being “inordinately pious.”<sup>92</sup> In a case of circular reasoning, he claimed that although there was no actual evidence of HD in the three original men who left Bures, “the evidence of criminality and of witchcraft must be regarded as highly suggestive of a Huntingtonian psychopathy if not chorea.” (p 214) Mary H. is now named as Mary Haste, and she has now become “wanton” with “sinister charms.” Critchley’s 1984 article briefly restated and summarised his previous articles.<sup>93</sup> Despite the title claiming the article is a history of Huntington’s chorea; in fact most of the article rehashed the witchcraft claims, ignoring other aspects of the history of the disease. Voicing the concerns of eugenicists about the rapid spread of disease and increases in the numbers of the “unfit,” Critchley also claimed that “short of some drastic and unlikely eugenic

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<sup>89</sup> Critchley, "Huntington's Chorea and East Anglia," 575-587.

<sup>90</sup> Critchley, "Huntington's Chorea: Historical and Geographical Considerations," 210-219.

<sup>91</sup> Ibid.

<sup>92</sup> Ibid.

<sup>93</sup> Critchley, "The History of Huntington's Chorea," 725-727.

intervention, the disease will not die out naturally; more probably the numbers will increase from one generation to another like a hideous snowball.”<sup>94</sup> (p 211)

Many recent works examining the history of HD repeat Vessie’s and Critchley’s claims.<sup>95 96 97</sup>

Neurologist Harold Klawans detailed the links in one of his collections of neurological anecdotes.<sup>98</sup> In an otherwise sympathetic recent article highlighting the stigma surrounding the disease, claims of an association between HD and witchcraft are repeated without reference to the many subsequent critiques of the claims.<sup>99</sup> The alleged link has spread from the academic literature to texts with a wider readership. Wexler (2006) pointed out that the novelist Barbara Vine cited the witchcraft link in her novel featuring a character with HD.<sup>100</sup> A popular science book, Matt Ridley’s *Genome*, repeats the allegations of witchcraft in his chapter on HD.<sup>101</sup> The link has entered the digital age - even websites such as *Who Named It* include it in their brief history of HD.<sup>102</sup>

These claims have been decisively challenged by various researchers. As early as 1969, two HD workers, Mary Hans and Thomas Gilmore, questioned the accuracy of Vessie’s propositions.<sup>103</sup> In 1975, Vessie’s work was examined by two other researchers, Adrian Caro

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<sup>94</sup> Ibid.

<sup>95</sup> Okun, "Huntington's Disease: What We Learned from the Original Essay," 175-79.

<sup>96</sup> DeJong, "The History of Huntington's Chorea in the United States of America," 19-27.

<sup>97</sup> Porter, "Chorea and Huntington's Disease," 138-46.

<sup>98</sup> Klawans, *Toscanini's Fumble*.

<sup>99</sup> Loi and Chiu, "Witchcraft and Huntington's Disease: A Salutory History of Societal and Medical Stigmatisation," 438-41.

<sup>100</sup> Wexler, "Inventing the History of a Genetic Disorder: The Case of Huntington's Disease," 81-98.

<sup>101</sup> Matt Ridley, *Genome: The Autobiography of a Species in 23 Chapters* (London: Fourth Estate, 1999).

<sup>102</sup> Ole Daniel Enerson, "Whonamedit," (2013).

<sup>103</sup> Mary Hans and Thomas H Gilmore, "Social Aspects of Huntington's Chorea," *British Journal of Psychiatry* 114 (1968): 93-98.

and Sheila Haines, and once again major flaws in his conclusions were identified.<sup>104</sup> These papers were published in relatively obscure journals and therefore it is not surprising that later writers ignored or were unaware of their criticisms of what had become an important myth in the HD story. However, some authors with wider readerships began to look critically at the claims. As early as 1983, the prominent Canadian HD geneticist Michael Hayden contested Vessie, Maltsberger and Critchley's main claim, having conducted independent genealogical investigations.<sup>105</sup> In 1996, in one of the few authoritative general textbooks on HD at the time, Harper and Morris noted that the original investigations were at best exaggerated and most likely erroneous.<sup>106</sup>

Building on the work of these earlier researchers, Wexler has explored the issue in even greater depth. As outlined in a book chapter<sup>107</sup> and her most recent book<sup>108</sup> she found that Vessie's previous research contained errors and false assumptions. Wexler presented detailed genealogical evidence to support her case. A re-telling of the specific details is beyond the scope of this literature review, but the central point highlights the misidentification of the original alleged protagonists. Closer examination of the historical record revealed a simple but crucial misidentification. Wexler pointed out that Caro and Haines had noted that one woman "Elinor Knapp," who had descendants with HD but was not accused of witchcraft, was confused with "Goodwife Knapp," who was accused and executed as a witch, but had no offspring with HD.<sup>109</sup>

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<sup>104</sup> A. Caro and S Haines, "The History of Huntington's Chorea," *Update Medical History* July (1975): 91-95.

<sup>105</sup> Michael R. Hayden, "Reflections on the History of Huntington's Chorea," *Trends in Neurosciences* 6 (1983): 122-24.

<sup>106</sup> Harper and Morris, "Introduction: A Historical Background to Huntington's Disease," 1-29.

<sup>107</sup> Wexler, "Inventing the History of a Genetic Disorder: The Case of Huntington's Disease," 81-98.

<sup>108</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

<sup>109</sup> Wexler, "Inventing the History of a Genetic Disorder: The Case of Huntington's Disease," 81-98.



In recent papers repeating Vessie's claims by linking witchcraft with Huntington's disease, no refutation of these criticisms is made – they are simply ignored. The myth has become so deeply embedded in the HD historical narrative that it has become accepted as unquestioned historical fact. Two main reasons can be proposed for the persistence of these false claims, both of which Wexler has explored. The first is the eminence and authority of those who have repeated the claims. Vessie's and Maltsberger's articles were published in authoritative journals and repeated by prominent HD researchers. Critchley was one of the most prominent neurologists in the UK in the twentieth century and held major international appointments - he was the president of the World Federation of Neurology from 1963-1973.<sup>110</sup>

The second is the fact that the narrative sounds plausible and makes emotional sense, even if factually inaccurate, as Wexler has stated. Vessie's eugenic pronouncements and Critchley's stigmatising language have been omitted from the more recent papers linking witchcraft accusations and HD. Without these negative portrayals and eugenic conclusions, we are left with a narrative that sounds plausible. It is easy to imagine that a person exhibiting uncontrolled bodily movements might have been accused of witchcraft in earlier times and in other cultures. Wexler summarises the attachment some HD families feel to this myth: "Vessie's thesis continues to exercise cultural power as a primal myth about the beginnings of Huntington's chorea in North America, a parable of modern medicine and science, and a story of injustice and unwarranted suffering. In this guise, it has a certain emotional truth, no

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<sup>110</sup> R J Joynt, "In Memoriam - Macdonald Critchley," *Archives of Neurology* 55, no. 1 (1998): 22.

matter how ungrounded in historical fact.”<sup>111</sup> (p 174) Wexler has had at least some success in bringing this issue to a wider audience. In his 2009 review of her 2008 book in *Neurology Today*, neurologist Thomas Bird acknowledged the criticism and even drew salutary lessons. Of all the subjects covered in the book, he focused on her claim that the witchcraft accusations were false and concluded: “It is certainly a cautionary tale for neurologists trying to explain diseases to the public and grasping for colourful or dramatic stories.”<sup>112</sup> (p 21)

## 2.5 The Modern Era – The Centenary Conference and Genetic Discoveries

For much of the twentieth century, there were no medical breakthroughs in knowledge about HD and its treatment. In histories of the disease, the gap resulting from the absence of medical advances was filled with musings on the dancing manias and witchcraft. With little progress, there was little occasion for the telling of a “progress narrative.” In neurologist Michael Okun’s words, “the modern history of the disease remained relatively quiescent.”<sup>113</sup> (p 175) This changed in the early 1970s. Both Wexler and Harper have noted that 1972 was a landmark year in the history of HD. The “Centennial Symposium on Huntington’s Chorea” was held in Middleport, Ohio, where George Huntington had delivered his address 100 years earlier. The conference was organised by the Huntington Study Group of the World Federation of Neurologists in association with the New York and California chapters of the Committee to Combat Huntington’s Chorea.<sup>114</sup> Neurologists, psychiatrists, and scientists from around the world attended the conference in order to pool knowledge of the disease

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<sup>111</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

<sup>112</sup> Thomas D Bird, "Huntington Disease through the Prism of History and Social Anthropology.," *Neurology Today* 9, no. 7 (2009): 20-21.

<sup>113</sup> Okun, "Huntington's Disease: What We Learned from the Original Essay," 175-179.

<sup>114</sup> Alice Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (New York: Times Books, 1995)

and make plans for its study, which in turn sparked the interest of other researchers. It is widely held to have reinvigorated international scientific and medical interest in the disease.

Many positive developments came from this conference. Probably the most influential in biomedical terms concerned the exposure of the HD researchers to knowledge of a large kindred of HD families in Venezuela. Amongst the myriad presentations at the conference, Okun noted that a video about a group of people with HD from Venezuela was shown.<sup>115</sup> In the conference proceedings, the translation of a thesis by a Venezuelan physician, Dr Ramon Avila-Giron, was published, which outlined details of this kindred. It included the potentially interesting finding that there were people in this region who had both a mother and father with the disease, indicating that there might be some people who were homozygous – that is they carry two copies of the mutated gene.<sup>116</sup> The translator, Andre Barbeau, presciently stated in a note at the end of his paper that this region “can be considered a good isolate for the study of Huntington’s chorea.” (p 266)

Okun has investigated the background to the Venezuelan story.<sup>117</sup> A young physician, Dr Americo Negrette, was sent to work in a poor area of Venezuela in 1952, and subsequently identified the disease as Huntington’s chorea. There was resistance to the idea, and he was criticised by colleagues and even lost his university post, though was soon reinstated. He worked amongst these villagers for decades. Following the presentation at the 1972 conference by his student Avila-Giron, there was once again scepticism, but two neurologists

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<sup>115</sup> Michael Okun and Nia Thommi, "Americo Negrette (1924-2003)," *Neurology* 63 (2004): 340-43.

<sup>116</sup> Ramon Avila-Giron, "Medical and Social Aspects of Huntington's Chorea in the State of Zulia, Venezuela," in *Huntington's Chorea 1872-1972*, ed. Andre Barbeau, Thomas N. Chase, and George W. Paulson, (New York: Raven Press, 1973), 261-66.

<sup>117</sup> Okun and Thommi, "Americo Negrette (1924-2003)," 340-43.

visited Venezuela and confirmed the diagnosis.<sup>118</sup> Of particular importance was the large prevalence rate found in a region of Venezuela, which is consistently reported as 700 per 100,000. The issue of prevalence rates is controversial, since they have been consistently underestimated. Rates vary dramatically from country to country, with most European countries ranging from 4-8 per 100,000.<sup>119</sup> A more recent study gave a UK prevalence of 12.3 per 100,000.<sup>120</sup>

Alice Wexler elaborated on the story from there.<sup>121</sup> In the late 1970s, her father Milton Wexler, her sister Nancy and other HD workers organised a group of scientists to research the Venezuelan kindred. This involved multiple trips to Venezuela, getting to know the families intimately and drawing up complex pedigree charts. Blood samples were then taken and flown back to the US for analysis, all using cutting edge and often experimental genetic technologies. It was the study of this large HD cohort which led to successful isolation of the marker for the gene in 1983<sup>122</sup>, and the eventual discovery of the gene in 1993.<sup>123</sup> Harper and Morris, too, have outlined details of the “Venezuela Project.”<sup>124</sup> Gillian Bates, another HD researcher, has described in more detail the history of the scientific advances which led to the identification of the marker and the gene.<sup>125</sup>

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<sup>118</sup> Ibid.

<sup>119</sup> Louis T Giron and William C Koller, "A Critical Survey and Update on the Epidemiology of Huntington's Disease," in *Handbook of Neuroepidemiology*, ed. Philip B. Gorelick and Milton Alter, (New York: M. Dekker, 1994), 281-94.

<sup>120</sup> Stephen J. W. Evans et al., "Prevalence of Adult Huntington's Disease in the UK Based on Diagnoses Recorded in General Practice Records," *Journal of Neurology, Neurosurgery & Psychiatry* 84, no. 10 (2013): 1156-60.

<sup>121</sup> Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*

<sup>122</sup> James F. Gusella et al., "A Polymorphic DNA Marker Genetically Linked to Huntington's Disease," *Nature* 306, no. 5940 (1983): 234-38.

<sup>123</sup> Marcy E. MacDonald et al., "A Novel Gene Containing a Trinucleotide Repeat That Is Expanded and Unstable on Huntington's Disease Chromosomes," *Cell* 72, no. 6 (1993): 971-83.

<sup>124</sup> Harper and Morris, "Introduction: A Historical Background to Huntington's Disease," 1-29.

<sup>125</sup> G. P. Bates, "The Molecular Genetics of Huntington Disease - a History," *Nature Reviews Genetics* 6, no. 10 (2005): 766-73.

Several authors have noted the relatively unusual alliance which has been formed between the families affected by the disease and the medical and scientific community researching it. Wexler has noted this on many occasions in her work. Bates, too, pointed to the importance of lay organisations in fundraising and contributing to scientific research. Harper also pointed out the nature and advantages of collaborative research efforts between HD researchers and family members. He noted that HD was a prominent condition where “well-defined research communities had grown up involving intense loyalties and close friendships between laboratory scientists, clinicians, and patients and family members.”<sup>126</sup> (p 375)

All of these authors point to a mutually beneficial relationship between affected families and the medical-scientific community, a collaboration not uniformly encountered between patients and physicians. According to Wexler, the 1972 conference “marked another step towards the creation of a Huntington’s disease community, in which researchers and people with the illness might come together.”<sup>127</sup> (p 117) This is in stark contrast to the hostility towards medical professionals exhibited by the anti-psychiatry movement in its heyday of the 1960s and 1970s, and more recently by some disability activists. These groups have robustly expressed dissatisfaction with aspects of the doctor-patient relationship and the medicalisation of disability more broadly. The status of HD as a disability and the collaboration between HD families and the medical profession in the Australian context will be discussed in Chapter 6, with an emphasis on the changes which occurred in the 1970s.

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<sup>126</sup> Peter S. Harper, *A Short History of Medical Genetics* (Oxford ; New York: Oxford University Press, 2008)

<sup>127</sup> Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*

## 2.6 The Social History of HD- Peter Harper and Alice Wexler

The rise of social history in the past half century has had profound effects on historical enquiry broadly, and on the history of medicine in particular. In addition to medical advances, attention has been drawn to the experience of patients and their families. With two exceptions, this trend has yet to influence general histories of HD. The work of historian Charles Rosenberg is particularly relevant, especially his emphasis on the historical “framing” of disease. This approach encourages scholars to explore the effects of these different historical “frames,” in particular their effects on those living with disease. Rosenberg’s general criticism of the state of medical history could be applied specifically to the study of HD: “We have, in general, failed to focus on the connection between biological event, its perception by patient and practitioner, and the collective effort to make cognitive and policy sense out of those perceptions.”<sup>128</sup> (p309)

An exception who might have been expected to provide novel perspectives on the social history of HD is Roy Porter, the eminent historian who encouraged the consideration of social influences in the study of medical history. Apart from the works of Harper and Wexler which will be explored later in this review, he has written the only ostensibly “social history”

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<sup>128</sup> Charles E Rosenberg, "Introduction. Framing Disease: Illness, Society and History," in *Framing Disease: Studies in Cultural History*, ed. Charles E Rosenberg and Janet Lynne Golden, (New Brunswick, N.J.: Rutgers University Press, 1992), xiii-xxvi.

of HD, a chapter in a book entitled “A History of Clinical Psychiatry.”<sup>129</sup> Disappointingly, his article broke no new ground and was content to rehash the well-worn paths of witches and dancing manias previously outlined. This is particularly surprising, given that in his other work he was a pioneer in calling for the broadening of historical inquiry. He was a staunch advocate for including the patients’ voice and experience and was also alive to the question of stigma. His positions were outlined in papers such as “The patients’ view: doing medical history from below”<sup>130</sup> and “Can the stigma of mental illness be changed?”<sup>131</sup> In the former he bemoans the fact that “the sufferers’ role in the history of healing – in both its social and cognitive dimensions –has been routinely ignored by scholars.” (p 176) It is a curious paradox that in the case of HD, Porter did not heed his own advice – he made no mention of the stigma and secrecy surrounding the disease – indeed his chapter on the history of HD notably made no mention of the varying experiences of HD family members over time.

Geneticist Harper and historian Wexler, between them, have focused on four primary areas regarding stigma in their consideration of the social history of HD. First, they have drawn attention to the effects of stigma on HD families. Second, they challenged the idea that stigma is a necessary and unchanging force in the lives of people with HD. Third, they explored the forces which may have exacerbated stigma, such as the eugenics movement and wider social attitudes towards disability and health. Finally, they examined the circumstances which resulted in a reduction of stigma from the late 1960s and 1970s. Their research has focused on the unfolding of the disease in the US, Germany and the UK.

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<sup>129</sup> Porter, "Chorea and Huntington's Disease," 138-146.

<sup>130</sup> Roy Porter, "The Patient's View: Doing Medical History from Below," *Theory and Society* 14 (1985): 175-98.

<sup>131</sup> R. Porter, "Can the Stigma of Mental Illness Be Changed?," *Lancet* 352, no. 9133 (1998): 1049-50.

Apart from these pioneers, the question of the historical roots of HD stigma has gone unexplored. In the broader medical literature on HD, stigma has been the subject of considerable academic research, and despite improvements, it remains a salient issue.<sup>132 133</sup> Wexler, in particular, has given substance to the stigma “skeleton” by describing her family’s experience and outlining testimony given to a congressional hearing in the US.

Wexler explored her own family history in her 1995 memoir, *Mapping Fate*.<sup>134</sup> She focused on the secrecy surrounding the disease and the shattering implications of finding out in her twenties that her mother had the disease and that she and her sister were therefore at risk. She later wrote of this time: “Until my mother was diagnosed with Huntington’s disease ... she never mentioned that her father and three brothers had all died with this disease. Perhaps that missing family history was why I became a historian. I wanted to understand my mother’s shame, and origins of her devastating silence.”<sup>135</sup> (p 18) This first-hand account traces her own family history, from her mother’s university training in biology to the mysterious illnesses which affected her uncles, to the changes in her mother’s behaviour which were the first signs of the disease to the consequences of finding out that this disease was in the family. Her personal account revealed the stresses which can emerge when previously hidden information is discovered. In her words: “Who we were had suddenly been called into question and everything had to be reconfigured taking into account the presence of the disease.”<sup>136</sup> (p 75)

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<sup>132</sup> Janet K. Williams et al., "In Their Own Words: Reports of Stigma and Genetic Discrimination by People at Risk for Huntington Disease in the International Respond-HD Study," *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics* 153B, no. 6 (2010): 1150-59.

<sup>133</sup> H Etchegary, "Discovering the Family History of Huntington Disease," *Journal of Genetic Counselling* (2006): 105-17.

<sup>134</sup> Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*.

<sup>135</sup> Alice Wexler, "Stigma, History and Huntington's Disease," *Lancet* 376 (2010): 18-19.

<sup>136</sup> Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*.



Having described her personal experience, Wexler then presented evidence that this was a broader narrative by providing information about the experience of other families. She reported how in the 1970s in the US, HD families were invited to share their experiences of living the disease.<sup>137 138</sup> A panel was mandated by the US Congress, and in 1976 and 1977, the Commission for the Control of Huntington's Disease and Its Consequences took evidence from 2000 people affected by HD, mostly family members and health professionals. Common themes emerged. People spoke of their distress in being repeatedly told by doctors not to have children. Many individuals from affected families were unaware of the disease until a close family member was diagnosed. They advocated for further research and expressed a desire for a test which would tell them whether or not they would get the disease. Finally, large numbers spoke of the stigma and secrecy surrounding the disease - Wexler quotes one witness: "If I had one wish that this Commission would accomplish, it would be to take away the stigma of Huntington's disease and take it out of the closet."<sup>139</sup> (p 181) She quotes another person as recalling that "one of the recommendations our first neurologist made was that we all ought to be sterilized. That was the first thing he said after he announced the diagnosis."<sup>140</sup> (p 18) Another stated that "there is a shame associated with the disease, and they (family members) are so embarrassed by the whole thing that they just want to forget it."<sup>141</sup> (p 18)

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<sup>137</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>138</sup> Wexler, "Stigma, History and Huntington's Disease," 18-19.

<sup>139</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>140</sup> Wexler, "Stigma, History and Huntington's Disease," 18-19.

<sup>141</sup> Ibid.

Many of the historical accounts of HD from the twentieth century give the impression that the stigma surrounding the disease has been uniform, unchanging and inevitable. The source of the stigma is focussed solely on the disease itself, rather than the social forces which might influence stigma. Wexler questioned this assumption by exploring the lives of families with HD in the nineteenth century. Having established that stigma profoundly influenced the experience of living with HD in the twentieth century, Wexler chose to examine a community of people living with “St Vitus Dance” in the 1800s.

The first publication was a 2002 journal article, “Chorea and Community in a Nineteenth Century Town.”<sup>142</sup> She then elaborated on this story in her 2008 book *The Woman Who Walked Into the Sea*.<sup>143</sup> Both works challenged the prevailing portrayals of HD as being inevitably and invariably stigmatised. Using archival sources, she argued that in certain cases, in the nineteenth century, HD families were well accepted in their communities. In the preface to this work she wrote:

I was well acquainted with the stigma and silences surrounding it in the late twentieth century. But I wanted to know whether it had always been this way, or whether in the past this illness – and those affected by it – may have been viewed differently. As a historian, I had learned to see disability and disease as socially as well as biologically constructed, and as conditions whose meaning could change over time and across place. I had also learned the importance of the “patient perspective.”<sup>144</sup> (p xix)

In choosing a community to study, the East Hampton families first described by Huntington had left behind various historical traces. Her primary sources included: the records of

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<sup>142</sup> Alice Wexler, “Chorea and Community in a Nineteenth-Century Town,” *Bulletin of the History of Medicine* 76, no. 3 (2002): 495-527.

<sup>143</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>144</sup> Ibid.

Elizabeth Muncey (b1858, died ?) who alongside eugenicist Charles Davenport (1866-1944), had conducted the largest study of HD families in the US; newspaper articles; doctors' day books and other genealogical information found in local history societies' archives. Using these sources, Wexler told the story in particular of "Leah Smith" whose mother had HD and who apparently suicided by drowning in 1806. The local newspaper reported sympathetically how this woman was "much esteemed by her neighbours." Wexler then went on to trace the fate of some of Smith's descendants. Although she also outlined evidence of some negative attitudes towards some families, and admitted that there may well have been subtle forms of stigma and ostracism in this community, the overall impression was one of social integration and acceptance. As evidence of this she cited the results of her genealogical research which indicated that members of these affected families "held high office in the town and church, mostly married and raised families, labored, loved and lived out their lives." (p 514) The East Hampton families studied were visible in their communities, "working in their houses or yards, assisting at boarding houses, driving wagons, walking on the paths and attending church." In her book, while acknowledging that the disease was rarely spoken of in public, she nevertheless concluded that "St Vitus Dance/hereditary chorea ... was a source of dread but was not an emblem of family exclusion" and that "a disabling behavioural disorder perceived as inherited did not exclude or marginalize the families it touched."<sup>145</sup> (p 52)

In her first paper, Wexler chose to mask the identities of the family. The first two chapters of her 2008 book elaborate on that story, with "Leah Smith" now revealed as Phebe Hedges. This time, she chose to use the real names of the individuals concerned. The main reason to

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<sup>145</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*

de-identify individuals is to protect the privacy of current and future generations. She decided to change her approach in the second work, partly in response to the requests of the relatives of these eighteenth and nineteenth century families who told Wexler that they wished real names to be used. She also explained her own reasons - these mostly concern her goal to expose the secrecy and stigma around the disease, and thus help to reduce it. She claimed that in telling this story of real people using real names she would: “honor the historical presence of these individual lives” (p xxi) while noting the fine line between medical confidentiality and contributing to the ongoing shame of the disease by keeping it hidden.

Wexler offers further evidence of the integration of the Hedges family in East Hampton life. They include a detailed social history of East Hampton, in particular the town’s “deep reverence for ancestors and ancestry, organized around distinctions of race, religion, wealth, education and also length of residence” (p 49) which she suggests may have contributed to the absence of overt stigmatisation of these HD families. Additional source material included the archives of George Huntington’s family, a vast array of official records and general histories of East Hampton and its prominent families and letters between doctors which were located in the Eugenics Record Office. This influential organisation, run by Charles Davenport, was funded by philanthropists to study eugenics, and between 1911 and 1924 employed 250 field workers to collect pedigrees.<sup>146</sup>

Wexler also made a detailed study of the case records of Elizabeth Muncey, providing some background on this Eugenics Field Worker, who was one of a large number of women

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<sup>146</sup> Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Knopf, 1985).

employed for this purpose by Charles Davenport at the Eugenics Record Office in Cold Spring Harbor. Trained as a doctor, there were few employment pathways open for women at the time and Muncey took on the job of investigating families with HD in the north-Eastern US. Over 10 months, her records suggest she formulated pedigrees of 4,529 people, 949 of those with HD, though three quarters of those were deceased. Unlike so much of HD's history, this archival record has survived, and in Wexler's words offers "valuable glimpses into the social world of Huntington's chorea, heredity and eugenics at the turn of the twentieth century. Her archive remains one of the few early-twentieth century efforts to record, however briefly and inaccurately, the voices, outlook and activities of families with this disease."<sup>147</sup> (p 136)

Examining these records from a different perspective to that of Muncey a century earlier, Wexler summarised aspects of this voluminous research. Once again searching for evidence of stigma or social acceptance, Wexler found evidence of both, though much more of the latter. Muncey stated how some HD families were "shunned by neighbours" and there were cases described where marriage into choreic families was forbidden. However, many other stories revealed a different kind of experience. One person with HD was recorded as marrying "a man of wealth and high standing"<sup>148</sup> (p 141) and one was described as "a woman of fine character and good poise."<sup>149</sup> (p 141) In contrast with the narratives by Vessie and Critchley which claimed HD was brought to the US by "unsavoury characters," Muncey's origin stories mostly began with "a respected male ancestor, often of elite status" such as a merchant and even an aristocrat, e.g. a "Lady Ann Millington." Wexler also looked into

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<sup>147</sup> Ibid.

<sup>148</sup> Ibid.

<sup>149</sup> Ibid.

questions of class – it was claimed throughout the twentieth century that HD families were most commonly from lower socio-economic groupings. Once again, Wexler found much evidence to the contrary, with members of choreic families identified by Muncey holding the following professions: small businessmen and shop owners, a school principal, a professor of surgery at a New York City medical college, the wife of an elite physician, the president of a shipping line, justices of the peace, clergymen, a university professor, town clerks and a newspaper editor.<sup>150</sup>

Wexler's research into these families with HD showed how stigma can vary over time, and be subject to a range of forces in addition to a particular disease state. Class, rank in society, being a member of an established family, race and wealth, combined with broader social attitudes towards disease and a host of other factors will all determine the degree of stigma expressed towards people with HD (or any other disease). In contrast with depictions of HD families being “ne’er do wells,” a term favoured by Macdonald Critchley, Wexler uncovered a range of responses to the disease in the nineteenth century.

The role of stigma in the lives of HD families throughout the twentieth century has been ignored by historians, with the exception of Harper and Wexler. Harper broke from the previous traditions in exploring HD's history, carving out a new area of historical enquiry. Whereas most histories jump from George Huntington's contribution to the genetic discoveries of the early 1980s, Harper was the first to draw attention to the influence of eugenics on HD. In his 1992 paper “Huntington Disease and the Abuse of Genetics”<sup>151</sup>

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<sup>150</sup> Ibid.

<sup>151</sup> Peter Harper, "Huntington Disease and the Abuse of Genetics," *American Journal of Human Genetics* 50 (1992): 460-64.

Harper referred to growing concerns about the potential abuses which could occur as a result of the rapidly expanding field of human genetics. Using HD as a warning about what might happen in the future, he drew attention to abuses which had already occurred in the past.

In particular, he described the role of physicians in the eugenics movement in the US and the influence they had on Nazi policies of forced sterilisation and extermination of people with disabilities, including those with HD. He pointed out that one of the first bills passed by Hitler's regime was the Law for the Prevention of Genetically Diseased Offspring in 1933.<sup>152</sup> HD was listed as one of the nine conditions requiring compulsory notification by doctors and subsequent referral to hereditary courts. These courts decided on issues such as compulsory sterilisation and whether people were allowed to marry. Harper raised this history as a warning about the potential for the abuse of new genetic knowledge and technologies: "Geneticists and clinicians directly involved with HD have been prominent among those responsible for both the abuses and for the policies underlying them. It is thus essential that we be prepared to recognize what has happened in the past, if we are to avoid even greater dangers in the future."<sup>153</sup> (p 464) Wexler, too, has also explored the treatment of people with HD in Nazi Germany.<sup>154 155</sup> Both Harper and Wexler noted that physicians with expert knowledge of HD were a central part of the Nazi programmes and also noted the close ties with the US and German eugenics movements.

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<sup>152</sup> Ibid.

<sup>153</sup> Ibid.

<sup>154</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>155</sup> Alice Wexler, "Eugenics, Heredity and Huntington's Disease - a Brief Historical Perspective," *Journal of Huntington's Disease* 1, no. 2 (2012): 139-41.

Harper was also the first person to draw attention to the relationship between HD and the eugenics movement in the US, focussing on the work of Davenport.<sup>156 157 158</sup> Wexler has explored similar terrain, in her 2008 book<sup>159</sup> and a briefer account in a more recent journal article.<sup>160</sup> They both describe how Davenport, in his role as the head of the Eugenics Record Office, undertook the largest study of families with HD in the US. Relying on the detailed pedigrees collected by Muncey, the results of this study were brought together in two papers called: "Huntington's Chorea in Relation to Heredity and Eugenics."<sup>161 162</sup> These papers have been regularly cited in the HD literature for almost a century.

With the exception of Harper and Wexler, Davenport's legacy with respect to HD has not been scrutinised and the influence of his eugenic ideas on conceptions of HD in particular has rarely been acknowledged. In the tradition of those writing on the history of HD, Wexler explored biographical details of Davenport's life, outlining the following details.<sup>163</sup> He gained his PhD in zoology from Harvard University and went on to become the Director of the Biological Laboratory at Cold Spring Harbor on Long Island. He met the founder of eugenics, Sir Francis Galton, in 1902, and although his studies were initially restricted to plants and animals, his interests broadened and he became increasingly interested in human heredity and in particular eugenics. He founded the Eugenics Record Office at Cold Spring Harbor, and initiated the study into HD in 1911.

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<sup>156</sup> Harper, "Huntington Disease and the Abuse of Genetics," 460-64.

<sup>157</sup> Peter Harper, Gary Houlihan, and Audrey Tyler, "Genetic Counselling in Huntington's Disease," in *Huntington's Disease*, ed. Peter Harper, (London: W.B. Saunders, 1996), 359-94.

<sup>158</sup> Harper, *A Short History of Medical Genetics*.

<sup>159</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.

<sup>160</sup> Wexler, "Eugenics, Heredity and Huntington's Disease - a Brief Historical Perspective," 139-141.

<sup>161</sup> Charles B. Davenport, "Huntington's Chorea in Relation to Heredity and Eugenics," *Proceedings of the National Academy of Science (Washington)* 1 (1915): 283-85.

<sup>162</sup> Charles B. Davenport and Elizabeth B. Muncey, "Huntington's Chorea in Relation to Heredity and Eugenics," *American Journal of Insanity* 73, no. 2 (1916): 195-222.

<sup>163</sup> Wexler, *The Woman Who Walked into the Sea : Huntington's and the Making of a Genetic Disease*.



Davenport was not one to mince words. He used the results of his extensive research to argue for a eugenic approach to the disease. He advocated the screening of immigrants and the sterilisation of those with symptoms of HD, which Harper described as “frankly totalitarian” in his more recent work on the history of medical genetics.<sup>164</sup> Drawing on his eugenic beliefs, Davenport focussed on two aspects of HD. First, he applied the eugenic doctrine of “the excess fertility of the “unfit” to HD. The fertility rates of HD families, of individuals both with and without the disease, would become a major area of study for the whole of the twentieth century. Once again, this fitted into one of the most common eugenic narratives – fears were repeatedly expressed that vast numbers of the “unfit” would eventually outnumber the fit, and “problem families” were to be targeted on eugenic grounds. Despite most authors acknowledging the relatively low prevalence of the disease, author after author in the twentieth century expressed concern that the disease was increasing over time.

Another of Davenport’s pre-occupations was his claim that small numbers of original descendants with HD could result in such large numbers of people in subsequent generations. Wexler reprints an oft-quoted passage from his 1916 paper: “All these evils in our study trace back to some half-dozen individuals ... Had these half-dozen individuals been kept out of this country much of misery might have been saved.”<sup>165</sup> (p 158) Davenport is presumably referring to the “misery” of the American society having to deal with the disease, given that individuals concerned were going to develop HD whether they were in

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<sup>164</sup> Harper, *A Short History of Medical Genetics*.

<sup>165</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

the UK or the US. This reinforced his call for the screening of immigrants to the country as part of the broader eugenic goal of decreasing the numbers of the “unfit” in the US.

Both Harper and Wexler have described the potential influence of eugenic thinking on HD-affected families, but the mechanism through which eugenic ideas spread has not been a focus of major attention in relation to HD. Wexler briefly alluded to the role of popular culture in spreading eugenic ideology to the broader population, and the effects this may have had on families with a hereditary disease. She noted how in 1910, “the newspapers of eastern Long Island reported regularly on eugenics, race suicide, and the survival of the fittest.” In particular she cited a front page article of the *Sag Harbor Express* which praised the work of the Eugenics Record Office and advocated promoting “the best strains” and fostering “methods of restricting the defective and delinquent classes.”<sup>166</sup> (p 148) She also noted the work of eugenics scholars such as Steven Selden, who described the dissemination of eugenic thought into mainstream biology textbooks. In brief, she noted the popularisation of the ideology through magazines, films, books, lectures, exhibitions and the “Fitter Families” contests which were held around the country to promote eugenic practices. An examination of these questions is found in various histories of eugenics, starting with the work of Daniel Kevles in his groundbreaking 1985 work *In the Name of Eugenics*<sup>167</sup> and Martin Pernick’s examination of eugenic films *The Black Stork*.<sup>168</sup>

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<sup>166</sup> Ibid.

<sup>167</sup> Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Knopf, 1985).

<sup>168</sup> Martin S. Pernick, *The Black Stork: Eugenics and the Death Of "Defective" Babies in American Medicine and Motion Pictures since 1915* (New York: Oxford University Press, 1996).

The stigma, shame and secrecy which surrounded HD through much of the twentieth century began to wane, beginning in the late 1960s and early 1970s. Once again, Wexler and Harper are the only historians to examine this change. Wexler charted the efforts of motivated individuals, mostly family members affected by HD, to end the silence shrouding the disease. From the mid to late 1960s, two spouses of people with HD whose own children were at risk began to challenge the secrecy which dominated the disease and to speak of it openly. In her memoir *Mapping Fate*, Wexler details the efforts of Marjorie Guthrie, widow of the singer Woody Guthrie, and her own father Milton Wexler.<sup>169</sup> Guthrie founded the Committee to Combat Huntington's Chorea in 1968, which spread firstly across the United States. The development of these organisations will be further outlined in Chapter 6. Furthermore, Wexler placed these changes in HD in the context of broader social movements, such as feminism and the civil rights movement, which she claimed helped to create an environment that allowed people affected by the disease to begin to speak out. Harper has noted the close collaboration between professionals and family members.

## 2.7 Conclusion

Many aspects of HD's history are well-known, though much remains to be explored. We know that George Huntington (not George Sumner Huntington), the American 22-year-old recent medical graduate, was the first person to delineate the most important features of the disease, and to describe these succinctly in a medical publication in 1872. He grew up amongst HD families, and his father and grandfather had passed their collective knowledge of the disease, gained from their personal and professional experiences, on to him. The close experience his family had with HD families over generations allowed him to see the patterns

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<sup>169</sup> Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*

before him and communicate them to a wider audience. Despite recognising the challenges the disease posed and responding to features of the disease in emotional language, he did not vilify these families. Other American descriptions of the disease made in the decades before Huntington were also recorded by people who seemed to have close knowledge of the condition. Two of these authors reported varying responses of the surrounding community to HD families – one reported some vilification, the other emphasized social inclusion.

Much has been written about dramatic historical epochs in relation to HD. First described in the 1930s, the alleged associations between witchcraft accusations and HD have become deeply entrenched. There are real and also erroneous links between HD and “St Vitus Dance.” HD families themselves used this term to describe the disease in the nineteenth and early twentieth century. However there are also completely unsubstantiated claims that people with HD were amongst those participating in the Dancing Manias in the Middle Ages – no such evidence has ever been presented to support this claim. Linking the disease with persecuted minorities insinuates inevitable persecution and stigmatisation of HD families. In what has become a common theme in HD’s history, various claims have been repeated without verification by later authors writing on the disease. From Huntington’s very identity to the witchcraft claims, to the Dancing Manias and “plagues of the Middle Ages,” many authors have simply repeated prior claims without checking their veracity, or interrogating the intentions of the previous authors making the claims. The unthinking repetition of the narratives of the past has perhaps prevented different kinds of histories being explored.

An alternative to these tired narratives came through the work of Harper and Wexler in the 1990s. Harper made many contributions to changing the course of the historiography of the

disease. A change in subject matter also involved changes methodology. Harper included the traditional themes in his histories of the disease, however looked to German history and historians of eugenics. The US eugenicist Charles Davenport was a well known contributor to the study of HD, yet no historians until Harper interrogated Davenport's advocacy of eugenics. Given that the title of Davenport's publication on the disease was *Huntington's Chorea in Relation to Heredity and Eugenics*, it is hard to see how this link between eugenics and HD has been, and continues to be, ignored, by those writing on the history of the disease (with the exception of Wexler and Harper).

In her many publications on the history of the disease, Wexler also wrote on these themes, but also expanded the social history of the disease even further. This has involved utilising a range of historical techniques to try to answer different kinds of questions about aspects of HD's past. Rather than simply accept the narratives of eugenicist Vessie, Wexler re-examined the documentary evidence for his claims and found them to be erroneous, with one crucial misidentification of two individuals. Using the notebooks of the Huntington physicians and the papers of Elizabeth Muncey, which were the basis of the later papers by Muncey and Davenport, she challenged assumptions that stigma towards HD families was inevitable and unchanging. By contrast, she found many individuals with a known hereditary disease (which later was identified by Huntington as hereditary chorea) who were highly thought of in their communities. She also began a more detailed examination of the stigma of the disease in the twentieth century by reference to her own family, and the testimony given by HD family member to a US congressional history.

To date, the focus on the history of the disease has been on the Northern Hemisphere, and most particularly the US. Whereas much is known about the early descriptions of the disease in the US, there is little information on how the history of the disease has unfolded in other countries. Unlike in Europe, where the disease extends back in time uninterrupted, in the US, as a settler country, it was at least theoretically possible to trace the earliest cases of the disease, and the means by which those with HD emigrated to the US. Much is known about the early physicians who described the disease in the US, but again little is known about physicians in other countries who first identified the disease in other places. Were Huntington and his other American precursors unique? Are they the only examples of early physicians describing the disease having close knowledge of the families with HD in their communities?

Many people affected by HD who reflect on their own experiences of the disease wonder why there has been such secrecy in their own families. Various researchers and historians of HD have remarked on the stigma surrounding the disease, but until Wexler and Harper, there were no academic publications researching why the stigma has been so intense. Instead, previous medical histories have reinforced the notion that the answer to this question lies solely in the biological symptoms of the disease, ignoring possible social forces which might also have played their part.

It has been established by Wexler's research that in the US, HD was deeply stigmatised in the twentieth century. Although there are several studies on the stigma currently experienced by HD families, there have been no other historical examinations of this question in other countries. Another related question concerns the potential influence of eugenics. The two

countries researched thus far in relation to this question are the US and Germany, who had highly influential eugenics movements. What of this connection in other countries which were not known for their enthusiasm for the eugenics project?

Wexler and Harper have also discussed the changes which occurred from the late 1960s, when the tools of political activism were utilised by families affected by HD who challenged the secrecy and stigma and began campaigning better ways of managing the disease. Again, the early activism of Marjorie Guthrie and Milton Wexler has been described in the US, but the story of this era in other countries has yet to be told. Even basic information about the unfolding history of HD in other countries has yet to be explored. Using a combination of traditional medical historical techniques and a suite of innovative research methodologies, in the following chapters I will answer questions of both medical and social significance about the history of HD in Australia.

### Chapter 3. The First Hundred Years: Convicts, Pioneers and their Stories

*One would have expected a disease so widely known and used for teaching purposes to have been investigated from every angle.*<sup>1</sup> Minski and Guttman, 1938.

Very little is known about either medical or social aspects of the early history of HD in Australia. The few claims made to date have been based on cursory assumptions rather than detailed examination. When the disease has been mentioned in the academic literature, the main focus has been the existence of a large Tasmanian kindred, though little apart from the high local prevalence has been reported. In this chapter, various questions will be answered concerning the early origins of the disease in Australia, from the first days of European settlement to the early twentieth century. Some of these are relatively straightforward. When did people with HD first come to Australia – have they been here since early European settlement, and were there no convicts with the disease, as has been claimed? What were the ethnic origins of the disease in Australia? Has the Indigenous population been affected? In keeping with the goal of this dissertation to investigate both medical and social features of the disease, much of the chapter is devoted to exploring the lives of people from HD families in the nineteenth and early twentieth centuries. In particular, questions of stigma, social inclusion or social ostracism will be explored, much as Wexler did in her examination of the disease in the US in the nineteenth century. Given that the disease was previously portrayed as universally stigmatised, with HD families in the US allegedly “shunned” by their communities, the historical record will be examined to see whether this was the case in Australia, a different country on the other side of the world.

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<sup>1</sup> L Minski and E Guttman, "Huntington's Chorea: A Study of 34 Families," *Journal of Mental Science* 84 (1938): 21-96.



Before presenting the results of my research, the current state of knowledge and the main claims which have been made about the history of the disease in Australia will be outlined. After drawing attention to the methodological challenges of investigating a hidden disease with limited primary source material, I will describe the methods I have used in this study to shed light on aspects of the social history of the disease in Australia. Next, I will present evidence from four different families which demonstrate that the origins of the disease in Australia were in the earliest days of European settlement. The majority of the chapter will present the results of extensive genealogical investigations, outlining aspects of the lives of HD families in the nineteenth and early twentieth century. Details of several families will be presented, each showing that while HD was a challenging condition, many families with the disease were well-integrated and respected in their communities. Most of the genealogical data on which these latter conclusions are based comes from the extended Tasmanian family which has been described in the medical literature. This family, already identified by those writing on the history of the disease, has left a more lasting impression on the historical record. As I was able to discover more about this family than others, a richer description of their lives was possible. I will end with a brief overview of the ethnic origins of the disease, followed by details about the introduction of HD into Aboriginal communities.

### **3.1 Current Knowledge**

There are two claims made about the history of the disease in Australia by the few authors who have investigated this subject. The first is that the Tasmanian kindred was the first family with HD in Australia. Over the past twenty years, in discussing the disease with various physicians, this claim has been made to me personally on numerous occasions. More formally, in the opening sentence of his 1979 “History of Huntington’s Disease in

Australia”, psychiatrist Edmond Chiu stated: “It is accepted that the first known sufferer of this disease was a twice married lady from Somerset, England.”<sup>2</sup> (p 4) This claim is repeated on the website of the Huntington’s Disease Society of Victoria.<sup>3</sup> This position has been maintained in the absence of a detailed study of the history of the disease – my research has uncovered evidence of earlier cases unrelated to the Tasmanian kindred.

The next and related claim refers to the absence of HD in the convict population which was sent to Australia from Britain between 1788 and 1868. In 1964, psychiatrist Charles Brothers, one of best known authors on HD in Australia, stated: “Contrary to expectations, there has been no evidence brought to light of pre-choreics being included in the large convict population sent out by Great Britain early last century – at least not in the Victorian or Tasmanian series of cases.”<sup>4</sup> (p 408) Brothers does not expand on why this situation would be “contrary to expectations,” though he hints at a relationship between the “convict taint” and “hereditary disease” - two potent tropes in early twentieth century Australian public discourse. He also recognised that families might have been as “motivated and adept at hiding their convict past as they were at hiding the HD in their families” (p 408), drawing attention to the secrecy associated with both of these conditions. The absence of an HD/convict nexus has been affirmed more recently (2000) by neurologist Mervyn Eadie in his history of Australian neurology. In the segment on chorea under “Involuntary movement disorders,” he stated: “It is perhaps of some interest that there was no record of

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<sup>2</sup> Edmond Chiu, "History of Huntington's Disease in Australia," in *1st Australian Huntington's Disease Conference*, ed. Robyn Kapp, (Melbourne: Australian Huntington's Disease Association (NSW), 1979), 4-5.

<sup>3</sup> Huntington’s Disease Society of Victoria Website. [www.huntingtonsvic.org.au](http://www.huntingtonsvic.org.au) Accessed 4 July, 2013.

<sup>4</sup> C R D Brothers, "Huntington's Chorea in Victoria and Tasmania," *Journal of the Neurological Sciences* 1 (1964): 405-20.

Huntington's disease in the convicts shipped to Australia in earlier times.”<sup>5</sup> (p 11) In his review of the epidemiology of HD, British geneticist Peter Harper's section on Australia also commented on the absence of HD in those transported to Australia for criminal offences.<sup>6</sup> In this chapter, I will present evidence of at least two convicts with the disease. In this and many other respects, the trajectory of Huntington's has parallels with the broader history of Australia – despite being hidden from public life, it has nevertheless been present in this country since European settlement.

### 3.2. Method

In order to examine aspects of the lives of people with HD in this era, the first step was to locate families with the disease. The hereditary nature of HD obviously aided this process. Wexler had identified the challenges of finding primary source material, though in her studies she had managed to locate the case books of George Huntington's grandfather and the records of Elizabeth Muncey. Having gathered material on some families, she was then able to use the tools of genealogical research, such as newspaper articles and official records, to explore details beyond the basics, such as the marriages people made, occupations and descriptions of important events in their lives.

Given the absence of any published histories of HD in Australia, the challenge of finding evidence of this generally unknown disease, which was not formally identified until the twentieth century, meant utilising novel historical techniques. Despite extensive searching, no diaries of HD family members or personal papers of physicians have emerged. There was

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<sup>5</sup> Mervyn J. Eadie, *The Flowering of a Waratah : A History of Australian Neurology and of the Australian Association of Neurologists* (Sydney: John Libbey, 2000).

<sup>6</sup> Peter Harper, "The Epidemiology of Huntington's Disease," in *Huntington's Disease*, ed. Peter Harper, (London: W.B. Saunders, 1996), 201-40.

no equivalent of Abel Huntington's notebooks, nor Muncey's pedigrees, as found by Wexler.<sup>7</sup> Nor was I able to find any mention of HD or hereditary chorea prior to 1902 in the Australian medical literature. The term "hereditary chorea" yielded no results in searching Australian newspaper archives pre-1900.<sup>8</sup> There were two potential sources of information which could serve as starting points. The first was early medical publications on the disease. Three papers proved useful in this respect. Dr Charles Hogg (1870-1951) wrote the first Australian description of the disease in 1902, and in this publication he gave the initials of two brothers, the month of their admission and the name of the hospital to which they were admitted.<sup>9</sup> In 1917, Dr Evan Jones (1887-1948) wrote an article on a cousin of these brothers, again indicating the initials, the name of the institution he was admitted to and the year.<sup>10</sup> Dr Charles Brothers (1905-1963) wrote important papers on the Tasmanian kindred, first published in 1949, and in these papers he included a genogram of this family.<sup>11</sup>

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A second source was constituted by the many individuals who have traced the historical roots of HD in their families. Having gained ethics approval,<sup>14</sup> my research project was advertised to members of the New South Wales Branch of the Australian Huntington's

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<sup>7</sup> Alice Wexler, "Chorea and Community in a Nineteenth-Century Town," *Bulletin of the History of Medicine* 76, no. 3 (2002): 495-527.

<sup>8</sup> <https://trove.nla.gov.au/newspapers> Accessed 30 Jan 2015.

<sup>9</sup> C.A. Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," *Australasian Medical Gazette* 21 (1902): 400-04.

<sup>10</sup> S. Evan Jones, "Huntington's Chorea," *Medical Journal of Australia* 1 (1917): 376-77.

<sup>11</sup> C R D Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," *Proceedings of the Royal Australian College of Physicians* 4 (1949): 46-50.

<sup>12</sup> C R D Brothers and A W Meadows, "An Investigation of Huntington's Chorea in Victoria," *Journal of Mental Science* 101 (1955): 548-63.

<sup>13</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-420.

<sup>14</sup> Ethics approval for this research was granted on 18 October, 2007 by the University of Sydney Human Research Ethics Committee, reference #10372.

Disease Association.<sup>15</sup> I asked interested family members to contact me if they wished to share information about their HD family history. Thirty-five family members contacted me, though only a few of these contacts yielded usable information. Some individuals were from the same families, and others led back to the same ancestors. Other individuals were from families who had come to Australia quite recently from countries such as New Zealand or the United Kingdom. For others, I was unable to trace the origins of the disease further because of the absence of genealogical data. A third source was a document lodged in the Mitchell Library in Sydney.<sup>16</sup> This included a family tree and brief details such as asylum admissions and the presence or absence of the disease.

Using these three sources as starting points, I was able to utilise a range of genealogical resources and archival material. Whenever possible, the material collected was checked against other sources, for example through Birth, Death and Marriage Certificates, newspaper articles, shipping records, online family history databases, convict records and colonial censuses. In NSW, Tasmania and Victoria, the patient records of individuals admitted to asylums were examined. Not surprisingly, these archives contained a wide range of material on the individual patients, ranging from the most basic, such as simply a name and date of admission, to rich detail such as the circumstances leading up to their admission and letters written by family members. Patient data from asylums have been used in historical research for a range of purposes, as discussed by medical historian John Harley Warner.<sup>17</sup> More recently, the psychiatric case notes of the Maudsley Hospital from 1924-35 were examined to provide details of different ways of diagnosing and thinking about mental

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<sup>15</sup> See Appendix A

<sup>16</sup> Mitchell Library, Manuscript Collection, State Library of NSW.

<sup>17</sup> J. Warner, "The Uses of Patient Records by Historians—Patterns, Possibilities and Perplexities," *Health and History* 1 (1999): 101-11.

illness in this era<sup>18</sup> prior to the existence of more formal classification of diseases. From a local perspective, historian Cathy Coleborne has used the records of asylums in Australia and New Zealand to explore relationships between asylum patients and their families, and encouraged the use of such records to broaden our understanding of asylum practices.<sup>19</sup> I have used asylum records to answer a range of questions about HD, which will be outlined in each section, in this and the following chapter.

Another methodological issue concerns the question of retrospective diagnosis, which is typically fraught with difficulties, not least because of the changing conceptual frameworks through which disease is perceived and characterised. The autosomal dominant nature of Huntington's disease, though, provides at least some greater certainty in examining its origins. If a person has HD, then either their biological father or mother must have carried the HD gene (excepting the small number of people with new mutations). I have taken care to include only information which is strongly suggestive of HD, though only a genetic diagnosis would confirm my impressions, which is obviously not possible in historical research. In this way, I was able to locate families where some members were affected by HD and describe details about their lives before the condition was known by physicians.

A central concern in the presentation of this material was the need to keep the families' identities anonymous - as a genetic disease, present-day individuals at risk could be identified if too much information was provided about their families' history. In addition to generic privacy concerns, there are very specific reasons for treading cautiously. Knowledge of a

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<sup>18</sup> Edgar Jones, Shahina Rahman, and Brian Everitt, "Psychiatric Case Notes: Symptoms of Mental Illness and Their Attribution at the Maudsley Hospital, 1924-35," *History of Psychiatry* 23, no. 2 (2012): 156-68.

<sup>19</sup> Cathy Coleborne, "Families, Patients and Emotions: Asylums for the Insane in Colonial Australia and New Zealand, C.1850-1910," *Social History of Medicine* 19, no. 3 (2006): 425-42.

person's at-risk status makes them vulnerable to genetic discrimination in areas like insurance and employment.<sup>20</sup> As noted in the previous chapter, Wexler faced this issue with her most recent book, which traced George Huntington's original families. She chose to use the actual names, stating that there were no known descendants still in the town which could be traceable by revealing their names.<sup>21</sup> In this dissertation, I have chosen to de-identify most of the information, apart from the names of the physicians concerned. Even the Tasmanian kindred, whose names have been published in numerous articles, are not identified by name in this dissertation. All of the individuals' names have been changed, regions have been referred to rather than specific towns or suburbs when possible, and no identifying features have been provided which would enable the identification of current HD families, other than what is already in the public domain. A code book has been created which is available for verification of these sources.

### **3.3 The Earliest Cases of HD in Australia**

In searching for the earliest arrivals of people with HD to Australia, HD-affected families who had researched their own histories were the original sources of the following information. Three people who contacted me as a result of my request had traced the HD in their families back to the earliest days of European migration in the late eighteenth and early nineteenth centuries. The manuscript which had been lodged in the Mitchell Library was the other source. Three of these kindreds had convict ancestors, and the following information provides strong evidence that families with HD have been present in Australia since early

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<sup>20</sup> Janet K. Williams et al., "In Their Own Words: Reports of Stigma and Genetic Discrimination by People at Risk for Huntington Disease in the International Respond-HD Study," *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics* 153B, no. 6 (2010): 1150-59.

<sup>21</sup> Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven: Yale University Press, 2008).

European settlement. It shows that some convicts had symptoms of HD, two of them dying in middle age in institutional care.

## Family A

Two people who were previously not known to each other, who both had HD in their families, independently traced the origins of the disease back to a couple, Thomas (1798-1843) and Ellen (1800-58). Convicted in 1816 in Lancashire, England of “horse stealing,”<sup>22</sup> Thomas’s death sentence was commuted and he was transported to Sydney, arriving in 1817. Ellen was born in Sydney,<sup>23</sup> one of the so-called “currency lasses.” The couple married in 1821<sup>24</sup> and had seven children who lived to adulthood. Evidence of the HD in their family comes from several independent sources. There is documented evidence that two of their seven children had multiple descendants who were diagnosed with the disease over the coming century. A third child died aged 43 of “congestion of brain, and effusion”<sup>25</sup> and her daughter died of “effusion of brain” aged 33.<sup>26</sup> Thomas himself was admitted to Tarban Creek Lunatic Asylum in 1841.<sup>27</sup> This institution was the first purpose built asylum in the colony,<sup>28</sup> and is now known as Gladesville Hospital. The asylum notes, which I was able to locate and consult, describe him as “intellect weak; reported to have been violent”<sup>29</sup> and in

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<sup>22</sup> Australian Convict Transportation Registers – Other fleets and ships, 1791-1868. Accessed through Ancestry.com. 15 Sep 2013.

<sup>23</sup> Death Certificate, 1858, NSW Registry of Births, Deaths and Marriages. (Hereafter NSWBDM). Transcript in the possession of the author. (Hereafter, all certificates cited are in possession of the author. Full details are not given to maintain anonymity.)

<sup>24</sup> Early Church Records Marriages, 1821, Minister NSW Registry of Births, Deaths and Marriages.

<sup>25</sup> Death Certificate, 1866. NSW Registry of Births, Deaths and Marriages.

<sup>26</sup> Death Certificate, 1876, NSW Registry of Births, Deaths and Marriages.

<sup>27</sup> State Records Authority of New South Wales; Kingswood, New South Wales, Australia; (hereafter, SRNSW), Tarban Creek Lunatic Asylum: Series number 5038: Admission Register 1838-1963.

<sup>28</sup> A. W. Ireland, "The Select Committee of the Lunatic Asylum, Tarban Creek, 1846" *The Medical Journal of Australia* 1 (1964): 90-97.

<sup>29</sup> SRNSW, Tarban Creek Lunatic Asylum: Series number 5038: Admission Register 1838-1963.



1843 report that he was “Discharged to his Wife, feeble and insane.”<sup>30</sup> He died ten weeks later.<sup>31</sup> Unfortunately, cause of death was not listed in death certificates at this time. Judging from the admission notes indicating that he had been violent, it seems likely that the behavioural manifestations of HD were the reason his wife was no longer able to care for him. This situation is an early forerunner to the numerous other people who were admitted to such institutions because of behavioural, psychiatric and personality changes associated with HD, and the lack of alternative care over the centuries for families dealing with this complex disease.

## **Family B**

Two brothers whose father had HD have traced the history of the disease in their family to a couple in the convict era. In this case, it is less clear than in Family A which of the married couple had HD. Michael (1794-1849) was convicted and sentenced for stealing and was transported to Australia in 1814.<sup>32</sup> His wife Elizabeth (1823-60) was born in Ireland. I have found no further information about her, apart from the fact that the couple married in 1843,<sup>33</sup> and that they had four children. There is solid evidence that two children inherited the HD gene, with a strong suspicion in a third. This son died in an asylum, his cause of death being listed as “sunstroke paralysis”<sup>34</sup> – sunstroke was thought to be a cause of mental

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<sup>30</sup> SRNSW, Tarban Creek Lunatic Asylum: Series number 5029: Record Book 1839-1846.

<sup>31</sup> Burial Certificate, Early Church Record Burials. 1843, NSWBDM.

<sup>32</sup> Australian Convict Transportation Registers – Other fleets and ships, 1791-1868. Accessed through Ancestry.com. 15 Sep 2013.

<sup>33</sup> NSW Births Deaths and Marriages Online Index. [www.bdm.nsw.gov.au](http://www.bdm.nsw.gov.au) Accessed 4 Nov, 2010.

<sup>34</sup> SRNSW, *Infirm and Destitute Asylums – Inmate Records. George Street Asylum, Parramatta*: Series number 4963 Register of Admissions and Discharges.

illness in the nineteenth century.<sup>35</sup> This couple had multiple descendants who have developed HD, some dying in asylums and others with current diagnoses.

The eldest son Joseph (1845-90) died after being run over by a train. According to the research of the brothers, the coroner's report into his death makes it obvious that he "was suffering from HD at the time of his death."<sup>36</sup> He had married aged 27 and was employed as a railway worker. Three of his 12 children are known to have developed the disease, all women dying at relatively young ages – 45, 48 and 37. The latter's death certificate stated the cause of death as "chronic dementia."<sup>37</sup> Two of the three were admitted to Kenmore Mental Hospital in Goulburn.<sup>38</sup> Regrettably there are few extant records available from this institution, so no further details are available on these people.

The next affected son William (1847-1924) had 11 children, at least three of whom were affected by HD. Family members recall stories of him regularly "waving his arms about" as he worked on his farm, which they later believed was a sign of his HD.<sup>39</sup> A local in the town stated that "old Mr x had "Parkinson's Disease."" Although he died at his home, two of his three sons who were diagnosed with HD died in Sydney asylums. Matthew (1876-1932) worked as a butcher/grocer and died of "Huntingdon's (sic) chorea" in Callan Park Mental Hospital.<sup>40</sup> His brother Robert (1876-1930) was a police constable, and died of "Huntington's chorea" in Gladesville Mental Hospital.<sup>41</sup> Both sets of records state that their

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<sup>35</sup> Graham Edwards, "Causation of Insanity in Nineteenth Century Australia," *Australian and New Zealand Journal of Psychiatry* 16 (1982): 53-62.

<sup>36</sup> Personal Communication with family historian, 17 January 2013.

<sup>37</sup> Ibid.

<sup>38</sup> Ibid.

<sup>39</sup> Ibid.

<sup>40</sup> SRNSW, Callan Park Mental Hospital, Series number 4987: Case Papers (Deceased Male Patients).

<sup>41</sup> SRNSW Gladesville Mental Hospital, Series number 5030: Admission Files.

father had Huntington's chorea. Robert was the grandfather of the brothers who contacted me about the research.

## **Family C**

The next kindred of interest is a Tasmanian family who have traced the HD in their family back to convict ancestry – I found out about this kindred through a descendant who contacted me having heard of my research.<sup>42</sup> The following information indicates that the disease was present in Tasmania prior to the more prominent Tasmanian kindred, which was first described by Charles Brothers in 1949. James (1772-1835) was initially transported as a convict to Sydney in 1791, then transferred to Norfolk Island. He came to Tasmania in 1807 and married Mary (1794-1853) in 1808. The couple had four children. In 1819 he was sent by ship to Sydney, as, according to a letter written by his wife, he had become “deranged.” One website reports that over the next sixteen years he was often homeless and ended up in a Benevolent Asylum.<sup>43</sup> One of his children, Anne (1817-77), presumably carried the HD gene – she died in an infirmary and over the next four generations there are numerous family members diagnosed with HD.

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<sup>42</sup> The following information comes firstly from the family member – her husband and many of his relatives have been diagnosed with HD. I was able to expand on this research and verify much of the information on through primary sources lodged on Ancestry.com. James and some of his family are also the subject of a book about early convict years, which verifies the above information, but the title cannot be named to maintain anonymity.

<sup>43</sup> Website devoted to early convict history, especially Norfolk Island, which cannot be named to maintain anonymity.

## Family D

The final family traceable to early colonial times was identified through a manuscript which had been lodged in the Mitchell Library in Sydney.<sup>44</sup> This brief record traced the origins of HD in this family to an English couple. Charles (1770-1847?) first arrived in Australia in 1798 as the master of a ship - he had the dual task of bringing female convicts from the UK and assessing the potential for whaling.<sup>45</sup> Over the next decade and a half he made trips back and forth between the colony and the UK, and travelled to New Zealand and Tasmania. He married Emily (1788-1854?) in the UK in 1804, the couple had children and in 1816-17 the family moved to Australia where more children were born. There are several mentions of this family in the colonial censuses and musters, the last record being the 1828 census.<sup>46</sup> Details of his life after this are not confirmed, though several genealogy websites record details about this family. One account suggests that he died in 1847 in Hobart, “a pauper” however I was unable to verify this information. Emily was reported as dying in Melbourne in 1854, but again I was unable to verify this claim. Their common surname made further investigations difficult, though later generations were recorded in this document lodged in the library.

The following table describes cases reported to have had HD in the manuscript. I was able to verify the details of four from their death certificates and the last two from asylum records.

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<sup>44</sup> Mitchell Library, Manuscript Collection, State Library of NSW.

<sup>45</sup> The following information comes from various records accessed through Ancestry.com, including shipping records, the Australian Birth Index, Musters and other colonial correspondence.

<sup>46</sup> SRNSW, *1828 Census Alphabetical Return*. Series Number NRS 1272. Accessed through Ancestry.com 4 Aug 2013.

Generation	M/F	Year of Birth	Year of Death	Death Details
1	M	1770	1847?	? Pauper
2	F	1816	1862	“Softening of the brain”(DC)
3	M	1841	1912	“Injuries accidentally received through being run over by a railway train” (DC)
4	F	1863	1909	Died at Callan Park, “choreic dementia” (DC)
4	M	1865	1913	?
4	M	1866	1925	Died at home “Huntington’s chorea” (DC)
5	F	1898	1953	?
5	F	1903	1971?	?
5	M	1910	1952	?
5	F	1912	1952	Died at Callan Park, “Huntington’s chorea”(HR) <sup>47</sup>
5	F	1917	1962	Died at Callan Park, “Huntington’s chorea” (HR) <sup>48</sup>

**Table 2 HD in Family D from Manuscript**

**KEY:**

**DC = NSW BDM Death Certificate**

**HR = Hospital Records, NSW State Records Office, Kingswood.**

The information presented about these four separate kindreds shows that people with HD have been present in Australia well before the previously given year of 1842. Contrary to prior claims, there were convicts with the disease.

### **3.4 Social Exclusion or Social Integration?**

Having established that HD has been a part of Australian society since the earliest days of European settlement, in this section I will present details of the social circumstances of several families living with the disease in the nineteenth century. I will answer the same questions about Australian families as those posed by Wexler about the experience of the disease in the nineteenth century in the US: were these families with a hereditary disease in

<sup>47</sup> SRNSW, Callan Park Mental Hospital Series Number 4988: Case Papers, Deceased Female Patients.

<sup>48</sup> SRNSW, Callan Park Mental Hospital Series Number 4988: Case Papers, Deceased Female Patients.

their midst stigmatised, ostracized and excluded from the broader society, or were they integrated in the life of their communities?

To address these questions I relied on the information described in the method section. I traced families with HD as far as I could from the information available to me. Many, if not most, searches led to dead ends. Asylum data was frequently missing. Some people had common names, which prevented me tracing their family history with any certainty. I have found isolated details on many individuals; however three particular families left marks on the historical record that were sufficiently detailed to allow some conclusions to be drawn. In particular, much information is already available about the Tasmanian kindred, not least their identities, and it is therefore the primary focus of this section. The information presented is representative of the other information I gathered on other individuals who were not included - the excluded material lacked the same level of detail, but did not differ in terms of themes uncovered and conclusions which could be drawn.

#### **3.4.1 Family A – Next Generations**

Details of the first generation of this family, described briefly above, were provided by a librarian and genealogist with HD in her family who contacted me and volunteered to share the results of her research, which I then extended and verified from primary sources such as asylum records and death certificates. In this section I will outline more of the social history of this family. Prior to his institutionalisation, Thomas was a self-employed tailor. Details of Thomas and Ellen's children follow – this kindred left residual traces of their lives in the historical record in the mid-nineteenth century. Like many families descending from convicts, there were a wide range of social outcomes in their descendants. A brief outline of the next generation of this family gives some indication of the varied occupations and social

standing. Following the summary, details of the more noteworthy members of the generation will be outlined.

#	DoB DoD	Date of Marriage	No. of Children	Occupation/ Husband's Occupation	Age At Death	Cause of Death/Circumstances
1 M	1821-1888	1864	3	Labourer	67	Heart Disease
2 F	1823-1871	1842	11	Farmer/ Sawyer	48	Gastritis
<b>3 F</b>	<b>1823-1866</b>	<b>1842</b>	<b>7</b>	<b>Publican/ Shipowner/ Landlord</b>	<b>43</b>	<b>Congestion of Brain, and Effusion</b>
4M	1824- ?	Unmarried		Convict	Alive in 1858?	Went missing in Tasmania following escape
<b>5 F*</b>	<b>1825-1909</b>	<b>1850</b>	<b>9</b>	<b>Mother/ Widow/ Prostitute</b>	<b>84</b>	<b>Cerebral Haemorrhage</b>
6 M	1831-1876	1853	9	Bootmaker	45	Cardiac Dropsy
<b>7 M*</b>	<b>1838-1899</b>	<b>1858</b>	<b>13</b>	<b>General labourer, horse driver</b>	<b>61</b>	<b>Heart disease</b>

**Table 3. Second Generation of Family A**

**KEY:**

**Bold = HD/Suspected HD**

**\* = Multiple descendants with HD**

Two of Thomas's daughters (2F and 3F) married while he was in the Tarban Creek Lunatic Asylum. It is very likely that 3F had HD – her death certificate stated that she had died of “Congestion of brain, and effusion.”<sup>49</sup> She and her daughter died young (aged 43 and 33 respectively), with her daughter also dying of “effusion of brain.”<sup>50</sup> Two of her grandsons died in their 20s of “alcoholism.”<sup>51</sup> Given that the symptoms of HD are often mistaken for drunkenness, it is possible that these two might also have had HD. 5F and 7M had multiple descendants with HD, down to the current generation.

<sup>49</sup> Death Certificate, 1866. NSWBDM.

<sup>50</sup> Death Certificate, 1876. NSWBDM.

<sup>51</sup> Death Certificates, 1893 & 1895. NSWBDM.

The historical footprint of 3F and her husband points to a woman who was well-connected and respected in her community. Her husband bought and sold boats and together they became proprietors of a Sydney hotel. She was highly involved in the business. In an advertisement in the local Sydney newspaper in 1859, she proudly advertised that she had been appointed by a committee of ladies to provide the catering for a prominent public day, providing food and refreshment.<sup>52</sup> A glowing account of the event appeared in the social pages of one of the Sydney magazines the following week.<sup>53</sup>

In 1862 she and her husband were among notables who donated money to the “mother country”<sup>54</sup> – they were listed as subscribers to a request for support of Britain’s industries which were in economic distress. They advertised in the local paper regularly for servants and in 1865 rented out a “snug cottage” in Pyrmont.<sup>55</sup> Further evidence of their position in society can be gauged from the marriages made by their daughters. The occupations of their sons-in-law included a chief clerk in the Supreme Court, a stock and station agent from a political family and a senior civil servant. Her death certificate indicated that she died at home.

The backgrounds of other family members revealed a rather different set of social circumstances. 4M was a convicted criminal who was transported to Tasmania. 5F’s first husband died and, left with the care of their children, at one point she was described as “a

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<sup>52</sup> *The Sydney Morning Herald* (NSW:1842-1954), p 4, 1859. This and the following newspaper references in this chapter are reported to maintain anonymity.

<sup>53</sup> *Bell’s Life in Sydney and Sporting Reviewer*, (NSW: 1860-1870), p 3, 1859.

<sup>54</sup> *The Sydney Morning Herald* (NSW:1842-1954), p 8 1862.

<sup>55</sup> *The Sydney Morning Herald* (NSW:1842-1954), p 8, 1865.



common prostitute.” Less colourful members of the family included bootmakers, labourers and clerks.

### **3.4.2 Family E**

The following family was found through the medical literature – several members of this immediate family and their cousins were admitted to asylums in the Sydney region in the first two decades of the twentieth century. In the state of NSW, records of mental hospitals have open access after 100 years. Special permission is required to access later records – this approval was sought and granted for this research.

#### **Source Material**

In 1902, in the first paper in the Australian medical literature to identify a person with HD, Charles Hogg outlined the cases of two brothers who had been admitted to Parramatta Hospital for the Insane.<sup>56</sup> As Hogg had published their initials in the paper, asylum records of this year were examined which allowed an exploration of details of these men’s lives, and the lives of their relatives. The cousin of these brothers was admitted to Callan Park Asylum a short time later, and a description of this case formed the basis of another paper, published by Evan-Jones in 1917.<sup>57</sup> I accessed asylum records to obtain information on these families, then investigated their lives further using techniques already described. These investigations yielded information about the lives of these families, the circumstances surrounding the admission of the brothers to asylums and the public attitudes towards the family expressed through newspaper references including an obituary of their mother.

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<sup>56</sup> Hogg, "Two Cases of Huntington's Chorea - with a Family History," 400-04.

<sup>57</sup> Evan Jones, "Huntington's Chorea," 376-77.

## Background Information

In the early 1850s, two brothers, Richard and Harold, who would both later develop HD, migrated to Australia from Cornwall in the UK. Shipping records indicate that their parents had pre-deceased them<sup>58</sup> – Hogg later reported that it was their father who was affected by HD.<sup>59</sup> I have investigated both families, and will report here on the family of the first brother as there was more information on this branch.

### Richard (1829-31?-1875) and Jemima (1833-1908)

Richard's exact date of birth is not clear. Born in Cornwall in an era when a third of the population emigrated,<sup>60</sup> he was one of those who chose to escape the poverty and lack of opportunities of his home county. An assisted immigrant, he arrived in Sydney in 1854.<sup>61</sup> His religion was noted on these records to be Church of England, though many of these Cornish agricultural labourers were Wesleyan Methodists, and his death certificate recorded his religion as Wesleyan.<sup>62</sup> Richard married Jemima, a Protestant Irishwoman, two years after arriving in Sydney,<sup>63</sup> and then the couple moved to a farming region several hours north of Sydney where there was a large Wesleyan Methodist population. Over the next half century the family had close ties with the church. Richard was apparently literate,<sup>64</sup> though was unable to write – his marriage certificate was signed with his “mark.”<sup>65</sup>

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<sup>58</sup> Assisted Immigrant Passenger Lists, 1828-1896. State Library of NSW.

<sup>59</sup> Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," 400-04.

<sup>60</sup> James Jupp, *The English in Australia* (Cambridge ; Port Melbourne: Cambridge University Press, 2004).

<sup>61</sup> Assisted Immigrant Passenger Lists, 1828-1896. State Library of NSW.

<sup>62</sup> Death Certificate, 1875. NSWBDM.

<sup>63</sup> Marriage Certificate, 1856. NSWBDM.

<sup>64</sup> Assisted Immigrant Passenger Lists, 1828-1896. State Library of NSW.

<sup>65</sup> Marriage Certificate, 1856. NSWBDM.

The couple took up land and farming. A year after their marriage they had their first child, and the couple went on to have seven or eight children – Richard is recorded as the father of the first seven. One died as an infant, and the last was possibly Jemima’s child to her second (and at the time future) husband. Richard died in the town where they had lived. The cause of death on his death certificate was “primary apoplectic seizure, secondary paralysis” and his illness was said to be “of several years’ duration.”<sup>66</sup> In Hogg’s paper describing the disease in Richard’s sons, Hogg reported that Jemima had told him that Richard was 38 when symptoms began. The first symptoms were “a slight twitching and nervousness of the limbs.”<sup>67</sup> (p 401) Later recollections of Richard’s niece and nephew from letters they wrote to an asylum gave slightly differing accounts of the onset of the disease. His nephew by marriage stated that he “did not develop any symptoms until about 10 years after I was first married ... (he) showed symptoms about 30 or 35 years of age, but there did not seem much insanity but stubbornness.”<sup>68</sup> His niece on the other hand reported in a letter that “my father’s brother had this affection slightly when he married and he gradually became worse until he was as helpless as a child.”<sup>69</sup>

One newspaper record indicates that he was active in the life of his town. In 1870, he was reported as being at a meeting of local “gentlemen,” where he volunteered to sit on a political committee.<sup>70</sup> I have not been able to locate his obituary. In the two decades between his arrival in the colony and death, the couple managed to purchase property. Despite his

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<sup>66</sup> Death Certificate, 1875. NSWBDM.

<sup>67</sup> Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," 400-04.

<sup>68</sup> SRNSW, Callan Park Mental Hospital. Series number 4987: Deceased Male Patients 1910-1963. Letters were located in these files referring to the cousin of this patient.

<sup>69</sup> Ibid.

<sup>70</sup> *Macleay Herald* (NSW: 1864-1883), p 3, 1870.

illness, they were relatively prosperous. His wife has left more traces in the historical record – there is an obituary in the local newspaper and some of the letters she sent to her son in the asylum have survived. As can be seen from the following information, this woman led a remarkable existence. Not only did she manage life as a young woman pioneer in an unfamiliar country, she also had to deal with her husband's disease, and then watch as each of her six children showed the early symptoms and then went on to die of the disease over the coming decades.

According to both Hogg and Evan Jones,<sup>71</sup> all six of their children had HD. This information was verified separately by two family members independently of Hogg a decade later.<sup>72</sup> The following table summarises details of this generation.

<b>M/ F</b>	<b>Occupation Of person or husband</b>	<b>Birth/Death</b>	<b>Age At Death</b>	<b>Place of Death</b>	<b>Cause of Death recorded on Death Certificate</b>
1M	Farmer	1857-1893	35	Home	Multiple Sclerosis of the Spinal Cord
2M	Gardener/ Farmer	1861-1902	41	Parramatta Hospital for the Insane	Huntingdon's Hereditary Chorea, Paralysis of Muscles of Pharynx Exhaustion
3M	Farmer/ Labourer	1863-1904	41	Parramatta Hospital for the Insane	Chronic brain disease
4F	Carpenter	1864-1906	41	Home	Locomotor Ataxy
5F	Postmaster	1868-1903	35	Home	Myelitis
6M	Child	1869-1879	10	Home	Pulmonary Consumption

**Table 4 Second Generation of Family E**

#### **1M. Ernest (1857-1893)**

Described as a farmer on his death certificate, Ernest presumably worked on his parents' farm. He never married, and according to Hogg's paper he began showing symptoms of the

<sup>71</sup> Evan Jones, "Huntington's Chorea," 376-77.

<sup>72</sup> SRNSW, Callan Park Mental Hospital. Series number 4987: Deceased Male Patients 1910-1963.

disease ten years before his death, at the age of 25.<sup>73</sup> The cause of death – “multiple sclerosis of the spinal cord” -- was diagnosed by the local doctor who had experience of other members of the family. He stated that the duration was “some years.”<sup>74</sup>

### **2M. Jonas (1861-1902)**

Jonas and his descendants have left more of a mark on the historical record, mostly in the form of asylum records. He too was a farmer. He was married aged 23 to a woman from a nearby town.<sup>75</sup> They had four children, who were born between 1885 and 1893. In 1901, his wife made the dramatic decision to send her husband to a government asylum in Sydney, their local doctor signing the request.<sup>76</sup> This doctor was well aware of the family, having signed the death certificate of Jonas’s elder brother Ernest. Given their year of death, their two sisters would have been showing symptoms of the disease. In signing the request for admission to the asylum, the doctor listed Jonas’s condition as “Friedrich’s ataxia,” another hereditary disease with motor symptoms which had been recognised a decade earlier than HD (in the 1860s) and was also much rarer. It seems that over the next year James spent some time in the George St Asylum, Liverpool Benevolent Asylum, but also in the Liverpool lock up. He was then admitted to Parramatta Hospital for the Insane in June 1902.<sup>77</sup>

### **3M. Edward (1863-1904)**

Edward also married a local woman.<sup>78</sup> Soon after their marriage they moved to a nearby town on the coast. The couple had eight or nine children, born between 1886 and 1901 and his wife also had children with a new partner, three while Edward was in the asylum. Edward seems to have run a business which did not succeed - he was noted to be bankrupt in 1890.

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<sup>73</sup> Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," 400-04.

<sup>74</sup> Death Certificate, 1893. NSWBDM.

<sup>75</sup> Marriage Certificate, 1884. NSWBDM.

<sup>76</sup> SRNSW, Parramatta Hospital for the Insane, Series number 5081: Case Papers 1870-1963.

<sup>77</sup> Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," 400-04.

<sup>78</sup> Marriage Certificate, 1886. NSWBDM.

Some arrangement must have been made for the brothers to go to the asylum together, as they were both sent to Sydney in June 1901. Edward's time in Sydney mirrored his brother, the pair of them moving between lock-ups and Benevolent Asylums. He too was admitted to Parramatta Hospital for the Insane in June, 1902.

Edward's symptoms were described as less severe by Hogg, presumably because he was less advanced in the disease. The uniformity in the trajectories of their disease and life more generally is notable – they were born two years apart, married two years apart and then died two years apart.

#### **4F. Beatrice (1864-1906)**

Beatrice married aged 21, in 1885 in the Wesleyan Church, and she and her husband had four children. Her death certificate reported the duration of her illness as “several years.”<sup>79</sup> The death of Elizabeth was briefly reported in the local paper. Just three years later the same newspaper wrote in glowing terms about her daughter, who was leaving the region following her marriage. This article from 1909 clearly indicates how well-respected the daughter of this woman was in her local community.

A representative gathering met in the Methodist Church to show their appreciation of ... who had taken an active part in Church work, and will be much missed ... the speakers bore hearty testimony to the good qualities possessed by the parting guest. [She] has devoted much time to the work of the Sunday school, Christian Endeavour and Band of Hope societies, and was a reliable worker in any special effort, and will be much missed in the choir.<sup>80</sup>

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<sup>79</sup> Death Certificate, 1906. NSW Registry of Births, Deaths and Marriages.

<sup>80</sup> Macleay Chronicle (NSW:1878-1952) 1909.

### **5F. Clara (1868-1903)**

Clara married the local postmaster of the town in 1889 – the groom’s father objected to the marriage on the grounds of his son’s young age (the case was dismissed), though other grounds for his objections may well have existed. The couple moved to another country town in NSW and no further information was found. Her death certificate does not record children and gives the cause of death as “Myelitis”<sup>81</sup>, but she is reported as having HD in Hogg’s paper.<sup>82</sup>

### **6M. Alexander (1869-79)**

Alexander would be the first recorded case of juvenile Huntington’s disease reported in the Australian literature. Despite Hogg recording that he had HD, he did not mark the significance of this in his published paper. I was unable to find any report of his death in the newspapers. His death certificate indicated that the duration of the illness was four years with the cause of death as “pulmonary consumption.”<sup>83</sup>

### **Jemima - Wife and Mother**

It is difficult to imagine the difficulties Jemima faced in caring for her family. At the age of 42, with six children in her care, her husband died after a protracted and complicated illness. Four years later, her ten year old son died - according to Hogg of HD. Over the next 20 years, she watched as each of her children began to show symptoms of the disease. All of Jemima’s children pre-deceased her, apart from the daughter presumably born to her second

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<sup>81</sup> Death Certificate, 1903. NSWBDM.

<sup>82</sup> Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," 400-04.

<sup>83</sup> Death Certificate, 1879. NSWBDM.

husband. While the statistical chance of a single person inheriting the disease from an affected parent is 50/50, in this family all children of this marriage had HD. Not only did all of them carry the faulty gene, they also developed symptoms at a young age. Given that their uncle and cousins also had the disease, other townsfolk must have been aware of its hereditary transmission. Yet despite this, there was no indication in the historical record that this family was ostracised in their community. This is perhaps in part due to their attachment to the local church. Jemima's obituary appeared in 1908 in the local paper:

Quite a gloom was cast over the town ... the deceased lady came to this state when she was 19 years old ... [She]... was well-known and deeply respected for her kind and sympathetic nature by the whole community, and her many acts of Christian charity will long be cherished. ...The late Mrs ... arrived here in the early days when true pluck and grit even in the gentler sex were necessary to enable the pioneer to succeed against floods &c, and many a thrilling story could this lady relate of the hardships and difficulties experienced then. The Methodist Church has lost a member of many years standing.

In this and other newspaper articles, these pioneering families were spoken of with respect and admiration. This disease had affected several generations of two brothers who had moved into the area in the 1850s, including children and those in middle age. The hereditary nature of this challenging disease must have been obvious, yet the obituary refers to Jemima's other achievements and contributions to the town rather than the presence of disease in the family.



### 3.4.3 Family F

#### Source Material

Unlike the previous families, which have come to light only through my own research, this Tasmanian family, first identified by Brothers in 1949, has been recognised internationally. They have received widespread and varied attention, within both the academic literature and in popular science texts (see the following chapter). But despite their prominence, little has been recorded about their lives, and some erroneous details still prevail. In order to explore social dimensions of these families, the starting point was obviously the published papers of Brothers, who provided an anonymised family tree in his (almost identical) publications in 1949,<sup>84</sup> 1950,<sup>85</sup> and 1964.<sup>86</sup> Although Brothers did not record the identities of the families, some of the names were later revealed by both Critchley<sup>87</sup> and Hayden,<sup>88</sup> and are now cited in several other popular works. In the course of the research, I was given a version of the family tree published by Brothers with the names of the individuals recorded – this genogram is identical to the version published by Brothers, with the addition of handwritten names of many of the individuals.

Another fruitful source was a self-published history of this family.<sup>89</sup> This 500 page book, published in 2000, consists mostly of rather skeletal genealogical information - names, dates and places of births, deaths and marriages. For a very few members, this narrow frame was expanded to include short biographies including details such as occupations. The book had

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<sup>84</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>85</sup> C R D Brothers, *The History and Incidence of Huntington's Chorea in Tasmania* (Sydney: Australasian Medical Publishing Company, 1950).

<sup>86</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-420.

<sup>87</sup> Macdonald Critchley, "The History of Huntington's Chorea," *Psychological Medicine* 14 (1984): 725-27.

<sup>88</sup> Michael R. Hayden, *Huntington's Chorea* (Berlin ; New York: Springer-Verlag, 1981).

<sup>89</sup> The title of this book cannot be cited here for privacy reasons. In the remainder of this chapter I will refer to it as *Family Book*, (2000).

its beginnings in a family reunion in 1996 – many of the people who attended had independently been researching their family histories, and they decided to pool their resources into book form. There is no reference in the book to HD. Combining these sources has allowed me to conduct further research, which has provided additional detail on some of these rural Tasmanian families living with HD. This information has come from newspaper articles, local histories, asylum records and genealogy websites.

Brothers himself made only brief comments on the social milieu of these families, details of which will be discussed in following chapter on the medical response to HD. Brothers' main conclusion was that the entire kindred came from "respectable industrious yeoman stock" and that they have been "drawn from rural communities and from the lower middle class."<sup>90</sup> (p 46) The only other comment of note was that the families had a "restless, wandering disposition" indicating that many had dispersed widely, a claim I will refute. Another researcher, psychiatrist Dr Saxby Pridmore, also published many papers on HD in this family in the 1990s.<sup>91 92 93 94 95 96 97</sup> Although he provided more accurate information, his papers lack the detail which would allow exploration of the social dimensions of these families' lives. Therefore Brothers' work is the main source for this study. It was not possible to present all

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<sup>90</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>91</sup> Saxby A Pridmore, "The Large Huntington's Disease Family of Tasmania," *Medical Journal of Australia* 153, no. Nov 19 (1990): 593-95.

<sup>92</sup> Saxby A Pridmore, "Age of Onset of Huntington's Disease in Tasmania," *Medical Journal of Australia* 153, no. Aug 6 (1990): 135-37.

<sup>93</sup> Saxby A Pridmore, "The Prevalence of Huntington's Disease in Tasmania," *Medical Journal of Australia* 153, no. Aug 6 (1990): 133-34.

<sup>94</sup> Saxby A Pridmore, "Age of Death and Duration in Huntington's Disease in Tasmania," *Medical Journal of Australia* 153, no. Aug 6 (1990): 137-39.

<sup>95</sup> Saxby A Pridmore, "Relative Fertility of Unaffected Siblings of the Huntington's Disease Families of Tasmania," *Medical Journal of Australia* 153, no. Nov 19 (1990): 588-92.

<sup>96</sup> S. A. Pridmore, H. D. Pridmore, and G. C. Adams, "Reproduction and Age of Onset of Huntington's Disease in Tasmania," *The Medical journal of Australia* 153, no. 10 (1990): 589.

<sup>97</sup> Saxby A Pridmore and Adams, "The Fertility of Hd-Affected Individuals in Tasmania," *Australian and New Zealand Journal of Psychiatry*. 25, no. 2 (1991): 262-64.

the material I have gathered on this family. Once again, the information I do present is representative of the material on the whole.

### **Background Information**

1842 was an eventful year in the history of the young colony of Van Diemen's Land (as Tasmania was then known). The *Launceston Examiner*, which recorded aspects of the lives of the early settlers in the northern half of the state (and is still being published), produced its first edition. The first official census was conducted, giving a total figure of 57,471<sup>98</sup> (excluding the indigenous population, which was not included in census counts until the next century). The year also saw the arrival in the colony, in a village near Launceston, of a woman who carried the expanded HD gene. The disease would not only take her life, but would affect the lives of hundreds of her descendants, up to the present day. Because of the importance of the social environment of this kindred, a brief review of this region of Tasmania's early history will follow.

First settled by Europeans as a penal colony in 1803, Van Diemen's Land was granted independent status in 1825. In the early decades of the colony, most of the indigenous population around Launceston was rounded up and shipped to Flinders Island, making way for European settlement.<sup>99</sup> Amongst the first Europeans were a group brought from Norfolk Island in 1807 and 1808.<sup>100</sup> New Norfolk, where many settled, was to become the location of the state's mental asylum where several people with HD were admitted over the coming two centuries. As the era of convict transportation drew to a close in the 1840s, there were concerns about impending labour shortages. The Bounty Immigrant scheme was

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<sup>98</sup> [www.tasmaniaforeveryone.com.au/history\\_heritage-timeline.htm](http://www.tasmaniaforeveryone.com.au/history_heritage-timeline.htm). Accessed 1 Dec 2014.

<sup>99</sup> K. R. Von Stieglitz, *A History of Evandale* (Evandale, Tas.: Evandale History Society, 1992).

<sup>100</sup> Alison Alexander and Centre for Tasmanian Historical Studies., *The Companion to Tasmanian History* (Hobart: Centre for Tasmanian Historical Studies, University of Tasmania, 2005).

one response to this fear – the administrators of the colony arranged for agents to travel to the United Kingdom to bring farm labourers and other workers to the state. In 1842, one of the dozens of ships bringing assisted immigrants from Somerset carried the wife and children of John, an agricultural labourer. His wife Jane had been married previously, and children of both marriages inherited the expanded HD gene.

In this section, details of these families' lives will be outlined in order to explore the social dimensions of a hereditary disease in a range of geographically close and interconnected rural communities in Tasmania. Spanning the earliest years of European settlement, when neighbours knew each other intimately and depended on each other for their survival in the pioneering era, to the expansion of these communities into the early twentieth century, the following section will present fragments of the lives of people living with HD in this region. Extended families were common - many migrating to the region either came with other family members such as siblings and cousins or they joined later. John was a prime example of this – his brother migrated from Somerset in 1855 – and the published family history includes members of both branches of the family. This extended family settled in the same area, a little to the west of Jane and John's village, and there was some intermarriage between the two branches. Jane's brother Andrew joined them too, but there is little information about him.

### **Generation 1: Jane (1806? -1872) and John (1808-1862).**

Both Brothers and Pridmore report that Jane was the woman who carried the HD gene to Tasmania from the UK. She was christened in a village in Somerset, and it was reported by

Pridmore that her father was also affected by HD.<sup>101</sup> She first married in 1824 and had three daughters – her first husband presumably died (some records indicate he died in 1831) and she married again in 1831.<sup>102</sup> Her second husband, John, lived in a village less than four miles away and worked as an agricultural labourer.<sup>103</sup> The couple had five children – the family of ten migrated to Australia, leaving the UK at the end of 1841. Jane was pregnant for much of the journey, giving birth to a son just after their arrival in Australia. Labourers in Somerset at the time lived in grinding poverty, and Jane and John were one of hundreds who took up the opportunity offered by the Bounty Agent.

Records describe John as a “first class farm servant” and his character as “very excellent.”<sup>104</sup> He was indentured to a wealthy landholder in a town outside Launceston. He and his family lived and worked on one of the landowner’s estates for five years, after which he leased a nearby property. This was later leased by his sons and then purchased early in the twentieth century by his descendants. John’s elevation from labourer to lease holder was a prime example of how the new colony could allow social mobility undreamt of in rural Somerset. In 1855, a dinner in honour of the local MP was held, with various dignitaries attending.<sup>105</sup> John was listed as one of the guests, alongside the owner of the estate where he was initially employed as a farm labourer - he must have been considered a sufficiently respectable member of the town to attend such a function. Also in attendance was the local doctor – the

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<sup>101</sup> Pridmore, "The Large Huntington's Disease Family of Tasmania," 593-93.

<sup>102</sup> *Family Book* (2000).

<sup>103</sup> *Ibid.*

<sup>104</sup> *Ibid.*

<sup>105</sup> *Launceston Examiner* (Tasmania:1842-1899) 1855.

grandfather of Charles Hogg, who wrote the first article on the disease in Australia.<sup>106</sup> One of John's future son-in-laws was also present.

Six more children were born in Australia, the first of these dying as an infant - giving a total of 13 children. Of these, Brothers indicated that nine showed symptoms of the disease in life, and another two had descendants with the disease.<sup>107</sup> Over the subsequent decades, many of the families remained in or close to this town. Brothers states: "It was apparently quite soon after her arrival in Tasmania that she showed signs of chorea, which her family referred to as 'St Vitus Dance.'" (p 46)<sup>108</sup> Given that she died in 1872, this would give a very long duration of symptoms. She was buried with her husband in their local town.

Unfortunately I have been unable to discover any mention of her medical condition in the historical record, apart from the fact that her death certificate lists the cause of death as "convulsions."<sup>109</sup> Her death was noted in a letter written by the trustee of their leased property who was also a local politician. Although it was sufficiently newsworthy to mention it to his friend in England, her death was recorded without fanfare. The sentence "Mrs x dead" was lodged between a comment on having seen a "6 lb trout" and gossip about another family "going to (the) dogs."<sup>110</sup>

The health of Jane's husband John has never been mentioned in the literature. His death certificate records his cause of death as "softening of the brain,"<sup>111</sup> indicating that he too died of a neurological condition, ten years before Jane. The following section will outline

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<sup>106</sup> Ibid.

<sup>107</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>108</sup> Ibid.

<sup>109</sup> *Family Book* (2000).

<sup>110</sup> This quote comes from a collection of letters published by the Tasmanian Historical Research Society, 1991. The author and title are not revealed to maintain anonymity.

<sup>111</sup> *Family Book* (2000).

details of the subsequent generations, following the order used by Brothers (which deviates slightly from the *Family Book*).

### **John & Jane's children**

The following section provides a summary of demographic and personal details of the next generation of this family spanning over a century, from the first birth in 1824 to the last death in 1936. Before describing the specific details of individual families, some observations about the entire generation are noteworthy. Despite the presence of a neurological disorder in both of their parents, all of them married, most in their 20s. Furthermore, the age at death is roughly equal to that of their spouses, regardless of their HD status – there is some evidence that the age of onset is relatively late in the Tasmanian kindred as a whole,<sup>112</sup> which could also have implications for the way people thought of the disease. Onset when someone is 50 or 60 places a much lower burden of care than earlier onsets, though any children born to them still have a 50/50 chance of inheriting the disease.

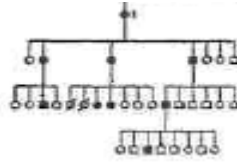
Brothers' description of the family from the 1949 version of the paper will be provided in italics – these mostly cite the number of individuals in each generation with and without the disease, and his confidence in the completeness or otherwise of his investigations. This will be followed by the segment of his genogram relevant to that family. Filled in symbols denote the presence of the disease, circles females and squares males. Some are marked as deceased with a line struck through, others who are obviously deceased are unmarked, a fact which later led to significant confusion. I have provided references to newspaper articles, though some details have been omitted to retain anonymity.

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<sup>112</sup> Pridmore, "Age of Onset of Huntington's Disease in Tasmania," 135-37.

### Family 1: Grace (1828?-1894)

*The first member of her family has produced a total of eight affected descendants, four being males and four females. The record of this family is actually complete. Inheritance of the disease has obeyed Mendelian law very well, except in one group, and in that particular family there were three members who died before middle age. It is possible that if they had lived certain of these members might also have shown signs of the disease.*<sup>113</sup>  
(p 46)



Giving birth to her first child in 1847, Grace married George (1819-1919), a former convict, a year later. In the early 1850s the couple and their two children left the safety of their relatively well-established small community and moved to the developing north-east of the state, 150 kilometres from their home town, along with Grace's sister and her family (Family 2) – at that time, they were two of only five families in the region. This information and much of what is to follow is included in a book on the history of the North East of Tasmania, referred to from now as *Local History Book*.<sup>114</sup> Life in this pioneering era was full of enormous challenges and survival itself entailed extremely hard work. The region developed over the following decades, the main economic activities revolving around sheep and cattle runs, tin mining, timber gathering and later a small tourist industry.

Of their seven children who survived to adulthood, all married local townspeople and most remained in the town. Brothers' genogram recorded that three of Grace and George's children had HD. I was unable to find records regarding Grace's death. Like so many women of the day, she herself was mostly absent from the public record, but there are

<sup>113</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>114</sup> This 1934 history was informed by the oral testimony of local residents, and provides a rich glimpse into life in the region in the pioneering era. Once again, the title of this book cannot be revealed as it could allow the family names to be identified. It will subsequently be referred to as *Local History Book*.



notable mentions of her husband and one of her sons. (According to Brothers, this son also had HD.) These include a short article in the *Hobart Mercury* commenting on her husband's life as a centenarian, obituaries and the *Local History Book*, asylum records and other genealogical sources. George seemed not to have re-married after his wife's death in 1894.<sup>115</sup> His mark on the historical record does not include problems caused by the disease and the early death of his wife, sister-in-law and son, but emphasizes his contribution as a pioneer in the town. His 100<sup>th</sup> birthday in 1919 was sufficiently newsworthy to transcend the local press. Reporting on a celebration which had been held in the district on the occasion of this event, an article in the *Hobart Mercury* focused on his resilience in surviving a shipwreck in South Africa and his contribution as a farmer in the district. Rather than expressing fears about the spreading of an inherited disease, the article proudly stated that: "He has 2 sons, five daughters, 50 grandchildren, 58 great-grandchildren and 2 great-great-grandchildren."<sup>116</sup>

Grace and George's son, Peter (1856-1932) who died with HD, was also considered to be a valued member of the community, judging from his obituary in a Tasmanian newspaper. By the time he died, his mother and two sisters had died with symptoms of the disease and his aunt and cousins were affected, but there is no indication that the family was thought less of as a result of the illness, though his own ill health was mentioned:

Another of Tasmania's pioneers ... died after an illness of several months.... The late Mr ... was a keen sportsman and hunter, expert horseman, and bushman in his earlier life and could tell many stories of when the forester kangaroo were more plentiful and the now almost extinct Tasmanian hyena. Of late years Mr ... devoted his attention to farming, and by courage and hard work had carved out of the virgin

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<sup>115</sup> *Family Book*, (2000).

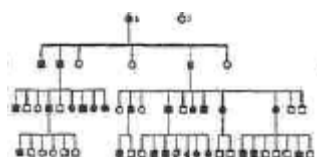
<sup>116</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 6, 1919.

bush a farm ... in addition to his farm at ... Honest and industrious to a degree, he set an example to the younger generation.<sup>117</sup>

This simple farming family made its mark on the historical record of their region by dint of hard work. Their legacy as pioneers in this region seemed to outweigh the fact that a hereditary disease was in their midst. Other newspaper articles confirm their acceptance and integration in the community – events such as the children's participation in a Sunday school picnic held in 1911. The families into which they married must have had some awareness of the disease considering the closeness of the communities. The 1934 history concluded that "Their successive families have merged into the citizenship of the District"<sup>118</sup> - a statement made without alarm, reflecting the reality of pioneer life in a small rural community, but also the absence of stigma attached to this family in the nineteenth and early twentieth century.

### **Family 2: Hannah (1824-1857)**

*In the case of the second member, there is a total of twenty-four affected descendants, fifteen being males and nine females. The family record is here again absolutely complete, but descendants of non-affected members are not always shown. Again, Mendelian law has been fairly well obeyed.*<sup>119</sup> (p 46)



In 1844, Hannah married Henry, who, like her step-father, was a Somerset farm labourer who came to Tasmania under the Bounty Immigrant scheme. They had six children who lived to adulthood, three of whom Brothers recorded as having had HD. Probably a year before Family 1, in the early 1850s, the couple left the family home and moved to the

<sup>117</sup> *Examiner* (Launceston, Tas.:1900-1954), 1932.

<sup>118</sup> *Local History Book*, (1934).

<sup>119</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

uncultivated North East of Tasmania. As recorded by Brothers, this family had the highest number of descendants with HD of all the families he described. In the following section, we will see that this large family played a prominent role in the development of this region of Tasmania. The challenges the families faced, including early deaths, were recorded in various newspaper articles of the day and in the *Local History Book*.

The first tragedy for the family was the death of Hannah in 1857.<sup>120</sup> Just a few years after moving to the region, she was the first to die with HD of all the family. Her death even predated her mother's by 15 years. Her tombstone inscription reports that she died aged 33, "leaving a numerous family to deplore her loss." The family farm was named after her, and was reported in 1934 to be the "most important farm in the district"<sup>121</sup> - until a few years ago it was still owned by the family.<sup>122</sup>

Alongside another pioneering family, they were described as "the uncrowned kings of the territory. All local activities emanated from them."<sup>123</sup> (p 6) After taking up land in 1852, they soon employed labourers and expanded their farms. They were the "fathers of cheese-making in the district."<sup>124</sup> (p 6) After Hannah's death, Henry married the daughter of the other "uncrowned king" and had two more children.

The prominence of the family in the district is further evidenced in the life of one of Hannah and Henry's sons, William (1853-1918). Brothers stated that he too had HD, and he was also

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<sup>120</sup> *Family Book*, (2000).

<sup>121</sup> *Local History Book*, (1934).

<sup>122</sup> *Tasmanian Country*. (Tasmania, Australia), xxx era ends, (2001).

<sup>123</sup> *Local History Book*, (1934).

<sup>124</sup> *Ibid*.

highly active in the life of the town. Marrying into a well-known local family, the couple had 11 children.<sup>125</sup> Newspaper articles reported on his appointments over the years to the Road Trust and various other town committees. He died aged 65.<sup>126</sup> Although I have been unable to find an obituary, the 1934 history marked his contribution to the community and is worth noting in full:

[William] is worthy of more than passing comment. As a citizen, farmer and public man he played an honourable and conspicuous part. His philanthropy knew no bounds, nor did it seek any publicity. With his decease, the District was the poorer for the loss of just one citizen pioneer, whose precept was a worthy example to those who remained to regret his exit from his sphere of activity and integrity of purpose.<sup>127</sup>

Once again, the historical record points to the fact that this family was integrated into community life and married into other families, and that the disease did not preclude them from full acceptance in their town.

### **Family 3. Eunice (1830-1863)**

*No statistics are given for the third member of the family, since she and her descendants were known to be completely free of any trace of Huntington's chorea.*<sup>128</sup> (p 46)

Eunice also married a convict who was sent to the same district. They had nine children, and the family moved to a town approximately 40 miles away. She died aged 33, reportedly from consumption. I have not been able to trace any further information about this family.

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<sup>125</sup> *Family book*, (2000).

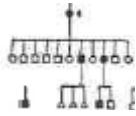
<sup>126</sup> *Ibid.*

<sup>127</sup> *Local History Book*, (1934).

<sup>128</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

#### Family 4. Violet (1832-1901)

*In the case of the fourth member, the information is not complete, but we do know of four sufferers who include one illegitimate patient. It is possible that other members of the family may have suffered from this disease.*<sup>129</sup> (p 46)



Violet was the first child born to Jane and John. She married the son of an ex-convict in 1849, had 11 children and remained in the Launceston district for most of her life. Her husband pre-deceased her by two decades. Like many ex-convicts, his status changed quickly and he became part of the life of the community. His name appeared on several occasions in the local press, attending committee meetings in the town. Press reports indicate that the couple had at least two convict servants assigned to them. Violet herself must have received some education – records indicate that she applied for a teaching position in 1862.<sup>130</sup> The only other mention of her in the local press was in 1896. In a forerunner of the suffragette movement, she pressed her right to vote to the officials monitoring a local election (Road Trust). The following was reported in the local press:

An interesting incident occurred in the course of the election at Patersonia when Mrs ... demanded a right to vote. After much discussion the precedent was allowed by the presiding officer, and Mrs ... has the record of being the first female to exercise the right to vote in Patersonia.<sup>131</sup>

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<sup>129</sup> Ibid.

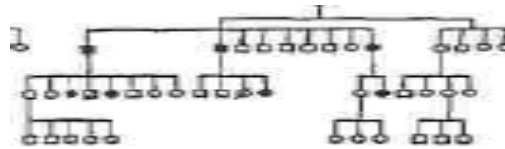
<sup>130</sup> Tasmanian Archives. ED2 Applications for Teaching Positions and Associated Correspondence. Jan 1862. [www.search.archives.tas.gov.au](http://www.search.archives.tas.gov.au). Accessed 4 July 2009.

<sup>131</sup> *Examiner* (Launceston, Tasmania:1900-1954), 1896.

Just five years later, in 1901, Violet died in the town where they first settled, aged 69, with the cause of death being recorded as a cerebral haemorrhage.<sup>132</sup> I was unable to find further information about her death.

## 5. William (1833-1900)

*In the case of the fifth member, the records are incomplete, but there are seven known cases, two of the patients being males and five females.*<sup>133</sup> (p 46)



The eldest son of Jane and John, born in Somerset, William left a more comprehensive mark in the historical record. There are multiple references to him in the local paper, the most notable being details of his illness, and as was the case with his elder sisters and their families, references to his good reputation in the district. William married a local woman in 1859, and between 1860 and 1875 they had nine children. His first wife died, he remarried in 1878 and they had four more children, between 1878 and 1882. All of these children married, and only two of the thirteen moved away from Tasmania. One died in Melbourne but lived in Tasmania. Another son moved to Sydney and was elected as a member of the NSW parliament. The other children remained either in the district or in Hobart. At least one of his sons attended the school run by Charles Hogg's father.

William went into the business of his father-in-law – in the late 1850s he ran a large hotel in a nearby town, 90 kilometres away. After the relatively early death of his father in 1862, William was entrusted with the management of the family business, returned to his home

<sup>132</sup> Record of Death, 1901. Tasmanian Department of Justice, Births, Deaths and Marriages.

<sup>133</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

town and became highly involved in local affairs. In the 1870s he was appointed the trustee of the local Roads Trust and elected to council. There are scores of references to his skills in sheep and cattle breeding – he was acclaimed in one article for bringing the Arab breed of horse to Tasmania.

William is the first of the siblings whose illness is alluded to in the historical record. He was sufficiently influential in the town for the details of his illness to be reported in both the *Launceston Examiner* and the *Hobart Mercury*. These reports record his struggle with the disease in sympathetic detail over several years. In 1897, the discussion of his health in the local press began. In September, an article stated that having wintered in NSW and Victoria, “excepting a slight attack of gout, his health is much improved.”<sup>134</sup> By May 1898 “he has been indisposed, but from latest reports, he is a trifle better.”<sup>135</sup> Later in the month “The friends of ... will be sorry to learn that he is ill again, but hopes to be sufficiently recovered to take his annual trip to Sydney and Melbourne.”<sup>136</sup> In June 1898 he moved to the east coast “with a view of recruiting his health, which is now so impaired that he will be unable to make his annual visit to the mainland”<sup>137</sup> and later in the month his health was reported as “none too good.”<sup>138</sup> In August, he was “somewhat improved” but “still bears the traces of his recent severe indisposition.”<sup>139</sup>

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<sup>134</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 4, 1897.

<sup>135</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 3, 1898.

<sup>136</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 4, 1898.

<sup>137</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 3, 1898.

<sup>138</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 3, 1898.

<sup>139</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 3, 1898.

There was no mention again until May 1900, when he contributed a large sum of money to the Church of England.<sup>140</sup> By June, he was “seriously ill” and “the services of a nurse had been engaged”<sup>141</sup> and a week later he “still continues in a critical state of health, and is causing his friends and relatives the gravest anxiety.”<sup>142</sup> He died soon after. The local doctor gave the cause of death as “Locomotor Ataxy Atrophy.”<sup>143</sup> His death was noted in both main Tasmanian papers, the *Launceston Examiner* noting that “King Death has been very busy during the past few years”, that William was “well and favourably known throughout the district” and had been “ailing for some time so that his death was not unexpected.”<sup>144</sup>

The Hobart newspaper provided the most thorough obituary. It noted his death “after a lingering illness.” He was “of an old Somersetshire family, and with his parents came out to this colony when quite a lad. Mr ... was well and favourably known throughout Tasmania and at the time of his death was possessed of considerable valuable property.” His achievements were discussed in the context of his health, stating: “It was only failing health of late years that caused him to relinquish active farming” and “offering his service to ratepayers.” The newspaper also commented on his other contributions, noting his “warm and generous support” to the Church of England. The service of one of his sons in the Boer War was remarked upon. Rather than commenting in a disparaging way about his disease, his last years were spoken of with great compassion and not a little understatement: “Although not over-blessed with good health of recent years, Mr ... always seemed pleased to have a

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<sup>140</sup> *Daily Telegraph* (Launceston), p 3, 1900.

<sup>141</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 4, 1900.

<sup>142</sup> *Ibid.*

<sup>143</sup> Record of Death, 1900. Tasmanian Department of Justice, Births, Deaths and Marriages.

<sup>144</sup> *Examiner* (Launceston, Tasmania:1900-1954), p 2, 1900.

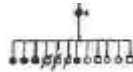


chat with almost everyone he met. He was a kind and indulgent father, and his well-known person will be much missed from our midst.”<sup>145</sup>

## 6. Harriet (1835-1903)

*In the case of the sixth member of the family, information for the first descendants of this member is complete, but their descendants are not known owing to the scattering of the family, and in particular to the removal of many members from the State. In the generation that is shown, one male and two female descendants are affected. It might also be noted that three of the descendants died in infancy.*

<sup>146</sup>(p 49)



At the age of 20, Harriet married into yet another of the larger local families in the district. Her husband’s father was an Irish immigrant, the survivor of a shipwreck who managed to make it to Van Diemen’s Land with his cousin and other family. Brothers’ records do not match the *Family Book* regarding the number of children Harriet and Herbert had – it was either 12 or 13. Brothers managed to identify only one generation of this family, partly, he claimed, because of their “scattering,” but in fact only three had moved to Melbourne, seven remaining in Tasmania. Six definitely married, and two brothers were unmarried. Most records indicate that one daughter, who was a trained nurse, did not marry.

Brothers noted that one of Harriet’s children had entered an asylum, but in fact Harriet herself spent two years in the New Norfolk asylum in the early 1890s.<sup>147</sup> She was taken to the asylum by her son-in-law, and records indicate that she spent two years there, before returning to the district, where she died just over ten years later. This is a relatively unusual pattern for people with HD admitted to asylums – of all those I examined, Harriet was one

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<sup>145</sup> *The Mercury* (Hobart, Tas.: 1860-1954), p 3, 1900.

<sup>146</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>147</sup> Tasmanian Archive and Heritage Office, Agency #TA465 Royal Derwent Hospital. Patient Records HSD/285 Admission Papers. HSD/284 Patient Files.

of only two who returned home, the others all dying in the institutions. Her cause of death was listed as “imbecile senility” on her death certificate.<sup>148</sup> I was unable to find an obituary.

One of Harriet’s daughters who Brothers stated had HD is noteworthy because of her work as a nurse and the fact that she ran a private hospital. Catherine (1867-1931) trained at the Queen Victoria Hospital in Launceston, graduated with Honours and received the medal for the year. She was registered to practice as a midwife,<sup>149</sup> and within months of graduating in 1907, she was seeing patients in her private hospital.

The local newspaper contains dozens of references to what seemed like a local institution - mostly birth notices, but also deaths, inquests, reports of her holidays and messages of thanks for her kindness and attention.<sup>150</sup> People from the town and surrounds were admitted with acute injuries such as falls, whereas others came from far-flung places such as Cape Barren Island and King Island. Family members were among her clientele. One member of Family 2 from the north-east of the state died in the hospital. The fact that this woman, whose mother had died of “imbecile senility” in the town was then able to run a successful hospital points to the absence of stigma and social acceptance of this family.

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<sup>148</sup> Record of Death, 1903. Tasmanian Department of Justice, Births, Deaths and Marriages.

<sup>149</sup> Tasmanian Government Gazette, Register of Midwives 1910. Information provided by Marian Sargent, Librarian Launceston Library, Tasmanian Linc.

<sup>150</sup> *Examiner* (Launceston, Tasmania:1900-1954). From 1907 to 1913, there were over 30 references to Nurse Catherine and her hospital.

## 7 Richard: (1840-1915)

*The seventh member died aged seventy-five years, apparently having shown no signs of chorea during his lifetime. It is known that five of his descendants have the condition, and are transmitting it in the accepted fashion. Possibly his clinical features were so slight as to pass unnoticed; possibly, as Kinnier Wilson (1940) has pointed out, "no doubt at times the carrier of a dominant may fail to develop the trait."<sup>151</sup> (p 49)*



Richard was two years old when he arrived in Australia. He married into one of the other large families in the region aged 20. They lived on his parents' farm until moving to an area 36 kilometres to the west in 1886, land which he later bought - he ended up being one of the large landholders in the area. Richard and his wife Georgina had five children who lived to adulthood – four of them married. Brothers does not provide any names in this pedigree, making it more difficult to trace those with the disease. He states that two of Richard's sons had HD, one son in the next generation and two daughters in the next generation.

Newspaper reports of Richard's activities once again reveal an engaged member of his community – he served as a juror on multiple trials through the 1860s to 1880s.<sup>152</sup> There are numerous references to his farming and sporting pursuits in the region and he was a member of several local associations.<sup>153</sup> In 1897, he attended a meeting of local luminaries discussing moves towards the Federation of Australia.<sup>154</sup> Further evidence of the role he played in the local community was a testimonial including an "Illuminated Address," given to him on his retirement from a Racing Club, six years before his death. In a long report of the meeting in the *Launceston Examiner*, it stated "his name was held highly, not only in sporting circles, but

<sup>151</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>152</sup> *Launceston Examiner* (Tasmania:1842-1899). Multiple references.

<sup>153</sup> Ibid.

<sup>154</sup> Ibid.

in private as well as in business life” and “it is a tribute to your honesty and uprightness of character.”<sup>155</sup> The newspaper article stated that a copy of the testimonial was posted in the town.

One of Richard’s daughters is also of interest. Although not identified by Brothers as having the disease, her history is highly suggestive of HD, and her death was reported by some as a suicide. Ellen had married aged 28. In the same year as the birth of her third child, she went out one Friday afternoon with a “pea rifle.” Rather graphic details of her death were reported around the country, as far away as Sydney,<sup>156</sup> Rockhampton<sup>157</sup>, Adelaide<sup>158</sup> and Kalgoorlie.<sup>159</sup> One newspaper reported that she was found “lying on the ground with a large part of one side of her head blown away.”<sup>160</sup> The same paper cited a local doctor: “The deceased had been mentally deranged for some months past, and about three months ago she went to Sydney to consult a specialist on brain trouble.”<sup>161</sup> While the jury at the coroner’s inquest recorded an open verdict – “there was no evidence to show how it was caused,”<sup>162</sup> some newspapers had reported the death as a suicide.<sup>163</sup> Despite the gruesome nature of her death, once again the response in the press was respectful and courteous. She was described as being well-known in the district, the funeral was noted as being “well-attended” and “The coffin was covered with costly and beautiful wreaths. Sincere sympathy is expressed for the

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<sup>155</sup> *Examiner* (Launceston, Tasmania:1900-1954), p 5, 1909.

<sup>156</sup> *The Sydney Morning Herald* (NSW:1842-1954), p 8, 1906.

<sup>157</sup> *Morning Bulletin* (Rockhampton, Qld: 1878-1954), p 5, 1906.

<sup>158</sup> *The Advertiser* (Adelaide, SA: 1889-1931), p 6,1906.

<sup>159</sup> *Kalgoorlie Miner* (WA:1895-1950), p 4, 1906.

<sup>160</sup> *Examiner* (Launceston, Tasmania:1900-1954), Inquest xxx, p 4,1906.

<sup>161</sup> *Ibid.*

<sup>162</sup> *Ibid.*

<sup>163</sup> *Daily News* (Perth, WA: 1882-1950), p 3, 1906.

bereaved husband and parents.”<sup>164</sup> A report on the inquest expressed “great sympathy” to her husband, noting the family were well-known in the district.<sup>165</sup>

## 8. Nathaniel (1838-1906)

*Although showing no evidence of chorea in himself or his legitimate family, nevertheless was the apparent father of an illegitimate child who in turn transmitted the condition to her son. The medical history of the mother of this illegitimate child is not known, but there are reasons for suspecting that she may have been the carrier of the dominant genes.*<sup>166</sup> (p 49)

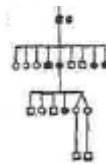


As noted, Brothers did not find evidence of HD in any of Nathaniel’s legitimate children.

Family histories record the mother of this illegitimate child as being his cousin, though I was unable to uncover further details.

## 9. Alexander (1844-1912)

*In the case of the ninth member of the family the records are fairly complete and all cases of Huntington’s chorea in this family are well-known and have been shown in the chart.*<sup>167</sup> (p 49)



Despite these claims of completeness, the copy I obtained of Brothers’ chart shows additional details which were presumably added after publication of the 1949 paper, including shaded areas (indicating uncertainty?) and details of one woman said to be unaffected but with two children with known HD. From the published chart, there are four out of the nine children had HD, with only one identified in the next generation.

<sup>164</sup> *Examiner* (Launceston, Tasmania:1900-1954), p 5, The late Mrs xxx. 1906.

<sup>165</sup> *Examiner* (Launceston, Tasmania:1900-1954), p 4, Inquest at xxx.1906.

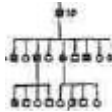
<sup>166</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>167</sup> *Ibid.*46-50.

Alexander was a farmer and landowner and also served on the council and as a juror. His wife's obituary stated that she was "well-known and respected" in the community.<sup>168</sup> There is little in the public record about this family. His death certificate states that he died of "bronchitis."<sup>169</sup>

#### 10. Horace (1846-1927)

*This also applies to the tenth member, who has five affected descendants – four males and one female – and again all the cases are shown in the chart.*<sup>170</sup> (p 49)



This man and his brother born two years later led intertwined lives – they married sisters, stayed in the same regions and worked in similar occupations. In the words recorded in the family history: "These two brothers and their families in the 1800s obviously worked and played together."<sup>171</sup> Horace worked mostly as a farmer, but also worked as a publican in the hotel owned by one of his elder brothers (Family 5). His death certificate stated that he died of "angina pectoris, pneumonia".<sup>172</sup>

<sup>168</sup> *The Mercury* (Hobart, Tas: 1860-1954), Mrs xxx, (1937).

<sup>169</sup> Record of Death, 1912. Tasmanian Department of Justice, Births, Deaths and Marriages.

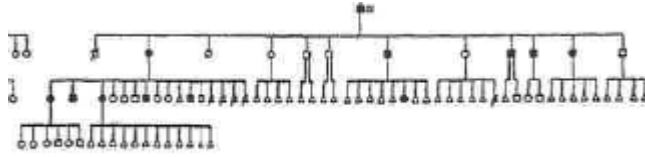
<sup>170</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>171</sup> *Family Book*, (2000).

<sup>172</sup> Record of Death, 1927. Tasmanian Department of Justice, Births, Deaths and Marriages.

### 11. Frederick (1848-1917)

*In the case of the eleventh member, there are to our knowledge eleven known sufferers. The record of the immediate descendants of the member is complete, but their children are not accurately known, and it is not known whether the disease has been observed in any of them.*<sup>173</sup>(p 49)



Frederick also worked as a farmer and publican, having the licenses to several hotels around the district. He married the sister of his brother's wife ten months after their marriage, and the couple went on to have 12 children. Frederick's wife was a noted pianist and music teacher in the district. Whereas most of the other families remained in Tasmania, the children of this marriage indeed dispersed to other states. Of the ten who lived to adulthood, only three remained in Tasmania, the others mostly moving to Victoria.

### 12. Elizabeth (1850-1936)

*In the case of the twelfth member there were only two known children, and again it has not been possible to determine whether or not they have Huntington's chorea or whether they transmitted it to their descendants.*<sup>174</sup> (p 49)



According to Brothers Elizabeth was affected with HD, and the *Family Book* indicates that she died in a "rest home" in New Norfolk.<sup>175</sup> Her death certificate identifies this as the "Mental Hospital."<sup>176</sup> The cause of death is recorded as arteriosclerosis and chronic myocarditis. One daughter died in Victoria, the son in Tasmania.

<sup>173</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>174</sup> Ibid.

<sup>175</sup> *Family Book*, (2000).

<sup>176</sup> Record of Death, 1936. Tasmanian Department of Justice, Births, Deaths and Marriages.

### 13. George (1852-1932)

*In the thirteenth and last member it is known that neither he nor any of his descendants has Huntington's chorea.*<sup>177</sup>(p 49)



George married his niece, who was only three years younger than him. Described in the *Family Book* as well-educated, he initially pursued farming, like much of the family. They had ten children - he was later employed as a health inspector and his wife was a Sunday school teacher.

#### Summary of Tasmanian Family Data

The residual traces of the lives of several members of this large Tasmanian family indicate that on the whole they were well-integrated into their communities in the nineteenth and early twentieth centuries, which corresponds to Brothers' description. One of the factors which influenced their inclusion in their communities was the fact that they had lived in the region for so long - their "pioneer status," which was described in obituaries and in a history of the region. Their contributions to their communities prior to their illnesses were the focus in the historical record. The presence of disease was occasionally alluded to but not dwelled upon. There was no evidence of stigma associated with the mysterious hereditary condition that ran in their families.

Of course it cannot be claimed that no stigma existed – there are many kinds of social disapproval which might well have been expressed by some in their communities. The information presented about the families is necessarily restricted - most aspects of these people's lives have not been recorded. There may well have been gossip in the town and the

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<sup>177</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.



kind of subtle social ostracism which is part and parcel of a stigmatised identity. However, there were not even subtle hints in the newspaper obituaries which were found and, without exception, the tone of newspaper articles was respectful and compassionate towards the families.

Contrary to Brothers' claims about the families scattering, many of the family members remained in the same district throughout their lives. Given that Brothers himself had moved to Melbourne, it was surprising that he would accuse those who had also followed this path of having a "restless, wandering disposition" especially given the small numbers who had actually done so. As we have seen throughout this chapter, the majority of descendants stayed close to the places of their birth. This geographical stability would also argue against systematic stigmatisation in this era – strong sentiments of disapproval would encourage children of the families to move to other parts of the state or country.

### **3.5 Ethnic Origins of HD in Australia**

The ethnic origins of HD have in many respects mirrored that of the wider population. Most of the early cases from the nineteenth century are traceable to either the United Kingdom or Ireland. Two publications have noted a wider range of countries of origin reflecting later migration. In 1955, Brothers and Meadows provided information on the multiple sources of origin of the disease into Victoria, in contrast with the Tasmanian kindred's British roots. In addition to people coming to Victoria with HD from other Australian states, they provided data to show families from England (7), Scotland (3), Ireland (2), Germany (1), Italy (1) Canada (1) and New Zealand (1).<sup>178</sup> Investigation of the country

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<sup>178</sup> Brothers and Meadows, "An Investigation of Huntington's Chorea in Victoria," 548-563.

of origin of Queensland cases of the disease was made in 1972.<sup>179</sup> This reported family origins from England (13), Scotland (6), Ireland (5), Sweden (1), Germany (1), Malta (1) and Russia (1). Brothers added Holland and South Africa to this list in his 1964 paper.<sup>180</sup> A more up-to-date exploration of the ethnic origins of the disease has not been undertaken, however in 2014, a review of the Westmead Huntington Disease Service, which cares for about 70% of the people with HD in NSW, found that 9.4% of the client base were from non Anglo-Saxon backgrounds, with ethnic origins as diverse as Chinese, Indian and Japanese, groups thought to have relatively low rates of HD.<sup>181</sup>

### 3.6 HD in Indigenous Australians

In considering the origins of HD in Australia, it is also important to recognise the introduction of the disease to Indigenous communities in Australia. While the impact of a range of introduced diseases such as smallpox and influenza on the Aboriginal population is well-recognised, a lesser known fact is that HD is yet another of the diseases introduced into Aboriginal communities as a result of European settlement. Two separate kindreds have been described in the medical literature, one in South Australia and the other in Western Australia. In 1969, a report of the existence of HD in a group known as the “Port Macleay aborigines” was published in the *Medical Journal of Australia*.<sup>182</sup> This article told the story of an indigenous woman who was said by elders of her community to be suffering from “the shaking madness.” According to this paper, two of her daughters were diagnosed with “chorea” by doctors, the first in 1924. Researchers investigating the origins of the disease

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<sup>179</sup> D C Wallace, "Huntington's Chorea in Queensland: A Not Uncommon Disease," *Medical Journal of Australia* 1 (1972): 299-307.

<sup>180</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-20.

<sup>181</sup> Personal Communication, Clement Loy, Director of Huntington's Disease Services at Westmead Hospital, Sydney, NSW, Australia. 20 Feb, 2015.

<sup>182</sup> Fay Gale and J H Bennett, "Huntington's Chorea in a South Australian Community of Aboriginal Descent," *Medical Journal of Australia* Sept 6 (1969): 482-84.

propose that it was introduced by a sailor. In 2008, Panegyres and McGrath reported on a kindred in the Kimberley area of Western Australia, with genetically proven HD.<sup>183</sup> The origin of the disease was thought to be one of the “Afghans” (who in fact came from what is now India and Pakistan, as well as Afghanistan) who introduced camels into Australia in the middle of the nineteenth century. He was said to have had five wives and an unknown number of descendants. Further details of the South Australian kindred will be described in Chapter 6.

### 3.7 Conclusion

This chapter contains the results of the first detailed study of the early history of HD in Australia, focusing on both social and medical aspects. The paucity of published material necessitated the use of novel strategies in the search for the earliest cases of the disease. Having identified these individuals with the aid of material collected by HD families themselves, and early medical publications written about the disease, it was then possible to explore the way HD families were viewed in the communities in which they lived. This approach is in the tradition of historical enquiry which in addition to uncovering medical aspects of disease, also seeks to examine the social forces which affect the way disease is experienced in different cultures and at different times.

As noted in the literature, stories of the origins of HD have tended to be uncritically repeated by those writing on the history of the disease. In the case of Australia, it has been claimed that the first cases of the disease were a Tasmanian kindred who arrived in the

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<sup>183</sup> P. K. Panegyres and F. McGrath, "Huntington Disease in Indigenous Australians," *Internal Medicine Journal* 38, no. 2 (2008): 130-32.

colony of Van Diemen's Land in 1842. Another repeated claim is that there were no convicts with the disease. I have presented compelling evidence that families with HD have been a part of the Australian historical landscape since the first decades of European settlement. In contrast to previous statements on this topic, it has also been revealed that there were several families with convict roots; however this did not prevent many of these family members from making prosperous lives in the new Antipodean colonies. Other information about the ethnic origins of the disease in Australia came from medical publications and its existence in two separate Aboriginal communities was also established.

Wexler challenged the narrative that HD was universally and inevitably stigmatised, and her study of families in the US found many HD families who were far from ostracized. They held office in their towns, and were spoken of with warmth and affection in the local newspapers. In this chapter, I have uncovered similarly well-respected members of HD families in the nineteenth century. In certain communities, some members of these families were treated according to their contribution to their broader society, and not on the basis of the disease. Where the disease was mentioned, it was with sympathy and not "shunning."

The most detailed information I was able to obtain was on the Tasmanian kindred. Despite the large numbers of individuals affected, there was not even a hint of a negative attitude expressed towards these extended families in the scores of newspaper articles which I researched. On the contrary, family members were specifically mentioned as being well-regarded in their districts, and their achievements, rather than their long illnesses, were recognised and commented on in their obituaries. HD certainly took its toll on the members of these families who lived with the disease in the nineteenth and early twentieth century –

there were suicides, asylum admissions and the families must have struggled to care for their family members in various stages of the disease. Despite this, it seems that HD was treated as just one of the many unexplained diseases which people succumbed to in the course of their lives. At least in the rural areas, the local people must have known of the hereditary nature of the disease, but this did not result in the overt stigmatisation of these families. Data from other two other families told similar stories. The methods described at the beginning of the chapter resulted in the collection of a large volume of material. It was not possible to include details of every individual I have researched, though the material presented is representative of the collection as a whole.

Of course there is much that we don't know about the way HD families were treated in the past. Many forms of stigma are subtle and would have left no trace in the historical record. My purpose is not to argue that there was no stigma, even though my examination found no evidence of it. My argument is that stigma was not inevitable – many families with HD played active roles in their communities, were well- respected and held in esteem. Wexler already established this in the case of the US families – evidence from Australia points to this being a more universal phenomenon. This chapter has focused mostly on aspects of the disease in the first century of European settlement. The twentieth century would prove a much more challenging time for HD families. In the following chapter, various aspects of the medical response to this condition will be explored. This will once again make use of the methodologies outlined in this chapter - physicians' papers, family histories and asylum records.

#### 4. HD Becomes Visible: Medical Responses in Australia

*"Unhappily, the treatment of chronic progressive chorea is futile."*<sup>1</sup> 1894, William Osler, Physician

*"There is never nothing you can do for a person with Huntington's Disease."*<sup>2</sup> 2014, Martha Nance, Neurologist and Clinical Geneticist

The interactions between families with Huntington's disease (HD) and the medical profession have varied considerably over time. Osler's quotation above exemplifies the therapeutic nihilism which dominated the response of many physicians throughout much of the twentieth century. The second is from a present-day leader in the field, who spends much of her time working with HD families, and educating other physicians about how they can assist in the management of this complex disease. In this chapter, various aspects of the medical response between these two periods will be presented, from early European settlement to the early 1970s. Once again, there is little published information on this subject. As with the previous chapter, novel methods and source materials were utilised to answer questions about these features of the history of the disease in Australia. Information gained from medical journal articles, death certificates and asylum records reveal different aspects of the ways physicians responded to the disease. As noted in the literature review, the background of US physicians, especially George Huntington, has been a major focus of the study of the disease in the US. There has been no such examination of the background of the physicians studying the disease in Australia. Such investigations may reveal whether the conclusions drawn from the history of the disease in the US are more universal, or whether they represent an isolated, local story. One question to answer therefore is whether

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<sup>1</sup> William Osler, *On Chorea and Choreiform Affections* (London: H.K. Lewis, 1894).

<sup>2</sup> Martha Nance, "Comprehensive Care," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (Oxford University Press, 2014), 393-409.

there are similarities in the way the early history of the disease unfolded in the US and Australia.

The medical response to HD in Australia has come in many forms – no study can provide a definitive description of the entire history. Instead, in this chapter, specific aspects of the interplay between HD families and the medical profession will be described. This chapter begins with a review of the current literature describing what is known so far about medical responses, which is limited. Prior to outlining the way physicians wrote about HD after it was better recognised as a clinical entity in the twentieth century, the different ways it was conceptualised earlier will be revealed by reference to the different diagnoses ascribed to people with the disease. Details of the kind of physicians who encountered HD families in the nineteenth century will also be provided. While HD-affected family members were mostly cared for in the home, many were admitted to asylums, and in this chapter the reasons for this will be outlined, and the relationships between family members and asylum physicians will also be explored.

The bulk of the chapter will focus on two Tasmanian-born doctors who have played important roles in bringing HD to the attention of the medical profession. While George Huntington has received widespread attention because of his initial identification of HD, the first people to identify the disease in other countries have not been investigated in any detail, one exception being the history of the physicians involved in studying the disease in Venezuela.<sup>3</sup> In this chapter, the background of Dr Charles Hogg, who wrote the first paper on the disease published in the Australian medical literature in 1902, will be described. Much

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<sup>3</sup> Michael Okun and Nia Thommi, "Americo Negrette (1924-2003)," *Neurology* 63 (2004): 340-43.

has been made of the fact that Huntington, his father and grandfather lived amongst HD families, and the situation in Australia has a remarkably parallel trajectory. If anything is known about HD in Australia in international circles, it is the fact that the island state of Tasmania has an extremely high prevalence of the disease – previously cited as 17.4 per 100,000, triple the estimates of similar countries. This figure was based on the work of psychiatrist Dr Charles Brothers, and I will explore his large scale investigations of the disease in Tasmania. His influential papers of 1949,<sup>4</sup> 1950<sup>5</sup> and 1964<sup>6</sup> have been cited internationally, and their recognition marked a new chapter in the history of the condition in Australia and the rest of the world. His work put Australia on the international HD map, simultaneously raising awareness of the disease here and abroad. However little is known of his background – this too I will describe.

Brothers' Tasmanian survey provided the impetus for an examination of the prevalence of the disease in other Australian states. These efforts will be outlined – Brothers himself went on to study the disease in Victoria. In Queensland, this took the form of two surveys of the disease, designed to assess its prevalence, but also focusing on broader aspects of the disease. In South Australia, the existence of HD in an Aboriginal community was described, and a brief history of this story will be provided. Next will follow an overview of the medical publications on the disease, listing all of the papers until the early 1970s, followed by a thematic analysis of their content.

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<sup>4</sup> C R D Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," *Proceedings of the Royal Australian College of Physicians* 4 (1949): 46-50.

<sup>5</sup> C R D Brothers, *The History and Incidence of Huntington's Chorea in Tasmania* (Sydney: Australasian Medical Publishing Company, 1950).

<sup>6</sup> C R D Brothers, "Huntington's Chorea in Victoria and Tasmania," *Journal of the Neurological Sciences* 1 (1964): 405-20.



#### 4.1 Current Knowledge of HD's History in Australia

The absence of information about the early origins of HD in Australia is matched by a lack of information about the medical response to the disease in early times. While many Australian physicians have published articles on HD, there have been no attempts to provide an overview or examination of these publications, though two brief surveys have been conducted. In 1974, the result of an exhaustive attempt to draw together all of the published articles on HD, from all countries around the world, was published in book form.<sup>7</sup> Of the 1,963 articles recorded, 29 from Australia were identified, ranging from Hogg's 1902 article<sup>8</sup> to one published in the proceedings of the international 1973 Centenary conference.<sup>9</sup> This survey only contains bibliographical citations, though the articles are also grouped in indices according to certain themes, such as country and subject matter. The geographical index notes the first publications in each country – Australia (1902) was the 16<sup>th</sup> nation in the world to identify the disease in a medical journal article.

Psychiatrist Dr Edmond Chiu provided a brief, two page summary of the Australian medical literature for the first Australian HD conference in 1979.<sup>10</sup> Year of publication, authorship and a brief summary of 16 articles were outlined, though this text did not include references.

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<sup>7</sup> G. W. Bruyn, F. Baro, and Ntinos C. Myrianthopoulos, eds., *A Centennial Bibliography of Huntington's Chorea 1872-1972*, The Hague,: Leuven University Press, 1974), 314.

<sup>8</sup> C.A. Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," *Australasian Medical Gazette* 21 (1902): 400-04.

<sup>9</sup> D C Wallace and N Parker, "Huntington's Chorea in Queensland: The Most Recent Story," in *Advances in Neurology: Huntington's Chorea 1872-1972*, ed. Andre Barbeau, Thomas N. Chase, and George W. Paulson, (New York: Raven's Press, 1973), 223-36.

<sup>10</sup> Edmond Chiu, "History of Huntington's Disease in Australia," in *1st Australian Huntington's Disease Conference*, ed. Robyn Kapp, (Melbourne: Australian Huntington's Disease Association (NSW), 1979), 4-5.

This review also reported on developments such as the founding of an HD clinic in Melbourne. This paper did not appear in a peer-reviewed journal - it was edited by the conference organiser and it is not widely available, not even in university libraries.

Amongst the many histories of medicine, psychiatry and neurology in Australia, only two mention HD. Eric Cunningham Dax, who also wrote Brothers' obituary<sup>11</sup> mentioned the disease in relation to epidemiological research in his 1989 article on the history of Australian psychiatry.<sup>12</sup> Neurologist Mervyn Eadie also included a brief paragraph on the disease in his book on the history of neurology in Australia.<sup>13</sup> A recent book on the history of neurology did not mention HD in its section on Australia.<sup>14</sup>

## 4.2 Descriptions of HD in the Nineteenth Century

How did Australian physicians describe the disease prior to its recognition in the early twentieth century? Two sources of information about this question are asylum records and death certificates. As noted in the previous chapter, there is evidence that a person with HD was admitted to Tarban Creek Lunatic Asylum (later known as Gladesville Mental Hospital) in 1841, just three years after it was established.<sup>15</sup> <sup>16</sup> On discharge, the asylum doctors noted that he was "Discharged to his wife, feeble insane." Throughout the nineteenth century,

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<sup>11</sup> Eric Cunningham Dax, "Obituary Charles Ronald David Brothers," *Medical Journal of Australia* (1964): 289-90.

<sup>12</sup> Eric Cunningham Dax, "The First 200 Years of Australian Psychiatry," *Australian and New Zealand Journal of Psychiatry* 23, no. 1 (1989): 103-10.

<sup>13</sup> Mervyn J. Eadie, *The Flowering of a Waratah : A History of Australian Neurology and of the Australian Association of Neurologists* (Sydney: John Libbey, 2000)

<sup>14</sup> P Foley and C Storey, "History of Neurology in Australia and New Zealand," in *History of Neurology*, ed. Stanley Finger, François Boller, and Kenneth L. Tyler, (Edinburgh ; New York: Elsevier, 2010), 781-800.

<sup>15</sup> State Records Authority of New South Wales; Kingswood, NSW, Australia (hereafter SRNSW), Tarban Creek Lunatic Asylum: Series number 5029: Record Book 1839-1846.

<sup>16</sup> SRNSW, Tarban Creek Lunatic Asylum: Series number 5038: Admission Register 1838-1963.

however, families usually managed the disease within their community, with most people dying in their own homes. The physicians in the nineteenth century who documented the causes of death came from a wide range of backgrounds and although some were specialists of some kind, most were family doctors. One physician who in 1875 diagnosed a person with HD as having “primary apoplectic seizure” and “secondary paralysis” was a family doctor who lived in a medium-sized country town, who had come to Australia from Martinique. An ophthalmologist gave the cause of death in 1866 as “Congestion of the brain, and effusion.” Other causes of death included the terms “softening of the brain” (1862), “effusion of the brain” (1876), “multiple sclerosis of the spinal cord”, “sunstroke paralysis” and “chronic chorea” (1893). The phrase locomotor ataxy/ataxia was used in relation to the disease, and there were occasional references to St Vitus Dance, but this seems to be a term more used by families than physicians. General Paralysis of the Insane (tertiary syphilis) was often suspected initially in asylum notes, though as the disease progressed this diagnosis was discarded.<sup>17</sup>

### **4.3 HD in the Asylum**

The proportion of people with HD who have been admitted to asylums has been a topic of interest in both the international and Australian literature. For families, the fact that asylums were the only kind of support offered reflected the lack of appropriate care for their unwell relatives. Surveys of the disease in the Australian states of Tasmania, Victoria and Queensland have all included information on this subject. In the case of the Tasmanian

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<sup>17</sup> These descriptions were found in Death Certificates. The individuals concerned were located from the family histories discussed in the previous chapter, from papers published by physicians, family descendants who contacted me and asylum records. Specific details are not included to maintain anonymity.

group, Brothers reported that 10 out of 86 identified with HD were admitted to the “mental hospital.”<sup>18</sup> The Victorian surveys resulted in much higher rates. The first survey in 1955 reported 74 out of 150 cases<sup>19</sup> and the updated numbers in 1964 reported 154 out of 312.<sup>20</sup> In Queensland in 1958, a figure in between was noted - 25 out of 65 cases.<sup>21</sup> This figure was updated in a later survey in 1972. Of 111 people identified, 27 were in “mental hospitals” and an additional 23 in nursing homes.<sup>22</sup> These figures, when converted into percentages vary enormously, from 12% for the Tasmanian group, to 50% for the Victorian group and 38% in Queensland.

The reasons for these vastly differing rates have not been explored. One likely explanation concerns the accuracy of the overall prevalence rates. The estimates of the number of people with HD admitted to asylums were probably relatively accurate - estimating the number of people with HD in the community at large presented a much bigger challenge. One possible reason for the different findings was the reliance by the authors on asylum data which do not always provide an accurate estimate of the number of affected individuals living in the community. In the case of Brothers, he knew the affected families and relied much less on asylum data for the Tasmanian sample. In Victoria and Queensland, both research programs started with asylum records and worked from there, probably omitting many people living with HD in the community - a fact which the authors of the studies mention themselves. Another possibility is that the Tasmanian kindred trusted Brothers and were less reticent

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<sup>18</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>19</sup> C R D Brothers and A W Meadows, "An Investigation of Huntington's Chorea in Victoria," *Journal of Mental Science* 101 (1955): 548-63.

<sup>20</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 46-50.

<sup>21</sup> Neville Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," *Medical Journal of Australia* 45 (1958): 351-59.

<sup>22</sup> D C Wallace, "Huntington's Chorea in Queensland: A Not Uncommon Disease," *Medical Journal of Australia* 1 (1972): 299-307.

about revealing details of the disease to him. In the case of the Queensland studies, both authors spoke of the reluctance of some family members to engage with the researchers. Most researchers realise that prevalence rates have been consistently underestimated, a matter of recent debate in the medical literature,<sup>23</sup> including Australia.<sup>24</sup> Other implications of over-reliance on asylum data in drawing conclusions about HD families will be discussed in the following chapters.

In order to investigate various aspects of the experience of asylums for HD families, including interactions with medical staff, I examined some of the asylum records of individuals admitted to institutions in NSW, Victoria and Tasmania. Each state varies considerably in the amount and type of information held, with the NSW records being the most comprehensive. The information was obtained from similar sources to those described in Chapter 3. These include the papers of Hogg<sup>25</sup> and Evan-Jones<sup>26</sup> for the NSW cases, Lind<sup>27</sup> for the Victorian cases and Brothers for the Tasmanian cases.<sup>28</sup> Families who had responded to my request for information about their history provided some material, the material from the Mitchell Library was used and another family who had lodged information on a family history website was consulted. Asylum records were then accessed in the various states.

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<sup>23</sup> Michael Rawlins, "Huntington's Disease out of the Closet," *The Lancet* Volume 376, no. 9750 (2010): 1372-73.

<sup>24</sup> Clement Loy, A Lownie, and E McCusker, "Huntington's Disease," *The Lancet* 376 (2010): 1463.

<sup>25</sup> Hogg, "Two Cases of Huntingdon's Chorea - with a Family History," 400-04.

<sup>26</sup> S. Evan Jones, "Huntington's Chorea," *Medical Journal of Australia* 1 (1917): 376-77.

<sup>27</sup> W.A.T. Lind, "The Mental Symptoms and Post Mortem Appearances in Huntington's Chorea," *Medical Journal of Australia* 2 (1927): 53-56.

<sup>28</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

A total of 27 usable records were identified extending from 1841 to 1952. Although these numbers represent a small number of those admitted to asylums, there is no reason to suppose that they are not a representative sample. An analysis of these records will therefore give an indication of the reasons parents and spouses admitted their family members, provide demographic data, and offer insights into asylum practices of the physicians concerned. The first notable finding was the much higher number of males admitted, with 17 males and 10 females – the reason for this is not clear.

The exact causes of admission are too complex, numerous and varied to report individually, but consistent patterns emerged. Most of the people admitted were brought in as a result of their families no longer being able to manage them at home, for three main reasons. The first was due to psychiatric symptoms. One person who was admitted was severely depressed and had attempted suicide<sup>29</sup> - four months earlier her sister had died of the disease in Callan Park Mental Hospital.<sup>30</sup> One of the Tasmanian kindred was admitted with delusions to an institution in 1891, with the following description: “She believes herself to be St Eugene and as such has had ever since her birth the power of raising the dead to life.”<sup>31</sup>

Second, and the most common cause, was the person exhibiting a range of behaviours likely to cause themselves or others harm. For example, in 1936, an 18 year old girl was pregnant and, amongst other things, “had broken nearly all the teacups in the house, throwing them at her mother.”<sup>32</sup> Of another man, admitted to the asylum in 1905, it was said: “He is violent

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<sup>29</sup> SRNSW, Callan Park Mental Hospital: Series 4988: Case Papers Female Deceased 1907-1963.

<sup>30</sup> Ibid.

<sup>31</sup> Tasmanian State Archives: Royal Derwent Hospital TA465: AB365 Case books 1891.

<sup>32</sup> Tasmanian State Archives: Royal Derwent Hospital TA465: HSD284 Patient Files 1936.

and uncontrollable. Smashing windows and furniture in his bedroom.”<sup>33</sup> The third main cause was when the person’s movements and physical debilitation meant that the family could no longer care for them – they usually died soon after admission, some within days, others a few months. The following table shows the length of time people stayed in the asylum, which was highly variable, from four days to fourteen years.

TIME	< 6 months	6 months-3 years	4 to 9 years	10 + years
# of people	8	7	9	3

**Table 5: Length of Stay in Asylum after Admission**

The age on admission also varied across a wide spectrum, the youngest being 18 and the eldest 58. The following table breaks the numbers down by decade:

AGE	0-19	20-29	30-39	40-49	50-59
# of people	2	2	4	11	8

**Table 6: Age on Admission to Asylum**

There was also a wide range of family involvement once the person was admitted. A small number were admitted with no known relatives, never received visitors and seemed to die alone and forgotten. A larger number were admitted and had intermittent contact with family members. For those who were admitted to city institutions from country towns, visits were generally rare partly due to the difficulties of long distance travel. Despite this, several stayed in contact through letters to the institutions.

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<sup>33</sup> SRNSW, Callan Park Mental Hospital: Series 4994: Medical Case Books 1878-1910.

In other cases, family members maintained much closer relationships with the person admitted and with asylum staff. Some were keen to know about potential treatments, one asking whether her relative had been given ECT.<sup>34</sup> In 1918 another asked the medical superintendent whether he could provide his ex school-teacher son with a “tin of antineurasthenia,”<sup>35</sup> which he had apparently been taking prior to his admission. There were expressions of gratitude to staff, even in this era, when the reputation of asylums was often unfavourable. Two examples of patients admitted during those times follow. At the age of 43, Mary was admitted to the asylum, where she remained for seven years. Her daughter sent a letter to asylum staff on the death of her mother in 1928. Part of the letter read:

My father and I would be very grateful if you would convey to the nurses both day and night of No2 hospital wards our deep gratitude for their kindness to us during the last few days of Mother’s illness, not only then but for the whole time that she was a patient at the hospital. The kindness of the nurses to us and their wonderful attention to our mother helped a great deal to make our task of waiting and watching much lighter than it might have been.<sup>36</sup>

In 1934, another family member wrote a letter to staff. The story of Adam (1891-1934) was one of the more tragic cases unearthed in this research. He had been extremely bright at school and won prizes for his studies in science at university. His mother and brother died when he was a child, and his father, who had HD, was admitted to an asylum when Adam was only fourteen. He himself died aged 34, ten years after being admitted, having had frequent visits from various family members. His uncle wrote to staff after his death:

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<sup>34</sup> SRNSW, Callan Park Mental Hospital: Series 4988: Case Papers Female Deceased 1907-1963.

<sup>35</sup> SRNSW, Callan Park Mental Hospital: Series 4984: Admission Files 1878-1962.

<sup>36</sup> SRNSW, Callan Park Mental Hospital: Series 4988: Case Papers Female Deceased 1907-1963.



I wish to express our very sincere thanks for the care and kindness of those of your staff who had the care of our unfortunate nephew who died last Friday week after some years in the care of your Institution. ... Mr xxx let us know immediately and his courteousness when we saw him on the Friday was of such a good-heartedness that I feel that I should mention it., also Mr George xxx in whose care he had been for a considerable time always did his very best to make the unfortunate inmate comfortable. ... Also Dr I wish to express my sincere thanks to you personally for the care you have always given the unfortunate that has just passed away.<sup>37</sup>

Many criticisms of the asylum system in the twentieth century were certainly valid – the lack of scrutiny, the neglect and abuses which occurred, the paternalism of many staff, the lack of a family and patient-centred focus, and the overarching concept that people with mental illness needed to be removed from broader society, were worthy of criticism. However, an overly negative and monochromatic interpretation has dominated portrayals of the asylum in the last half of the twentieth century. Stemming from the work of Foucault, asylums have often been characterised only in terms of their role as forms of social control which accompanied the rise of scientific knowledge, as places “within which unruly bodies were exposed to detailed control.”<sup>38</sup>

By contrast, researchers have more recently shown that there were aspects of asylum life which deviated from this negative portrayal. The “social control” model of an oppressive medical establishment exercising the powers of the state over individuals is in contrast to the findings of more recent scholars, such as Catherine Coleborne, who has examined involvement of family members in asylum life.<sup>39</sup> In the case of HD too, it was almost always

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<sup>37</sup> SRNSW, Parramatta Hospital for the Insane: Series 5081: Case Papers 1870-1963.

<sup>38</sup> Bryan S. Turner, "The Discourse of Diet," *Theory, Culture & Society* 1, no. 1 (1982): 23-32.

<sup>39</sup> Cathy Coleborne, "Families, Patients and Emotions: Asylums for the Insane in Colonial Australia and New Zealand, C.1850-1910," *Social History of Medicine* 19, no. 3 (2006): 425-42.

families who sought care for their HD-affected relatives, not an oppressive state trying to restrict the liberty of the mad. When they were able, many family members were involved in the care of their relatives, made enquiries about treatments, and as the previous letters show, were in at least some cases grateful and appreciative of the care their relatives received.

Another observation from viewing the asylum information was the absence of a eugenic agenda emanating from the asylum staff. The written hospital records provide only a small glimpse into the clinical practices of the institution, and of course many things went on inside the asylum that were not recorded. However, in all of the records which I managed to examine, which ran to hundreds of pages, there was not even a hint that eugenic advice was or should be given to family members. On the contrary, when a general practitioner (GP) actively sought information regarding the possibility of a hereditary disease in one of his patients, he was actually given misleading information. In 1926, this GP voiced his concerns that his patient's symptoms were "similar to those of onset of the mother."<sup>40</sup> The mother had been in the asylum for five years, and her family history was well known to asylum staff. The medical officer advised the GP that the person's mother was suffering from "presbyophrenia, with premature Senile Decay,"<sup>41</sup> though two years later her death certificate clearly stated that she had HD. Others seemed coy rather than obfuscating. In 1927, in a letter to her son who had enquired about her health, a physician noted her "enfeebled" mental condition "which is to be expected in the particular form of nervous disease from which she suffers."<sup>42</sup>

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<sup>40</sup> SRNSW, Callan Park Mental Hospital: Series 4988: Case Papers Female Deceased 1907-1963.

<sup>41</sup> Ibid.

<sup>42</sup> Ibid.

Within the asylum, there were also cases where the disease was never identified, with people being diagnosed with “general paralysis of the insane,” “Parkinson’s Disease” and a range of other conditions. Even these asylum experts often failed to identify HD. There are many reasons why physicians misdiagnosed this condition, ranging from lack of knowledge about the disease to active suppression of the information.

Another finding of note is that four members of one family were admitted to an asylum in Ararat, in Victoria, covering the period from 1875 to 1904, but no diagnosis of Huntington’s disease was entertained, judging from the asylum notes.<sup>43</sup> While the term “choreic dementia” was used, there was no indication that these asylum doctors recognised the disease as hereditary, even when its primary features, were recorded in their notes. This fact makes the first identification of the disease by Dr Charles Hogg in 1902 even more notable, as we will see in the following section.

#### **4.4 Charles Hogg’s 1902 Paper and Background**

Just as it has been instructive to analyse the early background of physicians in the US who took an interest in HD and published their observations, research into two Australian physicians has been equally illuminating. In this section, I will describe the background of Dr Charles Hogg (1870-1951) who reported the first Australian cases of “Huntingdon’s (sic) chorea” in 1902 in the *Australasian Medical Gazette*, the forerunner of the *Medical Journal of Australia (MJA)*.<sup>44</sup> There is sufficient circumstantial evidence to suggest that he would have been aware of the disease because of his early life and family connections in Tasmania where

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<sup>43</sup> This family history was found on an internet website. Details of their admission to the asylum were located in the online records of the Public Record Office Victoria, Ararat VA 2841, Nominal Register of Patients 1867-1906.

<sup>44</sup> Hogg, "Two Cases of Huntington's Chorea - with a Family History," 400-04.

he grew up. As with the American physicians, it is likely that his exposure to the disease in his youth enabled him to identify HD when other physicians around him did not. In Australia and internationally, many people are aware of the link between Tasmania and HD; however this is mostly derived from Charles Brothers' publications. By contrast, Hogg's exposure to the Tasmanian kindred and his role in being the first to identify HD in Australia has not previously been identified.

Two sources in relatively inaccessible publications had named Hogg as the first person to identify the disease in Australia,<sup>45 46</sup> though his contribution has not been recognised more widely. In order to explore his family background, his obituary in the *MJA*<sup>47</sup> and a biography written by his nephew which was lodged in a Tasmanian library<sup>48</sup> were consulted. Further information was uncovered by searching newspaper archives, asylum records, family history databases and a memoir of a fellow psychiatrist. Unfortunately, despite extensive efforts, I was unable to find any of Hogg's personal papers or diaries in libraries in either NSW, his adopted state, or Tasmania, his home state.

Hogg was born in 1870 in a small town in north eastern Tasmania,<sup>49</sup> the same town settled by the HD family in 1842 which was described in the previous chapter. The woman with HD identified by Brothers died in the same town in 1872, just two years later. As we saw in the previous chapter, over the next decades, while some family members spread across the state and even interstate, most people in this kindred remained in close proximity. As the

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<sup>45</sup> Bruyn, Baro, and Myrianthopoulos, eds., *A Centennial Bibliography of Huntington's Chorea 1872-1972*.

<sup>46</sup> Chiu, "History of Huntington's Disease in Australia," 4-5.

<sup>47</sup> Oliver Latham, "Obituary Charles Alfred Hogg," *Medical Journal of Australia* June 2 (1951): 813-15.

<sup>48</sup> Richard Hogg, "A Short Biography of Charles Alfred Hogg," (1986). 1-18.

<sup>49</sup> W.S. Dawson, "Annals of Psychiatry in New South Wales: 1850-1900," (Sydney, NSW: 1965).

following section will outline, this family interacted with Hogg's over the decades, providing a strong case that Hogg himself would have had some knowledge of the disease in his local community. In 1873, Hogg's family moved to nearby Launceston. Charles' father Thomas (1845-90) was the founder and principal of the "Collegiate Institute."<sup>50</sup> My genealogical research has revealed that at least one child of a Huntington's family attended Hogg's father's school.<sup>51</sup>

Three members of Hogg's family were medical doctors in the region, two in the same town as the original HD family. Hogg's mother, Mary Anne Huxtable (1842-1935) was the daughter of Dr William Jones Huxtable (1815-62). Like the Tasmanian HD family, Dr Huxtable was one of the many immigrants to come to the state from Somerset in the 1840s. He had a medical practice in this same town from 1841 to 1849, and again from 1855 to 1862.<sup>52</sup> On his death in 1862, another relative, Dr William Robert Stewart, took over the practice. Hogg's mother's cousin, Dr Charles Stewart, worked at the Launceston General Hospital.<sup>53</sup> Brothers stated that the woman with the HD gene showed symptoms soon after her arrival. Given the many deaths from HD which occurred during the doctors' tenure and the long duration of the disease, it is difficult to imagine how these physicians and Hogg's family more broadly could have been unaware of her condition and that of her children.

Unfortunately, I have been unable to find doctors' casebooks or notes bearing on this question. In 1852, Dr Huxtable published a booklet called *The Domestic Medical Friend*, which

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<sup>50</sup> Obituary The Late Mr Thomas Hogg. *Daily Telegraph*, (Launceston, Tas.: 1883-1928), 18 July 1890.

<sup>51</sup> Obituary of xxx Examiner (Launceston, Tas: 1900-1954) 1942. (Date not included to maintain anonymity.

<sup>52</sup> K. R. Von Stieglitz, *A History of Evandale* (Evandale, Tas.: Evandale History Society, 1992).

<sup>53</sup> Ibid.

was advertised in newspapers in Melbourne and Hobart, described as “A brief and familiar description of the diseases generally prevalent in the climate of Van Diemen’s Land.”

Unfortunately there are no extant copies of this volume.<sup>54</sup> It is a tantalising prospect that this text may have included the first ever description of the disease, even predating the US pre-Huntington descriptions. Newspaper articles of this period reveal that Dr Huxtable interacted with HD family members, though of course there is no way of knowing whether they were symptomatic at the time.<sup>55</sup> Dr Huxtable was a witness in a case where two Huntington family members served as jurors in 1862. He and HD family members were both petitioners signing a letter to an aspiring MP. In a close knit pioneering community, living in close proximity to each other, it is highly probably that Hogg and his physician relatives would have some knowledge of this hereditary disease.

Hogg followed the traditional path of Australians wishing to study medicine in the late nineteenth century in travelling to Britain for his medical training. He was the winner out of three contenders for the “Richard Green Scholarship”<sup>56</sup> at the age of 15. Later, he won another scholarship worth £300, which enabled him to study medicine at the University of Edinburgh. He graduated in 1893, and worked briefly at a hospital in Manchester, then returned to Australia. He began his career in the NSW Mental Hospital Service at Gladesville Hospital for the Insane in 1896.<sup>57</sup> He was Senior Medical Officer at Parramatta Hospital for the Insane until June 1903, when he moved to Kenmore Hospital in Goulburn. After a brief return to Parramatta in 1921, he was appointed Inspector General of the Insane from 1926

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<sup>54</sup> Ibid.

<sup>55</sup> References are not provided so as not to reveal the names of the family members, but are available from the author on request.

<sup>56</sup> The Richard Green Scholarship. *Daily Telegraph* (Launceston, Tas.: 1883-1928), 14 Oct, 1885, p 2.

<sup>57</sup> Hogg, "A Short Biography of Charles Alfred Hogg."

until his retirement in 1935.<sup>58</sup> Although I was unable to find when he was first elected, he was re-elected as the vice-President of the NSW Council for Mental Hygiene in 1933.<sup>59</sup> Hogg did not publish any other articles on HD, though he published on other topics.<sup>60 61 62</sup> His tenure as Inspector General of Mental Hospitals has been described as mediocre<sup>63</sup> though there were more generous appraisals.<sup>64</sup> He died on 15<sup>th</sup> March, 1951, aged 80.

In common with all the Australian papers published in the first half of the twentieth century, the first identification of the disease occurred as a result of people with HD being admitted to asylums. This family was identified as Family F in the previous chapter. In 1901, two brothers were sent from two nearby towns in the NSW mid-north-coast to a Sydney asylum, one being diagnosed by the admitting doctor with “locomotor ataxia” the other with “Friedrich’s ataxia,” two terms for movement disorders in use at the time, the latter known to be a hereditary condition. In addition to a short period in the “lock-up”, the brothers spent a year in a Benevolent Asylum prior to their admission to Parramatta Hospital for the Insane, and the physician there described “an exaggerated form of choreic spasms” but no diagnosis apart from “insane, and not under proper control and care.”<sup>65</sup>

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<sup>58</sup> C J Cummins, *A History of Medical Administration in New South Wales 1788-1973* (2nd) (NSW Health, 2003).

<sup>59</sup> Mental Hygiene: Proposed Measure for Defectives *The Sydney Morning Herald* (NSW:1842-1954), 1 Dec 1933, p 10.

<sup>60</sup> Charles Hogg and Oliver Latham, "Encephalitis Lethargica," *Medical Journal of Australia* 2 (1923): 90-95.

<sup>61</sup> Charles Hogg, "Twelve Cases of Insanity in Australian Aborigines with a Commentary," *Medical Journal of Australia* (1924): 455-58.

<sup>62</sup> Charles Hogg, "University Teaching of Psychiatry," *Medical Journal of Australia* Supplement (1927): 290-95.

<sup>63</sup> Stephen Garton, "Seeking Refuge: Why Asylum Facilities Might Still Be Relevant for Mental Health Care Services Today," *Health and History* 11 (2009): 25-45.

<sup>64</sup> Alfred Theophilus Edwards, *Patients Are People* (Sydney: Currawong Publishing. Company, 1968).

<sup>65</sup> SRNSW, Parramatta Hospital for the Insane, Series number 5080: Admission Files 1880-1865.

Within two months of their admission, Hogg, Senior Medical Officer at the time, had pieced together an extensive family history, conducted a thorough neurological and general medical examination of the brothers, and outlined seven potential differential diagnoses, prior to reaching his conclusion of “Huntingdon’s (sic) family chorea.” It is clear from Hogg’s description that he had extensive communication with the brothers’ wives and mother about the duration of the illness, initial symptoms, age of onset of symptoms, and details of family members similarly affected. This is in stark contrast to the previous description at Ararat asylum in Victoria, where four members of one family were admitted to an asylum in the same period, yet HD was not identified by any physician. Hogg was not a recent graduate at the time, though at the age of 32 he was still a junior doctor, early in his career. Hogg’s approach exemplified the importance of listening to family members to get a history of the symptoms and patterns of transmission, which would allow its identification.

The brothers died two years apart, in 1902 and 1904, and while the death certificate of the first brother references “Huntington’s Hereditary Chorea,” by the time the second brother died this diagnosis seemed to have been forgotten and he was listed as dying of a “chronic brain disease.” Hogg left the hospital in 1903 and his previous diagnosis of HD seems to have been forgotten following his transfer. Hogg’s insights and presence were crucial not only to the identification of the disease, but in maintaining knowledge of the diagnosis within the asylum system.

The largest part of Hogg’s three and a half page paper concerned motor symptoms, with very specific neurological details expressed with confidence and certainty.<sup>66</sup> Hogg was clearly

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<sup>66</sup> Hogg, “Two Cases of Huntington’s Chorea - with a Family History,” 400-04.



on less steady ground in describing the “mental symptoms” with vague and slightly contradictory descriptions of dementia. It is clear that Hogg gained some insight into the brothers’ state of mind, which he presented in several asides in the article. He noted of both brothers that he “realises his condition and wants to be cured.” (p 402) About one of the brothers he stated: “When in bed he will lie curled up on his side, resenting any movement or any questions which are asked him”, “he tends to burst into tears” and “threatens to slit his throat.” (p 402) Despite these emotionally striking descriptions, Hogg maintained a “scientific silence” on these issues, following the standard model of medical papers presenting information in an objective manner, in contrast with later descriptions.

Hogg seemed to be aware of the significance of describing this new nosological entity: His paper meticulously outlined all of the potential alternative diagnoses. He details the possibilities of Marie’s cerebellar ataxia, ataxic paraplegia, disseminated sclerosis, general paralysis of the insane, Friedrich’s ataxia and paralysis agitans, which he later refers to as “Parkinson’s disease.” After considering the weight of evidence, he stated that “The only conclusion I can come to is that these are cases of Huntingdon’s family chorea” (p 403) citing specifically “the family history, incurability, age of onset, mode and place of onset and the choreiform movements.” (p 403) In keeping with medical publications of the day, minimal references were provided. The only reference to another paper stated that “Peterson (page 511) describes a case of Huntingdon’s chorea.” This presumably refers to a widely used reference book called *Nervous and Mental Diseases* by the American neurologists Frederick Peterson (1859-1938) and Archibald Church.<sup>67</sup> Hogg makes no mention of George Huntington’s original description, nor of other publications on the disease. Interestingly, he

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<sup>67</sup> Archibald Church and Frederick Peterson, *Nervous and Mental Diseases*, 2d ed. (Philadelphia,: W.B. Saunders, 1900)

uses the same incorrect spelling “Huntingdon” that William Osler also used, indicating that he might also have been aware of his writings on the disease.

Numerous other asylum doctors had been exposed to people with HD, yet despite his relative inexperience, Hogg was unique in identifying it before all others. In fact, eleven years lapsed before the next publication on HD appeared.<sup>68</sup> Hogg’s role as the first physician to identify the disease in Australia has never been acknowledged in the published medical literature, with the exception of the brief bibliographic indexes described at the beginning of the chapter. The first reference to his paper is a 1917 publication in the *MJA* by Evan Jones<sup>69</sup>, which mentions that the brothers were cousins of the cases under study. Hogg’s obituary, published in the *MJA*, failed to mention any of his publications.<sup>70</sup> His own nephew’s short biography does make a brief mention of Hogg’s description of HD, but not his position in being the first Australian to identify the disease.<sup>71</sup> Interestingly, Dr Julia Bell cited Hogg’s paper in her monumental study of the disease in Britain, published in 1934.<sup>72</sup>

Regardless of his legacy more broadly, Hogg’s under-recognised contribution deserves acknowledgement in the historical record. Furthermore, the circumstances surrounding this first identification of the disease in Australia are significant. There are strong parallels between George Huntington’s and Charles Hogg’s situations. Both had close relatives who worked as doctors, their families both came from communities with relatively large numbers of people with HD. Neither had established reputations. The first published medical

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<sup>68</sup> J. Catarinich, "Huntington's Chorea," *Australian Medical Journal* 3 (1914): 1509-11.

<sup>69</sup> Evan Jones, "Huntington's Chorea," 376-77.

<sup>70</sup> Latham, "Obituary Charles Alfred Hogg," 813-15.

<sup>71</sup> Hogg, "A Short Biography of Charles Alfred Hogg," 1-17

<sup>72</sup> Julia Bell, *Huntington's Chorea* (London: Cambridge University Press, 1934).

recognition of the disease in Australia provides an example outside the US of how recognition of this complex disease was most likely aided by prior familiarity with its symptoms.

#### **4.5 Charles Brothers and Tasmania**

The life of another Tasmanian is a similar case in point. In 1937, psychiatrist Dr Charles Brothers (1905-1963) began his study of HD families in Tasmania. I have provided details of this family in the previous chapter. Brothers' three publications drew international attention to the presence of the disease in Australia, and the family he described has become a widely known part of the HD story to the present day. Until the revelations about the vast Venezuelan kindred in 1973, Tasmania was reported as having the highest prevalence of the disease in the world.<sup>73</sup> In this section, Brothers' studies, the background to his research and the local and international attention they received will be explored. Like Charles Hogg, Brothers grew up in Tasmania and lived among HD families. Another survey of the disease in Tasmania was conducted by psychiatrist Dr Saxby Pridmore in the early 1990s – while outside the time period of my dissertation, this extensive study is relevant for correcting some errors arising from Brothers' original work.

There are few clues as to why Brothers embarked on his extensive and time-consuming studies of HD in two Australian states, and despite my efforts to find answers to this question, only fragmentary details have emerged. I was unable to find any of his personal or professional papers in any Australian library. The State Archives Office of Tasmania has records relating to Brothers' time as Director of Mental Hygiene, however I was unable to

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<sup>73</sup> Myrianthopoulos, "Huntington's Chorea," *Journal of Medical Genetics* 3 (1966): 298-314.

find any reference to his HD study in these records - they mostly contained administrative matters such as leave and employment.<sup>74</sup> Researching the Public Records Office of Victoria proved similarly fruitless. Brothers died suddenly of a heart attack in 1963<sup>75</sup> and, unfortunately, many of his papers were lost.<sup>76</sup> After his death, the Charles Brothers Museum was set up in Parkville, Victoria, to house his clinical records, medical artefacts and possibly other papers, however this museum was closed in 1987 and the material was dispersed.<sup>77</sup>

Some of his personal records surfaced for a short time in the mid-1970s, when one of Brothers' successors found them in a box under his desk.<sup>78</sup> Sadly, these records have once again gone missing.<sup>79</sup> The only sources of information available are Brothers' obituaries, medical journal articles, newspaper articles reporting on his speeches to various institutions and his own publications. I managed to contact his daughter-in-law, who also contacted Brothers' daughter, but unfortunately they had no knowledge of his interest in HD beyond the fact that he had published on the disease.<sup>80</sup> The main relevant fact to emerge from his obituaries and his posthumously published 1964 paper was the fact that he was born in a region of Tasmania which had a relatively large number of HD families and that he had a close association with many families from a young age.<sup>81</sup>

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<sup>74</sup> Tasmanian State Archives HD6/1/18. General Correspondence Hospital and Health Administration.

<sup>75</sup> Dax, "Obituary Charles Ronald David Brothers," 289-90.

<sup>76</sup> Encyclopaedia of Australian Science (2011) <http://www.eoas.info/biogs/P004804b.htm>. Accessed 22-1-2013.

<sup>77</sup> Encyclopaedia of Australian Science (2011) <http://www.eoas.info/biogs/A002358b.htm>. Accessed 22-1-2013.

<sup>78</sup> Edmond Chiu and Betty Teltscher, "Huntington's Disease in the Department of Psychiatry," in *The Department of Psychiatry at the University of Melbourne 1969-2009*, ed. Edmond Chiu and Joy Preston, (Melbourne: University of Melbourne, 2010), 176-79.

<sup>79</sup> Personal Communication, Edmond Chiu, 11 Jun, 2011.

<sup>80</sup> Personal Communication, Ann Brothers, 7 Jan 2014.

<sup>81</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-20.

From a professional point of view, one reason for his interest in the disease can be found in newspaper articles describing talks he had given. Brothers' name appeared in the Tasmanian press on several occasions throughout the 1940s – there are many articles related to his position as the Director of Mental Hygiene. One article, published in 1941 with the headline “Improvement of Race: Doctor Discusses Problems of Tasmanian ‘Hill Billies’” provides some insight into Brothers’ public pronouncements regarding the reasons for his study, if not his private views. In a newspaper account of a talk he had given to the Royal Society, Brothers concluded that “investigation of the problem of inheritance ... had been haphazard and frequently inexact” and called for “prolonged research to be undertaken in which psychiatrists, statisticians and geneticists would collaborate.”<sup>82</sup> He particularly noted the factors in favour of Tasmania as an “ideal state” for the study of genetic diseases. While he did not note HD specifically in this context, his own study of the disease must have been a consideration. In the following section I will describe aspects of Brothers’ background which shed some further light on this question.

#### **4.5.1 Brothers’ Professional and Personal Background**

Charles Ronald David Brothers was born and completed his primary and secondary education in Northern Tasmania. Just as Charles Hogg had conformed to the conventions of the day in undertaking his medical studies abroad, Charles Brothers was amongst the next generation which remained in Australia to study medicine. Brothers moved from Tasmania to attend the University of Melbourne where he obtained a degree in Medicine in 1927.<sup>83</sup> He was employed as a Medical Officer at the Royal Melbourne Hospital and then joined the

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<sup>82</sup> Improvement of Race: Doctor Discusses Problems of Tasmanian “Hill Billies.”” *The Mercury* (Hobart, Tas.:1860-1954), 15 July 1941, p 2.

<sup>83</sup> Eric Cunningham Dax, "Charles Ronald David Brothers," review of Reviewed Item, *College Roll, Royal Australian College of Physicians*, no. (1964).

Victorian Department of Mental Health in 1929, where over the next years he worked in a number of different asylums.<sup>84</sup>

In 1936, at the age of 31, Brothers returned to Tasmania, and was appointed the Medical Superintendent of Lachlan Park Mental Hospital, the state's primary mental hospital. Within one year, he embarked on a study of an extended family with HD. Ten years later, in 1946, he was appointed Chairman of the Mental Deficiency Board, Director of the State Psychological Clinic and served as the Director of Mental Hygiene for Tasmania.<sup>85</sup> Honours include being made a fellow of the Royal Australasian College of Physicians. In 1950 he served as president of the Australian Association of Psychiatrists. He returned to Victoria in 1951, where he served under Eric Cunningham Dax as the Deputy-Director of the State Mental Hygiene Authority, later known as the Victorian Mental Health Authority. He held this position until his sudden death in 1963.<sup>86</sup>

Brothers had an interest in medical history, particularly asylum history. This interest culminated in a publication in the *American Journal of Psychiatry* in 1959<sup>87</sup> and later a book on early Victorian psychiatry.<sup>88</sup> He had a particular interest in medical artefacts, and collected items from the various asylums he visited. His early death perhaps prevented his own study of the history of HD. As noted above, after his sudden death, the artefacts he collected were gathered together and formed part of the Charles Brothers Museum. When the museum was

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<sup>84</sup> Dax, "Obituary Charles Ronald David Brothers," 289-290.

<sup>85</sup> Encyclopaedia of Australian Science (2011) <http://www.eoas.info/biogs/A002358b.htm> Accessed 22-1-2013.

<sup>86</sup> Dax, "Obituary Charles Ronald David Brothers," 289-90.

<sup>87</sup> Charles R D Brothers, "Letter from Australia: Psychiatry in the State of Victoria, Australia," *American Journal of Psychiatry* 116, no. 6 (1959): 492-94.

<sup>88</sup> Charles Ronald David Brothers, *Early Victorian Psychiatry, 1835-1905 : An Account of the Care of the Mentally Ill in Victoria, from the Time of the First Settlement to the Beginning of the Present Century* ([Melbourne: Government Printer, 1962).

closed, some clinical notes were transferred to the Public Records Office of Victoria. The artefacts now form the bulk of a collection called *Behind Closed Doors: A Catalogue of Artefacts from Victorian Psychiatric Institutions held at the Museum of Victoria*.<sup>89</sup>

Brothers' legacy was remembered in the decade or so after his death, and although the family he described has entered HD folklore, his contributions are rarely acknowledged. There was an obituary in the *MJA* in 1964 by Cunningham Dax with an additional contribution by Dr Crowther, a former Tasmanian colleague.<sup>90</sup> Dax reported that Brothers was "one of the world's experts on Huntington's chorea." Crowther noted his "remarkable follow-up study of Huntington's chorea in this state (Tasmania)" and told how he was present at the meeting of the Royal Australian College of Psychiatrists when Brothers presented the results of his research on the incidence of Huntington's chorea over the generations and the fact that the study had "created interest far beyond Australia." Dr John Cade, the Victorian psychiatrist who was instrumental in the discovery of lithium as a treatment for mania, was a friend and colleague of Brothers. The *American Journal of Psychiatry* thought fit to publish Cade's obituary of Brothers, bringing his legacy to an international audience. Cade reported that Brothers "was recognised as an authority on Huntington's Chorea,"<sup>91</sup> (p 205) noting particularly his study of the "relatively stable and limited population of Tasmania." (p205) Dax mentioned Brothers briefly in his publication on the history of Australian psychiatry.<sup>92</sup>

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<sup>89</sup> Encyclopaedia of Australian Science (2011) <http://www.eoas.info/biogs/P004804b.htm> Accessed 22-1-2013.

<sup>90</sup> Dax, "Obituary Charles Ronald David Brothers," 289-90.

<sup>91</sup> John Cade, "In Memoriam: Charles Ronald David Brothers," *American Journal of Psychiatry* 121, no. 2 (1964): 205.

<sup>92</sup> Dax, "The First 200 Years of Australian Psychiatry," 103-10.

Brothers' relationship to the HD families he studied was mentioned by several researchers in the period around his death. In his own 1964 paper, an additional comment noted that Brothers' research was made possible by "his intimate knowledge of a small but scattered population."<sup>93</sup> (p 405) The obituary by Cade went further in stating that "It would not be an exaggeration to say that he knew every affected family."<sup>94</sup> (p 205) The nature of the relationship between Brothers and HD families has not been further explored, and so much time has elapsed now that most people who might have had first hand information have died. In the course of the research, I was able to find details of one direct connection.

Brothers went to school in Tasmania with the mother of one of the founding members of the HD Association, whose family were affected by HD. She reported that Brothers, known as Charlie by her mother, had provided her mother with information about the disease.<sup>95</sup>

Brothers' early exposure to HD families, as revealed by these sources, is yet another example of the way in which early experiences of the disease by a physician were influential in later recognition and interest.

While the reasons which prompted Brothers to study this disease might never be known, his familiarity with previous studies might provide further insight. Brothers only cited one publication in the 1949 version of his paper – the general neurology text by the prominent British neurologist Kinnier Wilson.<sup>96</sup> His later works published in 1955 and 1964 showed that he had become aware of other large-scale studies of the disease. Like in Australia, much of the international literature on HD in the first half of the twentieth century consisted solely of single case descriptions or small cohort studies. Others, however, embarked on wider-

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<sup>93</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 46-50.

<sup>94</sup> Cade, "In Memoriam: Charles Ronald David Brothers," 205.

<sup>95</sup> Personal Communication, Joyce Abblitt, 25 Nov, 2012.

<sup>96</sup> S. A. Kinnier Wilson and Alexander Ninian Bruce, *Neurology* (London: E. Arnold & Co., 1940)



scaled investigations. The earliest of the papers Brothers referenced was Davenport and Muncey's 1916 publication<sup>97</sup> which was widely cited in the HD literature for much of the twentieth century. The study was initiated by the Eugenics Record Office (ERO) in the US, and the title made the linkage between HD with eugenics unavoidable: "Huntington's Chorea in Relation to Heredity and Eugenics." The methodology included "personal observation of choreics, both in and out of institutions, much from the records of state hospitals and of town clerk's offices, much from the memory of relatives or neighbours and much from the genealogical and town histories"<sup>98</sup>(p196). This wide-ranging approach, with a strong emphasis on reconstructing family histories, was the first of these large scaled studies of the disease, the one by Brothers included. He next cited another prominent text on HD, written by the British geneticist Dr Julia Bell as part of the series "Treasury of Human Inheritance" in 1934.<sup>99</sup> This study presented data from 151 kindreds reported in the world literature, some studied by Bell herself, with a primary emphasis on identifying the age of onset and clinical features of the disease. Minski and Guttman's 1938 study from the US of 90 cases of the disease from 34 different families resulted from contacting state hospitals.<sup>100</sup>

In 1949, Brothers published a journal article, entitled "The History and Incidence of Huntington's Chorea in Tasmania" in the *Proceedings of the Royal Australasian College of Physicians*.<sup>101</sup> This paper was reprinted in booklet form the following year by the Australasian Medical Publishing Company,<sup>102</sup> presumably because of interest in the paper

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<sup>97</sup> Charles B. Davenport and Elizabeth B. Muncey, "Huntington's Chorea in Relation to Heredity and Eugenics," *American Journal of Insanity* 73, no. 2 (1916): 195-222.

<sup>98</sup> Ibid.

<sup>99</sup> Bell, *Huntington's Chorea* .

<sup>100</sup> L Minski and E Guttman, "Huntington's Chorea: A Study of 34 Families," *Journal of Mental Science* 84 (1938): 21-96.

<sup>101</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>102</sup> Brothers, *The History and Incidence of Huntington's Chorea in Tasmania* 1-4.

and difficulties accessing it in this relatively obscure journal. International interest in Brothers' work is reflected in the fact that the editors of the *Journal of Neurological Science*, the official journal of the World Federation of Neurology, approached him to update his work, according to a footnote in the paper resulting from this request, his 1964 publication on the disease in Victoria and Tasmania.<sup>103</sup> As noted previously, he died in 1963. Dax's obituary bemoaned Brothers' relatively early death, stating: "It was a tragedy that his major work on this subject was not quite completed at the time of his death."<sup>104</sup> (p 289) While this 1964 publication lists Brothers as the sole author, a note on the front page of the paper states that the paper was "almost completed on the day before Dr Brothers' untimely demise."<sup>105</sup> (p 405) It is clear from these statements that an unnamed author finalised this work, though what parts, or by whom, is not revealed. One source stated that his interrupted investigations were "completed" by Dr Graeme Robertson.<sup>106</sup> In terms of the content, the Tasmanian section was only modified by slight changes in wording, whereas the Victorian section was updated with new material.

Brothers papers reported on his 11 years of study, which attempted to trace all cases of HD in Tasmania, making his research the first Australian study (and amongst the first international ones) to quantify the extent of the disease in a particular geographical region. His method was outlined, and was very similar to that used by other researchers, though in this case his emphasis on the families as the first source of information is noteworthy: "Most of the information has been supplied by patients and other members of the family, by

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<sup>103</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-20.

<sup>104</sup> Dax, "Obituary Charles Ronald David Brothers," 289-90.

<sup>105</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-20.

<sup>106</sup> Encyclopaedia of Australian Science (2011) <http://www.eoas.info/biogs/A002358b.htm> Accessed 22-1-2013.

various hospital records, church records and records of the Registrar-General's Department."<sup>107</sup> (p 46).

In his rather brief paper (it runs to only five pages, two of which contained the pedigree charts) Brothers provided no overview of the literature on HD and seemed to assume that those reading the paper would be familiar with the main features. He described the disease as "a well-known clinical entity" and noted that although it was regarded as "comparatively rare", that it was "relatively common in Tasmania" a fact which had been "known for some time."<sup>108</sup> (p 46) He traced the origins of the disease to a woman said to have migrated from Somerset in the UK to Tasmania in 1848 (later research found this date to be actually 1842). He also reported that she had come with all of her 13 children, (but in fact she came with eight and had six more in Tasmania, one of whom died soon after her arrival). As outlined in the previous chapter, her thirteen children were then described, detailing those with and without the disease. Brothers also included a pedigree chart outlining the numbers of recorded cases of HD extending to five generations in some families. Brothers reported on eight cases in Tasmania which could not be traced back to this common origin, one group having moved from another Australian state.

In terms of his portrayal of this extended family, several descriptions are noteworthy. In the first section of the paper, Brothers gave an overall impression of the entire kindred. He used a particular turn of phrase, which was previously employed by Kinnier Wilson in 1940<sup>109</sup> and

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<sup>107</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>108</sup> Ibid.

<sup>109</sup> Wilson and Bruce, *Neurology* .

earlier in 1930 by another author,<sup>110</sup> which must have rung true: the family were described as coming from “respectable and industrious yeoman stock.”<sup>111</sup> (p 46) This was a far cry from the criminality, witches and dancing manias cited in other studies of the origins of the disease. In his initial paper, Brothers’ speculated that the original descendent from Somerset had a French background, stating that “it is believed that she was of French descent, since her maiden name was an English corruption of a French surname.”<sup>112</sup> (p 46) His 1964 paper introduced the idea that the woman was of Huguenot descent, a claim which has been repeated frequently since that time.<sup>113 114 115 116 117</sup> I have used various online surname searches to try to identify the origins of her maiden name,<sup>118</sup> including lists of Huguenot surnames.<sup>119</sup> My research has failed to identify this as a Huguenot or even a French name – most people with this name come from Somerset.<sup>120</sup> As noted in the literature review, this has been a common theme in the HD literature, and the alleged Huguenot origin of the disease has been described in other kindreds.<sup>121 122 123</sup> These claims of Huguenot migration, in other countries may well be supported by better evidence, but in this case the link is tenuous

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<sup>110</sup> Curran, "Huntington's Chorea without Choreiform Movements," *Journal of Neurology and Psychopathology* (1930): 305-10.

<sup>111</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>112</sup> Ibid.

<sup>113</sup> Macdonald Critchley, "Huntington's Chorea: Historical and Geographical Considerations," in *The Black Hole and Other Essays*, ed. Macdonald Critchley, (London: Pitman Medical Publishing Company, 1964), 210-19.

<sup>114</sup> R J Berry, "Genetical Changed in Mice and Men," *Eugenics review* 59, no. 2 (1967): 78–96.

<sup>115</sup> Kenneth Heathfield, "Huntington's Chorea: A Centenary Review," *Postgraduate Medical Journal* 49, no. January (1973): 32-45.

<sup>116</sup> M. R. Hayden and P Beighton, "Huntington's Chorea in the Cape Coloured Community of South Africa," *South African Medical Journal* Nov (1977): 886-88.

<sup>117</sup> Eadie, *The Flowering of a Waratah : A History of Australian Neurology and of the Australian Association of Neurologists*.

<sup>118</sup> The name is not included to maintain anonymity.

<sup>119</sup> <http://www.huguenotsaustralia.org.au/name.html> Accessed 20-12-2014.

<sup>120</sup> <http://worldnames.publicprofler.org/> Accessed 2-7-2014.

<sup>121</sup> Myrianthopoulos, "Huntington's Chorea," 298-314.

<sup>122</sup> Hayden and Beighton, "Huntington's Chorea in the Cape Coloured Community of South Africa," 886-88.

<sup>123</sup> Macdonald Critchley, "The History of Huntington's Chorea," *Psychological Medicine* 14 (1984): 725-27.

at best and unsupported by the available evidence. It is hard to ignore the fact that one of the common themes of the Huguenots is their fleeing of persecution, and once again this is a tempting framework through which to view HD, regardless of the veracity of the claims.

Describing the entire kindred, Brothers reported on his overall impression of these families. He noted “a marked resemblance both in physical build and physiognomy,”<sup>124</sup> (p 50) including “a long, oval and somewhat pointed and puckish face.”<sup>125</sup> He also reported that in “earlier years they are usually mentally very alert and could best be described as rather extroverted.”<sup>126</sup> (p 50) He then goes on to outline aspects of the “pre-choreic personality” where he reported on many of the challenging behavioural features of the disease. Brothers’ results reported the age of onset, which many noted were higher than in other countries.

Brothers did not employ the kind of emotional language used by many others in their description of HD families, nor did he comment on the “neuropathic” or “psychopathic” traits of affected and non-affected family members which was such a notable aspect of other writing on the disease. An even more striking omission is the subject of eugenics. Firstly, he did not mention themes common to eugenic discourse, such as alleged high fertility rates, nor did he discuss in any way how the disease could be prevented by eugenic means. This is particularly surprising, given that he gave several lectures on eugenics to various organisations in Tasmania in the 1940s. He even had a paper published entitled “Psychiatry and Eugenics” in 1950<sup>127</sup> – his relationship with eugenics will be discussed in greater detail in the next chapter. Brothers himself offered two summations of his research - he confirmed

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<sup>124</sup> Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," 46-50.

<sup>125</sup> Ibid.

<sup>126</sup> Ibid.

<sup>127</sup> C R D Brothers, "Psychiatry and Eugenics," *Medical Journal of Australia*, no. 5 August (1950): 211-15.

the Mendelian dominant nature of HD and he reported how the register which recorded the occurrence of the disease in Tasmania had been useful in terms of diagnosis.

#### **4.5.2 Australian and International Response to Brothers' paper**

Whereas Brothers focussed on these relatively modest contributions, future authors highlighted other aspects of the research - the extremely high rate of the disease in Tasmania and the fact that this high rate could result from a single migrant source, which for many had implications for immigration policies. In order to show the impact of his research, the response to his papers will be outlined. The first two references to Brothers' papers were by Australian researchers in 1955<sup>128</sup> and 1958.<sup>129</sup> The first non-Australian article citing Brothers' work was by Reed and Neel in 1959,<sup>130</sup> which referenced his 1949 paper. Interestingly, they made no mention of the prevalence rate, instead focusing on the high age of onset of the disease which Brothers and other researchers had found. Later researchers have also commented on the comparatively late age of onset of the Tasmanian kindred.<sup>131</sup> Three American neurologists researching the disease in Michigan in 1960 commented in the influential journal *Neurology* on the "important geographical survey" Brothers had conducted,<sup>132</sup> bringing widespread international attention to his work.

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<sup>128</sup> Brothers and Meadows, "An Investigation of Huntington's Chorea in Victoria," 548-63.

<sup>129</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey.," 351-59.

<sup>130</sup> T E Reed and J V Neel, "Huntington's Chorea in Michigan," *American Journal of Human Genetics* 11, no. 2 (1959).

<sup>131</sup> Peter Harper, "The Epidemiology of Huntington's Disease," in *Huntington's Disease*, ed. Peter Harper, (London: W.B. Saunders, 1996), 201-40.

<sup>132</sup> J H Chandler, T E Reed, and R N DeJong, "Huntington's Chorea in Michigan Iii Clinical Observations," *Neurology* Feb, no. 10 (1960): 148-53.

The early second half of the twentieth century saw the publication of several major reviews of HD, all of which included Brothers' work.<sup>133 134 135</sup> Books on HD reported his observations,<sup>136</sup> and the high prevalence rate was also reported in general genetics textbooks.<sup>137</sup> All of these cited Brothers' works in relation to prevalence – in particular noting the widespread geographical distribution of the disease around the world and the fact that the prevalence in Tasmania was high. As noted previously, some explicitly mentioned the “Huguenot” woman who had brought the disease from Somerset.<sup>138</sup> Beginning with Parker's 1958 publication, a prevalence rate of 17.4 per 100,000 for the state of Tasmania has been reported in most major works on the disease.<sup>139 140 141 142</sup> There was no disputation of this claim until the 1990s, when psychiatrist Dr Saxby Pridmore's updated Tasmanian study found the prevalence of the disease in Tasmania to be 12.1 per 100,000.<sup>143</sup> Whereas more thorough and detailed studies of the disease have absorbed this new information,<sup>144 145 146</sup> the erroneous, higher figure remains in the medical literature, as recently as 2008<sup>147</sup> and 2012.<sup>148</sup>

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<sup>133</sup> Myrianthopoulos, "Huntington's Chorea," 298-314.

<sup>134</sup> G. W. Bruyn, "Huntington's Chorea: Historical, Clinical and Laboratory Synopsis," in *Handbook of Clinical Neurology*, ed. P.J Vinken and G. W. Bruyn, (Amsterdam: North-Holland Publishing Company, 1968), 298-378.

<sup>135</sup> Heathfield, "Huntington's Chorea: A Centenary Review," 32-45.

<sup>136</sup> Michael R. Hayden, *Huntington's Chorea* (Berlin ; New York: Springer-Verlag, 1981).

<sup>137</sup> R. T. C. Pratt, *The Genetics of Neurological Disorders* (Oxford: University Press, 1967).

<sup>138</sup> Critchley, "The History of Huntington's Chorea," 725-27.

<sup>139</sup> Myrianthopoulos, "Huntington's Chorea," 298-314.

<sup>140</sup> Heathfield, "Huntington's Chorea: A Centenary Review," 32-45.

<sup>141</sup> Hayden, *Huntington's Chorea*.

<sup>142</sup> P M Conneally, "Huntington Disease: Genetics and Epidemiology," *American Journal of Human Genetics* May, 36, no. 3 (1984): 506-26.

<sup>143</sup> Saxby A Pridmore, "The Prevalence of Huntington's Disease in Tasmania," *Medical Journal of Australia* 153, no. Aug 6 (1990): 133-34.

<sup>144</sup> Louis T Giron and William C Koller, "A Critical Survey and Update on the Epidemiology of Huntington's Disease," in *Handbook of Neuroepidemiology*, ed. Philip B. Gorelick and Milton Alter, (New York: M. Dekker, 1994), 281-94.

<sup>145</sup> Harper, "The Epidemiology of Huntington's Disease," 201-40.

<sup>146</sup> Francis O. Walker, "Huntington's Disease," *The Lancet* 369, no. 9557 (2007): 218-28.

<sup>147</sup> Aimee Aubeeluck and Eleanor Wilson, "Huntington's Disease: Essential Background and Management," *British Journal of Nursing* 17, no. 3 (2008): 146-51.

<sup>148</sup> Vivek Sharma, Priety Sharma, and Rahul Deshmukh, "Huntington's Disease: Clinical Complexities and Therapeutic Strategies," *Journal of Advanced Scientific Research* 3, no. 2 (2012): 30-36.

In investigating the reasons for this erroneous figure, Pridmore blamed other researchers for the error, however my research has uncovered further details which trace the origin of this mistake back to Brothers himself. The history of these claims necessitates a rather detailed explanation.

The title of Brothers' paper, "The History and Incidence of Huntington's Chorea in Tasmania", indicates that he would provide information on the "incidence" of the disease. In reality, he did no such thing. Brothers' description of the cases, and the pedigree chart, shows that he identified 86 people with HD, both living and dead, and it is not possible from either his text or the pedigree chart to know which are which. There is no figure estimating either incidence (usually meaning number of cases diagnosed in a year) or prevalence (number of living cases). This is a surprising finding - the impression gained from most publications is that Brothers cited the 17.4 prevalence rate in his papers. If not published in any of Brothers' papers, where did this statistic come from?

In addition to his prevalence study, Pridmore's extensive survey of the disease resulted in six other publications,<sup>149 150 151 152 153 154 155</sup> though his downward revision of the prevalence data

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<sup>149</sup> Pridmore, "The Prevalence of Huntington's Disease in Tasmania," 133-34.

<sup>150</sup> Saxby A Pridmore, "The Large Huntington's Disease Family of Tasmania," *Medical Journal of Australia* 153, no. Nov 19 (1990): 593-95.

<sup>151</sup> Saxby A Pridmore, "Age of Onset of Huntington's Disease in Tasmania," *Medical Journal of Australia* 153, no. Aug 6 (1990): 135-37.

<sup>152</sup> Saxby A Pridmore, "Age of Death and Duration in Huntington's Disease in Tasmania," *Medical Journal of Australia* 153, no. Aug 6 (1990): 137-39.

<sup>153</sup> Saxby A Pridmore, "Relative Fertility of Unaffected Siblings of the Huntington's Disease Families of Tasmania," *Medical Journal of Australia* 153, no. Nov 19 (1990): 588-92.

<sup>154</sup> Saxby A Pridmore and Adams, "The Fertility of Hd-Affected Individuals in Tasmania," *Australian and New Zealand Journal of Psychiatry*. 25, no. 2 (1991): 262-64.

<sup>155</sup> S. A. Pridmore, H. D. Pridmore, and G. C. Adams, "Reproduction and Age of Onset of Huntington's Disease in Tasmania," *The Medical journal of Australia* 153, no. 10 (1990): 589.



from 17.4 to 12.1 has received the most attention. In his prevalence study,<sup>156</sup> Pridmore himself makes some attempts to explain this erroneous figure, and although most of his conclusions are verified by my research, one claim is not supported by the evidence to hand. Pridmore concludes that the error lay in a paper by the American neurologist Dr P. Michael Conneally, published in 1984.<sup>157</sup> In this paper on the genetics and epidemiology of HD, Conneally cites Brothers' figure of 105 individuals with the disease from the Tasmanian Somerset kindred, and gives a Tasmanian population estimate of 60,334. Pridmore identifies four errors related to these claims, some of which are valid, others not. There are two main problems with these figures. First, the estimate of Tasmania's population is a gross underestimate: Pridmore states that in 1947, the year before Brothers' study was completed, the Tasmanian population was in fact 257,000. Both Dr Edmond Chiu and Ms Betty Teltscher, who worked with HD families in the early 1970s, claim that Brothers' figure was based on the population of the North East of Tasmania, not the whole state.<sup>158</sup> Secondly, as pointed out previously, Brothers' figures included both living and dead – from these numbers it was not possible to estimate the current prevalence.

In these respects, Pridmore is correct, however, Pridmore misapportions blame for this figure, stating that “He [i.e. .Brothers] did not determine the prevalence of the disease”<sup>159</sup> (p 133). Two sources of information readily refute the claim that the erroneous figure was traced back to 1984. Firstly, and most obviously, decades before the 1984 paper, there were multiple publications which note the figure of 17.4, dating as far back as 1958.<sup>160</sup>

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<sup>156</sup> Pridmore, "The Prevalence of Huntington's Disease in Tasmania," 133-34

<sup>157</sup> Conneally, "Huntington Disease: Genetics and Epidemiology," 506-26.

<sup>158</sup> Personal communication, Betty Teltscher. 12 June, 2011.

<sup>159</sup> Pridmore, "The Prevalence of Huntington's Disease in Tasmania," 133-34.

<sup>160</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," 351-59.

Furthermore, in the course of my research, I obtained a copy of a letter from Brothers himself which indicates that although he never published this figure, it was he who provided it to other researchers. The letter, dated 1960, is written to an American HD researcher, Dr Perry, who from Brothers' reply, seems to have written to him asking for information regarding rates of the disease in Australia.<sup>161</sup> Brothers includes the figure of 17.4 per 100,000, indicating that he calculated this figure himself and then communicated the information to people through unofficial correspondence. Two years earlier, Australian researcher Neville Parker had also noted this figure.<sup>162</sup> In his paper, he reported on a personal communication with Brothers from 1957. It is a fair assumption that Brothers repeated this figure in his correspondence to a range of colleagues, who then quoted it in their articles, and in this way the figure was never scrutinised until Pridmore's contribution in 1990.

Although we now have a clearer understanding of the reasons for the miscalculations of the previous figures cited by Brothers, there are indications that in Tasmania the disease is likely to have an even higher prevalence than Brothers' own figure. The question of the prevalence of the disease is still a contentious issue. One reason is that prevalence figures are used as evidence in arguments for the provision of care and in guiding research.<sup>163</sup> In 2010, Dr Michael Rawlins published an article in the *Lancet* on the complexity of estimating the prevalence of the disease, and argued that the current figures were likely to be underestimates. Citing the claim that the UK Huntington's Disease Association currently

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<sup>161</sup> Letter from Charles Hogg to Dr Perry. Obtained from Mrs Betty Teltscher. Copy in possession of the author.

<sup>162</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," 351-59.

<sup>163</sup> T Hoppitt et al., "Huntington's Disease," *Lancet* 376, no. 9751 (2010): 1463-64.

knew of 6,702 symptomatic individuals, this would yield a prevalence of 12.4 per 100,000.<sup>164</sup> A formal study of prevalence using data from primary care physicians published in 2013 confirmed this rate in the UK,<sup>165</sup> which is twice the previously cited figure. The question of the current prevalence rate in Tasmania is beyond the scope of this dissertation, however the President and Secretary of the Huntington's Disease Association of Tasmania advised me that they know of more than 100 people in Tasmania currently living with HD,<sup>166</sup> which would give a prevalence rate well in excess of even Brothers' original claim.

Leaving questions of the specific prevalence aside, even Pridmore's more modest statistic still indicates a high rate of the disease in Tasmania – this fact, and its origins in the “Huguenot woman from Somerset” has become one of the entrenched historical HD narratives. The reasons for this have not been explored. The person most likely to have popularised the Tasmanian story is the British neurologist Macdonald Critchley, who has focussed on social dimensions of the disease in his writings. As we saw in the literature review, his work on the history of HD mostly consisted of the wider dissemination of Vessie's claims of connections between witchcraft accusations and HD in the US. Critchley wrote about the Tasmanian family in 1964 in a book of essays about neurology, bringing the story to a wider, lay audience.<sup>167</sup> At the influential conference held in 1972 on the centenary of Huntington's original paper, Critchley, while President of the World Federation of Neurology, gave a paper on “Great Britain and the Early History of

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<sup>164</sup> Rawlins, "Huntington's Disease out of the Closet," 1372-73.

<sup>165</sup> Stephen J. W. Evans et al., "Prevalence of Adult Huntington's Disease in the Uk Based on Diagnoses Recorded in General Practice Records," *Journal of Neurology, Neurosurgery & Psychiatry* 84, no. 10 (2013): 1156-60.

<sup>166</sup> Personal Communications.

<sup>167</sup> Critchley, "Huntington's Chorea: Historical and Geographical Considerations," 210-19.

Huntington's Chorea."<sup>168</sup> In this paper, where he outlined the countries "infected by Huntingtonian migration from Great Britain" (p 16) he described the Tasmanian family as outlined in Brothers' papers. He presumably had other contact with Brothers, as he actually gave the maiden name, plus the name from both marriages of the "Huguenot" woman from Somerset. He repeated her surname in his 1984 article on the disease.<sup>169</sup> This information, for obvious reasons, is usually kept private, but her maiden name has now been repeated by others writing on the disease.<sup>170 171</sup>

The Tasmanian family is still discussed even in recent years. This includes texts as diverse as the recent medical literature,<sup>172</sup> the comprehensive online database of all genetic diseases, Online Mendelian Inheritance in Man,<sup>173</sup> genetics textbooks<sup>174</sup> and even popular science writing by Jared Diamond<sup>175</sup> and the prominent geneticist Dr Steve Jones.<sup>176</sup> These recent texts mentioning the high rate of the disease in Tasmania are most likely to refer to it as an example of the "founder effect." This is a feature of many genetic conditions, and refers to the situation when a new "colony" is started by a few members of the original population, giving a disproportionately large percentage in later generations.

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<sup>168</sup> Macdonald Critchley, "Great Britain and the Early History of Huntington's Chorea," in *Advances in Neurology* ; V. 1. *Huntington's Chorea, 1872-1972*, ed. Andre Barbeau, Thomas N. Chase, and George W. Paulson, (New York: Raven Press, 1973), 13-17.

<sup>169</sup> Critchley, "The History of Huntington's Chorea," 725-27

<sup>170</sup> Jared Diamond, "Founding Fathers and Mothers," *Natural History* 97, no. 6 (1988): 10-15.

<sup>171</sup> Hayden, *Huntington's Chorea*.

<sup>172</sup> Walker, "Huntington's Disease," 218-28.

<sup>173</sup> *Online Mendelian Inheritance in Man* (Johns Hopkins University, 2013).

<sup>174</sup> Richard A. King, Jerome I. Rotter, and Arno G. Motulsky, *The Genetic Basis of Common Diseases*, 2nd ed., *Oxford Monographs on Medical Genetics* ; No. 44 (Oxford ; New York: Oxford University Press, 2002).

<sup>175</sup> Diamond, "Founding Fathers and Mothers," 10-15.

<sup>176</sup> Steve Jones, *The Language of the Genes : Biology, History and the Evolutionary Future*, Rev. ed. (London: Flamingo, 2000).

There are two quite simple explanations for the high rate of the disease in Tasmania. Brothers' own charts indicate that eleven of the thirteen children either had the disease or had descendents with HD. Many of these also had large families – six of the thirteen had nine or more children. Another relatively unacknowledged explanation is the population structure of the state itself. Demographer Terry Dwyer noted how migration to Tasmania from the UK ended in the 1850s, in contrast to most other Australian states that continued to have large scale immigration. He reported that there were approximately 10,000 of these founder families, and that 65% of the current population descended from these original migrants, both convicts and free settlers.<sup>177</sup> Charles Brothers' own family was one of these founder families, again pointing to the close knit nature of the Tasmanian kindred and the physicians studying the disease.

#### **4.6 Brothers' Victorian Research**

Brothers returned to Victoria in 1951, taking up the position of Deputy Chairman of the Mental Hygiene Authority under Eric Cunningham Dax, who remained the Chairman until Brothers' death. After a settling in period of two years, among his many other duties, Brothers once again began a study of HD in the state. He knew already that some of the Tasmanian family had settled in Victoria, as described in his 1949 paper. The methodology was not outlined, but judging from the case descriptions, patients in mental hospitals formed the bulk of the initial cases from which family histories were explored.

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<sup>177</sup> Cathy Johnson, *Founder Families Treasure Island* (Australian Broadcasting Commission, 2003).

Brothers published two papers on the disease in Victoria: the first with psychologist Meadows in 1955,<sup>178</sup> and the second the 1964 paper described above. The first paper followed a rather similar format to the Tasmanian paper, in that a large proportion was devoted to describing 19 kindreds with the disease and included genograms. In addition to traditional subjects such as age of onset and early symptoms of the disease, this paper included a large amount of detail about the “mental state of the patients” including fashionable tests of the time like Rorschach inkblot tests. Brothers and Meadows provided information on the multiple sources of origin of the disease into Victoria, in contrast with the Tasmanian kindred.

As noted previously, Brothers was asked to update his 1955 paper by one of the regional editors of the *Journal of the Neurological Sciences*. His interest in the disease must have continued, as he writes in the article that over the subsequent years “many more cases personally (were) interviewed and examined by the writer.” (p 405) This 1964 paper updated the number of people living with the disease from 57 to 138. This paper omitted the previous detailed descriptions of the kindreds, summarising the information into statistical tables and descriptions of issues such as the large number of juvenile cases.

As with the Tasmanian papers, Brothers made no mention of eugenics and presented no data on the number of offspring of these families. While not using the vilifying language used in other publications, he did portray the personality changes that can be one of the first indicators of the disease, and the challenges these bring to the management of the condition

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<sup>178</sup> Brothers and Meadows, "An Investigation of Huntington's Chorea in Victoria," 548-63.

for other family members. At no point did he mention that people at risk should not marry or have children. Brothers made a few scattered references about the effect of the disease on families, and their reactions to it. He noted how in some families there was a tendency to “deny the presence of the disease itself” (p 409) and reported on the enforced secrecy in some. He described two families where “the topic of St Vitus’ dance or chorea was completely taboo”<sup>179</sup> (p 409) and that it was not possible to discuss it with outsiders or even within “the inner family group.” He also noted the contrasting reaction of families – some living in denial of the presence of disease, others who “watch their relatives very closely and frequently detect danger signs at a stage when perhaps a medical man could not yet demonstrate their existence.”(p 409) Brothers noted that Julia Bell had pointed out these differing reactions in her paper 30 years earlier. The acknowledgement of lay knowledge of the disease and responses to it can be seen as the first step towards a more patient-centred future, when families’ needs were considered part of medical care.

#### **4.7 Overview of Other Studies**

While Brothers’ papers are the most recognised publications on the disease in Australia, many other physicians have published articles on HD. The following table presents a list of Australian papers on HD up to 1970 (with a few additional texts cited in this study) based on the centennial bibliography, the survey of Chiu discussed in section 4.1, and additional papers I have located in the medical literature.

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<sup>179</sup> Brothers, "Huntington's Chorea in Victoria and Tasmania," 405-20.

Year	Author/Publication	State	Details
1902	Hogg/ Aust Med Gazette	NSW	2 cases, brothers, + fam hx
1913	Gamble, Congress Publication	VIC	2 cases
1914	Catarinich, MJA	VIC	2 cases, + fam hx and review
1915	Stawell, MJA	VIC	1 case
1917	Evan-Jones, MJA	NSW	1 case
1918	Anon, MJA	VIC	1 case
1919	Gamble, The Speculum	VIC	2 cases
1927	Lind, MJA	VIC	1 case
1934	Cantor, MJA	VIC	1 case
1941	Anon, MJA	NSW	1 case
1943	Anon, MJA	NSW	2 cases
1946	Anon, MJA	NSW	1 case + review
1948	Anon, MJA	NSW	1 case
1949	Brothers, Proceedings RACP	TAS	Origin of one extended family
1950	Brothers, booklet	TAS	Reprint of above
1955	Brothers and Meadows, J. Me Sci	VIC	19 pedigrees
1956	Morgan, MJA	NSW	Treatment
1958	Parker, MJA	QLD	Survey of Queensland
1964	Brothers, J Neur Sci	VIC & TAS	Review and update
1965	Mackiewicz, MJA	Not state-specific	Treatment
1966	Edmonds, MJA	Not state-specific	Dysphagia
1969	Gale and Bennett, MJA	SA	Aboriginal Family Group
1969	Sutherland, J	–	Geography and
1971	Vann, MJA	-	Hypnotherapy for HC
1971	Wallace, MJA	-	HC as model for aging
1972	Wallace	QLD	Update pedigrees
1972	McLeod	-	HC and tryptophan
1972	Teltscher & Davies, MJA	VIC	Social problems
1973	Wallace & Parker	QLD	Book Chapter summary

**Table 7. List of Publications on HD in Australian Medical Journals.** <sup>180 181</sup>

<sup>180</sup> A full list of references to these publications can be found in the bibliography.

<sup>181</sup> This list does not include the many publications by Colin Brackenridge, which can readily found using search engines, unlike many of the earlier publications listed here which are not found in databases.



Following Hogg's paper, it was to be eleven more years until the next article on HD appeared. Most of the published articles in the first half-century were written by asylum doctors and were brief articles in the section of the *MJA* where reports were made on the meetings of the British Medical Association in each state. These articles probably passed without notice, even to most readers of the journal, given their relatively obscure locations – most were not even included in the Table of Contents.

One exception was the work of psychiatrist Dr Sydney Evan-Jones (1887-1948), who contributed to three articles on the disease, later becoming superintendent of Broughton Hall, a major Sydney asylum. Following his graduation, he was employed on Mawson's Antarctic expedition from 1911-1914. Just three years after returning, he published the next major paper on HD,<sup>182</sup> describing a cousin of Hogg's 1902 cases who was admitted to the Callan Park asylum. This was one of the only papers of the half-century to reference other Australian literature on the disease. Despite the disease being well-known to some, many other doctors were less well-informed. In 1943, at a meeting of the NSW Branch of the British Medical Association, Dr Spearman presented one of Evan-Jones's patients with HD, and was reported as stating that "the chance of escape was about one in four at best."<sup>183</sup> (p 409) Evan-Jones is not reported as challenging these errors. This points to continuing ignorance of one of the major features of the disease, even amongst the asylum doctors. One physician was convinced of an association between HD and "General Paralysis of the Insane,"<sup>184</sup> now known as tertiary syphilis. Notably, no physician apart from Evan-Jones indicated awareness of previous Australian publications, and few other international papers

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<sup>182</sup> Evan Jones, "Huntington's Chorea," 376-77.

<sup>183</sup> Anonymous, "Bma News, Huntington's Chorea," *Medical Journal of Australia* 1, no. November 13 (1943): 408-09.

<sup>184</sup> Morris Gamble, "A Few Interesting Clinical Cases," *Australasian Medical Congress* 10 (1913): 747-54.

were cited. Hogg was obviously aware of the main features of the disease, but only cited a generic neurology text. Catarinich<sup>185</sup> (1914) referred to George Huntington's paper, but was the only author to do so. Lind in 1927 cited a range of papers published in the *British Medical Journal*,<sup>186</sup> and Spearman also cited the prominent neurologist Kinnier Wilson in his description of Huntington's chorea.<sup>187</sup>

Partly as a result of this ahistorical approach, there was no indication of progress being made in the understanding of the disease, and contradictory claims were made. Several authors described the condition as rare (Catarinich,<sup>188</sup> Stawell,<sup>189</sup> Gamble<sup>190</sup>). At Stawell's case presentation, Ernest Jones, who was the Director of Mental Hygiene, argued instead that the disease was "relatively common"<sup>191</sup> in Victoria's asylums. The impact of these publications was minimal. Taken as a whole, they offered little in the way of analysis or new scientific thinking, merely recording the presence of the people with the disease in their hospitals. As noted above, they were in obscure sections of the *MJA*, and received little attention - these papers were rarely cited by later authors. These isolated case reports did not give a sense that with each paper, more knowledge was being added to the understanding of this complex disease.

Of particular interest to this research is the way in which the HD patients and their families were described in the first half of the twentieth century. On the whole, the language used was measured and lacked the more florid and dramatic descriptions of the disease found in

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<sup>185</sup> Catarinich, "Huntington's Chorea," 1509-11.

<sup>186</sup> Lind, "The Mental Symptoms and Post Mortem Appearances in Huntington's Chorea," 53-56.

<sup>187</sup> Anonymous, "Bma News, Huntington's Chorea,"

<sup>188</sup> Catarinich, "Huntington's Chorea," 1509-11.

<sup>189</sup> Anonymous, "Huntington's Chorea," *Medical Journal of Australia* no. March 13 (1915): 245.

<sup>190</sup> Gamble, "A Few Interesting Clinical Cases," 747-54.

<sup>191</sup> Anonymous, "Huntington's Chorea," 245.

many of the papers published in the US and the UK. Evan-Jones in his 1917 article did use the phrase “psychopathic” in his descriptions of HD.<sup>192</sup> However in a later comment on a case presentation in 1946, his language was an object lesson in moderation. He described the primary mental features of HD as “changes in character, morality blunted, interest decayed and sense of responsibility failed.”<sup>193</sup> (p 308) The most denigrating description came from the pathologist Lind, who characterised people with HD in general as “dangerous and requiring institutional control”<sup>194</sup> however he was the exception. It is instructive to note the subjects which were not covered, and the words which were rarely used in all the publications I reviewed. The terms “hereditary taint,” “degeneration” and “neuropathic” were not used to describe either the patients or their families. The question of the fertility of HD families was not raised, and the advice to refrain from childbearing, ubiquitous from the 1950s, was notably absent.

The presence of two prominent eugenicists at case presentations is also of note – according to Ross Jones, these two “worked tirelessly for at least two decades from 1906 for the introduction of public policy measures that some would describe as broadly eugenic.”<sup>195</sup> (p 67). William Ernest Jones (1867-1957), who also was Victorian Inspector General of the Insane in 1905 and later Director of Mental Hygiene, was, as noted above, familiar with HD - he had commented on the disease being quite common in Victorian asylums. Another attendee at one of these case presentations<sup>196</sup> was Richard (RJA) Berry (1867-1962), anatomist at the University of Melbourne, an enthusiastic eugenicist who published widely

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<sup>192</sup> Evan Jones, "Huntington's Chorea," 376-77.

<sup>193</sup> Anonymous, "Huntington's Chorea," *Medical Journal of Australia*, March 2 (1946): 308-09.

<sup>194</sup> Lind, "The Mental Symptoms and Post Mortem Appearances in Huntington's Chorea," 53-56.

<sup>195</sup> Ross Jones, "Removing Some of the Dust from the Wheels of Civilization: William Ernest Jones and the 1928 Commonwealth Survey of Mental Deficiency," *Australian Historical Studies* 40 (2009): 63-78.

<sup>196</sup> Anonymous, "British Medical Association News," *Medical Journal of Australia* 2, July 27 (1918): 68.

on eugenics and also gave many public presentations. Berry's major eugenic concerns included the classification and control of the "feeble-minded" and Indigenous Australians, rather than those with hereditary neurological diseases. Fortunately for HD families, these eugenics enthusiasts did not seize on the disease as did some of their counterparts in the US. Medical attention to the disease in relation to eugenics increased in the following decades, which will be discussed in the following chapter.

#### **4.8 HD in Queensland: Drs Neville Parker and David Wallace**

The next large-scale studies of the disease took place in Queensland and for the first time in the Australian literature, physicians began to write on the ramifications of the disease for family members. In 1958, just three years after Brothers and Meadows' paper on the disease in Victoria, the results of a survey of HD in Queensland were published in the *Medical Journal of Australia*, authored by the psychiatrist Dr Neville Parker (1928-1992).<sup>197</sup> In 1972, another psychiatrist, Dr David Wallace, reported in the *MJA* on the results of his updated survey of the disease in Queensland<sup>198</sup> and a joint publication by Parker and Wallace on the disease was presented to an international audience in 1972, with the publication of this paper in 1973.<sup>199</sup> Parker's paper begins in an unusual manner for a scientific journal, and is an example of how HD can evoke strong reactions in those encountering it. It is worth quoting the opening sentence in full: "Few of us can fail to be moved to compassion by the grimacing and uncontrolled movements of the choreic."<sup>200</sup> (p 351) Parker stated that he conducted the study "with the aim of educating and helping affected members and their families." (p 351) Parker used Queensland Mental Hospital and Brisbane General Hospital

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<sup>197</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," 351-59.

<sup>198</sup> Wallace, "Huntington's Chorea in Queensland: A Not Uncommon Disease," 299-307

<sup>199</sup> Wallace and Parker, "Huntington's Chorea in Queensland: The Most Recent Story," 223-36.

<sup>200</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," 351-59.

records to find affected families and then traced their pedigrees. Parker found 65 people living with the disease, giving a prevalence (which he called incidence) of 2.3 per 100,000. Parker himself noted that this was likely to be a gross underestimate. Once again, like in Victoria, he found multiple kindreds responsible for the distribution of the disease in the State, with most coming from England, Scotland, Ireland and other Australian states. Parker's paper focussed on themes common to other accounts of HD.

Parker did attempt to educate family members about the disease: he noted that he sent all affected families an information pamphlet entitled *Huntington's Chorea and Your Family* which was produced by the Minnesota Genetic Research Unit.<sup>201</sup> Unfortunately, I have been unable to locate a copy of this, so it is unknown what kind of advice and information was given to families. He stated: "All living relatives were then approached by letter ... and the pamphlet was forwarded to them."<sup>202</sup> (p 352) Parker made no reference to questions of patient confidentiality or the ethical dilemmas involved in disclosing details of the disease to others, and one can imagine that this action may have had significant consequences for many families. Others at this time were well aware of these sensitivities – in 1962 in the US, the psychiatrist John Whittier published an entire paper on ethical and legal issues involved in working with HD families.<sup>203</sup>

Parker's paper also reflected the stigmatising narratives which were an important strand of medical articles on the disease. The subject headings he chose to focus on are revealing, and are worth recording in full. After sections on traditional medical concerns such as

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<sup>201</sup> Ibid.

<sup>202</sup> Ibid.

<sup>203</sup> J Whittier, "Research on Huntington's Chorea: Problems of Privilege and Confidentiality," *Journal of Forensic Sciences* 8, no. 4 (1963): 568-75.

“Diagnosis” (p 354) and “Age of Onset” (p 355), Parker had sub-headings for “Alcoholism” (p 355), Suicide (p 355), Crime (p 356) Fecundity (p 357) “Marriage and Reproduction” (p 358) and “Immigration” (p 358), with his approach to the latter two subjects having strong eugenic themes. Parker followed in Brothers’ footsteps in describing the families’ “wandering disposition” without providing any kind of support for this observation. In the section on immigration, discussing the rate of the disease, he also saw fit to comment on lessons to be learned from Brothers’ Tasmanian kindred: “Let us hope that it will not be at the same alarming rate as the Tasmanian family, in which one person was responsible for 86 cases in five generations.”<sup>204</sup> (p 358) He also ventured into the territory of eugenics more explicitly, which will be discussed in more detail in Chapter 5. In 1963, he was elected as a Fellow of the Eugenics Society of Great Britain.<sup>205</sup>

Following on from Parker’s work, another psychiatrist, Dr David Wallace (1925-1979), set about studying the disease in Queensland in 1969, this time with the explicit intention of studying the prevalence of HD – the subtitle being “A Not Uncommon Disease.”<sup>206</sup> As noted from the work of others, the prevalence of the disease has been an issue of ongoing concern for decades, and remains so. Working from Parker’s paper, and pedigrees which had been updated in the years since his study, he identified 111 people living with HD, almost double the number found by Parker just over a decade earlier. His methodology was more exhaustive than Parker’s in appealing to physicians directly and also in his approach to aged care facilities in addition to the usual mental institutions. This gave a prevalence rate of 6.3

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<sup>204</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey" 351-59.

<sup>205</sup> Anonymous, "Notes and Memoranda," *Eugenics review* 55, no. 1 (1963): 36.

<sup>206</sup> Wallace, "Huntington's Chorea in Queensland: A Not Uncommon Disease," 299-307.

per 100,000, almost three times Parker's initial figure of 2.2 per 100,000.<sup>207</sup> The joint paper from Wallace and Parker presented to the 1972 conference brought together their observations from their two surveys.<sup>208</sup> They reported no new findings, reiterating themes from the previous papers. They too describe "the well-documented social problems – the alcoholism, the broken families, the sexual promiscuity, the brushes with the law" and other descriptions of sufferers' "ruthless, self-centred, driving personality." (p 231) These depictions will be discussed in more detail in Chapter 6.

#### **4.9 HD in South Australia in an Indigenous Community**

As noted in Chapter 3, HD is one of the many diseases introduced to the Indigenous population of Australia. In 1969, medical attention was brought to bear on this issue: a report of the existence of HD in a group known as the "Port Macleay aborigines" was published in the *MJA*.<sup>209</sup> Fay Gale (1932-2008),<sup>210</sup> a cultural geographer, had come across the disorder in the context of her studies of Aboriginal communities in South Australia. Regarding her identification of this family, she later stated that "clearly it was out of my field,"<sup>211</sup> and she enlisted the help of Henry Bennett (1926-), Professor of Genetics at the University of Adelaide. Marjorie Angas (1919-1997), who was employed as a welfare officer for the South Australian Aborigines Department, was also involved in this research and worked extensively with these families over the coming decades.

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<sup>207</sup> Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," 351-59.

<sup>208</sup> Wallace and Parker, "Huntington's Chorea in Queensland: The Most Recent Story," 223-36.

<sup>209</sup> Fay Gale and J H Bennett, "Huntington's Chorea in a South Australian Community of Aboriginal Descent," *Medical Journal of Australia* Sept 6 (1969): 482-84.

<sup>210</sup> Nick Harvey, "Fay Gale Obituary," *Adelaidean*, (2008)

<http://www.adelaide.edu.au/adelaidean/issues/27061/news160html>. Accessed 27-9-2013.

<sup>211</sup> Email from Fay Gale, 7 Apr 2005.

Gale and Bennett's medical journal article echoed the familiar themes in the representation of HD in these decades - warnings about its spread were paramount, especially as many individuals had left the reserve and moved interstate. Once again, high rates of criminality, alcoholism and sexual promiscuity were reported, though the overall tone of the article was of sympathy and concern for the affected families. The article concluded with what we will see in the following chapter was a familiar message: "it is highly desirable that adults who may have the gene should not have children. With many members of these families now reaching reproductive age, it is a matter of some urgency to find a way of getting this point of view understood and accepted by these people."<sup>212</sup>(p 484) Social worker Angas' initial contact with HD was through her role as welfare officer which she commenced in 1957.<sup>213</sup> Her role broadened to include all families with HD in South Australia, including indigenous and non-indigenous families. She was employed as Research Officer for the Huntington's Chorea Project<sup>214</sup> and was involved in the production of three further information brochures/articles on HD. Angas' role in response to HD will be further examined in Chapter 6, which outlines developments in the management of HD in the 1970s.

#### **4.10 Overview of Australian HD Medical Literature**

Having described these medical publications spanning the first 70 years of the twentieth century in terms of the content, it is also important to point out the subject matter which did not appear. For much of the twentieth century, the primary focus has been on the diagnosis and identification of the disease. From Hogg's tentative 1902 paper which painstakingly identified the range of potential diagnoses, mentions of HD in the Australian medical

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<sup>212</sup> Gale and Bennett, "Huntington's Chorea in a South Australian Community of Aboriginal Descent,"

<sup>213</sup> Marjorie Alice Angas. <http://archives.samuseum.sa.gov.au/aa676/provlist.htm>. Accessed 14-10-2013.

<sup>214</sup> M. A. Angas, "Huntington's Chorea," ed. Department for Community Welfare (South Australia Department for Community Welfare, 1973).



literature over the next 50 years mostly consisted of a series of individual cases or groups of cases presented to other physicians. During this period, the only author to comment on possible treatments was Cantor in 1934, who reported on the use of “sodium phenobarbital”<sup>215</sup> (p 650) to control the restlessness of a patient in the hospital.

The next phase revolved around attempts to comprehensively survey individual Australian states to ascertain the prevalence rates of the disease. These surveys have been described above, but again these papers are mostly silent on the question of attempts at treatment or advice on management. There were a few exceptions. One paper on “tremor-rigidity syndromes” noted the partial success of reserpine in patients with HD,<sup>216</sup> and ten years later another study on the same agent was also reported.<sup>217</sup> Other treatments were attempted – a 1971 paper even suggested hypnotherapy.<sup>218</sup> But these were isolated cases, and Australian publications were not alone in this – very few papers in the international literature gave advice to physicians about what might be done to help manage the disease. The majority view expressed in the international literature was reflected in Wallace’s 1972 paper. Noting the absence of effective treatment, he stated that “nothing has been found which will in any way retard the inexorable progress of this horrible disease.”<sup>219</sup> (p 299)

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<sup>215</sup> S.J. Cantor, "A Case of Huntingdon's Chorea," *Medical Journal of Australia* 2, no. November 17 (1934): 650.

<sup>216</sup> D. R. Morgan, "Experimental Use of Reserpine in the Treatment of Tremor-Rigidity Syndromes," *The Medical journal of Australia* 43, no. 23 (1956): 973.

<sup>217</sup> J. Mackiewicz and A. A. Reid, "Clinical and Neuropathological Investigations of Four Cases of Huntington's Chorea Treated with High Doses of Reserpine," *The Medical journal of Australia* 1, no. 23 (1965): 833-35.

<sup>218</sup> D. Vann, "Successful Hypnotherapy for Anxiety Neurosis in Huntington's Chorea," *The Medical journal of Australia* 2, no. 3 (1971): 166-66.

<sup>219</sup> Wallace, "Huntington's Chorea in Queensland: A Not Uncommon Disease," 299-307.

In the absence of pharmacological treatments, physicians perhaps lost sight of other aspects of the medical role – such as providing expert, factual information, suggestions on how to manage the symptoms and what to expect. Later testimony provided by family members and those working with families in the 1970s outlined the consequences of this neglect, reporting on how difficult it was to manage the disease while being unaware of its major features. Even after the disease was identified by asylum physicians and reported in the medical literature, there was widespread unawareness of the disease in the community by local physicians. At one end of the spectrum was total ignorance. Unless they worked in one of the few areas with a high concentration of the disease, family GPs would rarely come across it. Secondly, even when they did know, they were often reluctant to diagnose the disease, perhaps because of stigma, perhaps because of the consequences for family members, perhaps because it is very difficult for physicians to give patients such bad news, an issue still relevant to physicians today.<sup>220</sup> Thirdly, even when the knowledge of the disease was openly acknowledged by the physician and family, misconceptions about the disease were rife. Once again, these issues will be discussed in more detail in Chapter 6

#### **4.11 Conclusion**

In this chapter, various aspects of the relationship between HD families and the medical profession in Australia were brought to light. While much remains unknown about how physicians responded to the disease, some parts of this story have been told here. The most notable finding regarding the early identification and study of this disease by physicians is the similarity between the situation in the US and Australia. Some myths surrounding the HD

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<sup>220</sup> Jill Phillips et al., "Difficulties in Disclosing the Diagnosis of Dementia: A Qualitative Study in General Practice," *British Journal of General Practice* 62, no. 601 (2012): 546-53.

story in Australia have been explored and flaws identified, and the response of physicians to the disease as described in the medical literature has been summarised and analysed.

Investigation into the backgrounds of physicians involved in the early identification and the study of the disease has revealed striking parallels with the history of HD in the US. Like George Huntington and other US physicians who were the first to describe the disease, the early experiences of two Australian physicians were also paramount. The disease was identified in Australia by Dr Charles Hogg in 1902, and he published the first article on HD in the Australian medical literature. He came from a region with a proportionately high concentration of HD families, and several of his close relatives, including his grandfather, were physicians in the town and surrounding regions. I have argued that his early familiarity with the disease allowed him to identify the condition more than a decade before other Australian physicians.

Charles Brothers, the person who made the most extensive study of the disease, was also born in this region of Tasmania and it is documented that he lived amongst HD family members. I found further evidence of his direct involvement with HD families.

Brothers' study of the Tasmanian family was one of the studies which changed the focus of the disease from what some previously described as "an American tragedy" to one of international significance. The existence of a large HD kindred in Australia reflected the increasing interest and recognition of the disease as a world-wide phenomenon. This was a far leap from the "medical curiosity," localised to Long Island that Huntington thought he was reporting in his original 1872 paper. Although Brothers' role was widely recognised in the past, it is now rarely acknowledged.

In the literature review, the tendency to repeat stories from the past without examination of the veracity of the claims was described in relation to the dancing manias, witchcraft accusations and even the correct name of George Huntington. Australia, too, has had its share of misinformation about the disease. Most notably, the incorrect Tasmanian prevalence rate of 17.4 per 100,000 individuals, which is still being cited in the literature, was corrected by Pridmore, but the roots of this error were explored here and found to stem from Charles Brothers himself. Another HD narrative is the identification of Huguenot populations with the disease, a claim made about the Tasmanian kindred. My research found no evidence for this contention.

Another contribution of this research is the examination of asylum data in three Australian states, which indicated that families only resorted to this option as a last resort. Although the reasons for admission to these institutions varied, it was usually as a result of challenging behaviour, frank psychotic symptoms or the emaciation, frailty and dependence that comes in the final stages of the disease. This led husbands, wives and parents to send their loved ones to the only type of help society had to offer these families. While some patients died alone in the asylum, many families remained engaged and visited regularly, became acquainted with asylum staff, and even wrote letters of gratitude to asylum staff after their family member had died. Building on more recent scholarship, this is one more piece of evidence that asylums played complex roles in society. These places were not simply the dark agents of social control, the narrative which permeated discussions of the role of asylums in the historiography of the mid to late twentieth century. Asylum staff cared for people who

no-one else could care for, sometimes for over a decade, sometimes in a humane manner, as evidenced by the response of letters I found in asylum notes.

An examination of the medical publications on HD provided further insight into the way the disease was thought about, the subject matter deemed worthy of attention and the omissions in this literature. For the first half of the twentieth century, there was little interest in the disease from physicians, judging from the sporadic and isolated reports of individual cases which made up the medical literature in this period. Brothers' study of the disease in Tasmania, by contrast, attracted international attention. Major surveys of the disease in Victoria and Queensland followed, and an Aboriginal kindred in South Australia was identified. These papers began to address the social issues which had a profound effect on HD families, however this attention came at a price. This chapter touched briefly on the depiction of "social problems" of HD families. In these papers, the researchers expressed some sympathy for those living with the disease, though they also reinforced negative portrayals of the disease in choosing to focus on issues such as "criminality" and "fecklessness." The implications of this framing of the disease will be considered in more detail in the following chapters.

The medical literature offered little advice to other medical professionals, let alone to family members, on the management of the disease. While several physicians understood the primary features of HD, it was also known that there were no medical cures or even treatments. This must have been a source of deep frustration for both physicians and families. While "therapeutic nihilism" still exists in the responses of some physicians, for many others the role of physician extends beyond pharmacological treatments or cures,

which will be discussed further in Chapter 6. In a nutshell, the primary focus was on the identification of the disease. In the first decades of the twentieth century, this seemed purely an academic exercise based in individuals identified in asylums. However, other social forces unexplored in this chapter also had an effect on HD families and the portrayal of the condition. Later surveys of the disease focused on the importance of trying to control its spread. In the next chapter, the role of the eugenics movement in contributing to this change in emphasis will be examined.

## Chapter 5: Stigma, Secrecy and Shame: Eugenics and Huntington's disease

*HD is a devastating disease. Yet not all of its misery comes from the illness (xxii).*<sup>1</sup>  
Alice Wexler, 1995

In the introduction to this thesis, many of the challenges posed by Huntington's disease were outlined. In addition to the extremely complex and harrowing features of the disease itself, for much of the twentieth century, HD families faced the additional burden of living with a deeply stigmatised condition. From being an unknown condition in the nineteenth century, where at least some families with a known hereditary disease were respected in their communities, the dominant narrative through much of the twentieth century depicted HD not only as tragic, but also a shameful disease; the response of many, if not most individuals, was to keep it a secret, even among family members, often with destructive psychological consequences when the disease was eventually diagnosed. The existence of this stigma has been noted by many authors writing on the disease, but there have been few attempts to explain its presence, or how and why this stigma has changed over time.

Two scholars of the history of HD, geneticist Peter Harper and historian Alice Wexler, first drew attention in the 1990s to the existence of stigma and the contributory role of eugenics in the US, Germany, and to a lesser extent the UK. These themes have not been explored by other authors, despite the importance of stigma in shaping the experience of the disease. Expanding on these foundations, the first half of this chapter provides a more detailed analysis of the relationship between HD, eugenics and stigma. Next, the influence of eugenics in Australian society will be explored, investigating both medical responses by

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<sup>1</sup> Alice Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (New York: Times Books, 1995).

physicians and popular representations of eugenic thought in educational institutions and the press in Australia, a country not known for embracing the eugenic message.

I will examine the concept of stigma itself, and in particular the stigma towards those with mental illness and disability, with special reference to the features of HD likely to encourage stigma, and the consequences of belonging to a stigmatised group. Evidence for the stigma felt by HD families in the US has been provided by Wexler, but there have been no studies examining this issue in other countries. I will therefore examine whether the existence of stigma was an issue amongst HD families in Australia. I will then explore the contribution of the eugenics movement to the exacerbation of stigma towards HD in the twentieth century, beginning in Europe and the US, then moving on to the situation in Australia.

While the history of eugenics has been explored from many angles, much remains to be discovered. The first concerns one of the philosophical underpinnings of eugenics. I will argue that in attempting to “improve the race” by focussing attention on out-groups classified as “the unfit,” the exacerbation of stigma was an inevitable outcome. Eugenics’ founder Sir Francis Galton (1822-1911), wanted the “unfit” to reproduce less. By spreading eugenic ideas throughout the community through education and propaganda, the eugenicists hoped that their ideas would become as second-nature as a “secular religion.” I will then explore the attention paid by early eugenicists to the existence of HD as a prime example of the need for eugenic measures. In investigating the influence of eugenics on HD, previous studies by Harper and Wexler have focused on North American eugenicists such as Charles Davenport. To these findings will be added additional references to the disease in primary eugenics journals such as the *Eugenics Review* in the UK and the *Journal of Heredity* in the US.



Synthesizing the work of Harper and Wexler, with other primary sources, I will examine the relationship between eugenics and HD in Germany. After describing the Nazi legislation and the close collaboration between eugenicists in the US and Germany, it will also be revealed that early eugenicists outside Germany were aware of the Nazi legislation which specifically mentioned “inherited St Vitus Dance.”

Having established that many prominent eugenicists were aware of the disease, and used it as a prime example of the need for eugenic activity, I will explore the influence of eugenic narratives on the medical depiction of HD. One aspect of its portrayal in particular had significant consequences for HD families. This concerned attempts to control the spread of HD – disease prevention became intertwined with the eugenic enterprise of preventing the procreation of the “unfit” through various measures including sterilization and the restriction of marriage of people with hereditary disease. The almost universal assumption was that those with HD in their families should not have children, with recommendations of how to achieve this ranging from persuasion to frank coercion through legislation. Writings on the disease indicated that it was the duty of physicians and the broader society to communicate these messages to HD families. As outlined in the literature review, Wexler has identified many papers where eugenic themes were intertwined into medical descriptions of the disease. These will be analysed together, and other examples such as the British neurologist Kinnier Wilson, will also be examined. Another source previously unexplored is the Merck Manual, a widely consulted medical reference which reiterated the eugenic theme urging doctors to advise their HD patients not to have children.

Next, I will describe the inter-relationships between eugenics and the unfolding of the HD story in Australia. Beginning with an overview of the eugenics movement in Australia, I will explore the involvement in eugenics of the main researchers of HD in Australia, alongside the medical response to eugenics more broadly. In considering potential contributions to the spread of eugenic thought, I will then explore the role of eugenics in popular culture. As I have argued, the infiltration of eugenic ideas into popular consciousness was central to the eugenic enterprise. Several scholars of eugenics have investigated various ways in which eugenics was promoted to the general public in the US. The achievements of eugenicists in popularising its ideas in the US in films, state fairs, pamphlets and other public meetings has been outlined in the many histories of eugenics which have been published.<sup>2 3</sup> Although mentioned in passing in various works on eugenics in Australia, there has been no systematic attempt to analyse the way eugenics was presented to the Australian public. This topic will be explored by reference to the reporting of eugenics in the popular press and the educational societies which played a large part in disseminating new ideas to the wider population in the first half of the twentieth century. In the final section, the ongoing legacy of eugenic thinking on HD after World War II will be explored. Eugenics quickly lost popularity in this era, though aspects of eugenic thinking continued to have a pernicious effect on HD families.

## **5.1 Stigma and HD**

The stigmatisation of specific groups has existed throughout history and across cultures.

While many scholars had examined the topic previously, Erving Goffman's 1968 work,

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<sup>2</sup> Daniel J. Kevles, *In the Name of Eugenics : Genetics and the Uses of Human Heredity* (New York: Knopf, 1985).

<sup>3</sup> Martin S. Pernick, *The Black Stork : Eugenics and the Death Of "Defective" Babies in American Medicine and Motion Pictures since 1915* (New York: Oxford University Press, 1996).

*Stigma: Notes on the Management of a Spoiled Identity*<sup>4</sup> was hugely influential in drawing attention to the phenomenon. In the following half-century, stigma has been examined from a wide range of perspectives. Aspects of Goffman's work remain highly relevant – in particular his observation that stigmatised groups become “disqualified from full social acceptance.”<sup>5</sup> (p 11) Other scholars, such as Susan Sontag, have explored the stigma associated with medical conditions such as AIDS, in particular emphasising the way that meanings which are ascribed to a disease can influence those affected by it.<sup>6</sup> From the 1970s, scholars began to explore the relationship between stigma, disability and mental illness, and there is now a robust literature on these topics.<sup>7 8 9</sup> However, there are only isolated studies exploring the stigma of neurological conditions with occasional papers on particular conditions such as multiple sclerosis,<sup>10</sup> epilepsy,<sup>11 12</sup> Tourette's,<sup>13</sup> and Parkinson's Disease,<sup>14</sup> rather than a solid body of integrated study. The lack of acknowledgement of the impact of stigma in neurological conditions was so pronounced that in 2003, the President of the Federation of Neurological Associations wrote an article specifically arguing for greater awareness of the

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<sup>4</sup> Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (Pelican Books.) (Harmondsworth: Penguin, 1968).

<sup>5</sup> Ibid.

<sup>6</sup> Susan Sontag, *Illness as Metaphor ; and, Aids and Its Metaphors* (London: Penguin, 1991).

<sup>7</sup> Patrick W. Corrigan, *On the Stigma of Mental Illness : Practical Strategies for Research and Social Change*, 1st ed. (Washington, DC: American Psychological Association, 2005).

<sup>8</sup> Andrea Stier and Stephen P. Hinshaw, "Explicit and Implicit Stigma against Individuals with Mental Illness," *Australian Psychologist* 42, no. 2 (2007): 106-17.

<sup>9</sup> G. Thornicroft et al., "Stigma: Ignorance, Prejudice or Discrimination?," *British Journal of Psychiatry* 190 (2007): 192-93.

<sup>10</sup> Nina Grytten and Per Maseide, "'When I Am Together with Them I Feel More Ill.' the Stigma of Multiple Sclerosis Experienced in Social Relationships," *Chronic Illness* 2, no. 3 (2006): 195-208.

<sup>11</sup> A. Jacoby, D. Snape, and G. A. Baker, "Epilepsy and Social Identity: The Stigma of a Chronic Neurological Disorder," *Lancet Neurology* 4, no. 3 (2005): 171-78.

<sup>12</sup> Joseph Schneider and Peter Conrad, "In the Closet with Illness: Epilepsy, Stigma Potential and Information Control.," *Social Problems* 28, no. 1 (1980): 32-44.

<sup>13</sup> Kat Kleman Davis, Jeffrey Sasha Davis, and Lorraine Dowler, "In Motion, out of Place: The Public Space(S) of Tourette Syndrome," *Social Science & Medicine* 59, no. 1 (2004): 103-12.

<sup>14</sup> Gerhard Nijhof, "Parkinson's Disease as a Problem of Shame in Public Appearance," *Sociology of Health and Illness* 17, no. 2 (1995): 193-205.

issue.<sup>15</sup> Since this time, examination of the stigma of dementias such as Alzheimer's disease has begun.<sup>16</sup> Disability scholars have also begun to address the relationship between eugenics and disability.<sup>17</sup>

Stigmatisation occurs when a particular group of people, because of some real or imagined trait, is singled out as having less worth than another, usually dominant group, in particular when compared to what is supposed to be the normal or average ideal. As a highly sociable species, the prospect of social exclusion, isolation and devalued worth is a potent threat to human beings. A natural response to the possibility of being identified as belonging to a stigmatised group is to hide the presence of the potentially stigmatising traits. Prior to outlining the social forces adding to the stigma of HD, it is important to acknowledge that there are inevitable, biological features of the condition which will evoke a reaction in those unfamiliar with the symptoms. One of the frequent complaints of people with HD and their families is that the movement disorder gets confused with drunkenness. People making unexpected movements can appear threatening. Facial expressions are an extremely important facet of human communication both with strangers and close associates. In HD facial expressions are often affected – for example choreic movements of facial muscles can be construed as grimacing. The fear of mental illness, the fear of cognitive decline, and the fact that the disease is genetic are also highly salient issues. Being reminded of our own vulnerability by witnessing the presence of disease in others can be confronting.

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<sup>15</sup> Mary G Baker, "Destigmatizing Stigma in People with Neurological Problems.," *Practical Neurology* 3 (2003): 2-3.

<sup>16</sup> Perla Werner, "Stigma and Alzheimer's Disease: A Systematic Review of Evidence, Theory, and Methods," in *The Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices.*, ed. Patrick W. Corrigan, (Washington, DC, US: American Psychological Association, 2014), 233-44.

<sup>17</sup> D. Mitchell and S. Snyder, "The Eugenic Atlantic: Race, Disability, and the Making of an International Eugenic Science, 1800-1945," *Disability & Society* 18, no. 7 (2003): 843-64.

The stigma and secrecy surrounding HD is frequently referred to incidentally, but has been examined by only a few researchers. As described in the literature review, Wexler first raised this question by reference to her own family history and the congressional hearings of the *Commission for the Control of Huntington's Disease and its Consequences* in 1977. Further evidence from another country that knowledge of the presence of the disease was hidden throughout the twentieth century is provided in a 2006 Canadian study.<sup>18</sup> Etchegary found that of her 24 interview participants questioned about their experience of HD, only eight grew up knowing about the presence of the disease in the family. Four were aware of the disease in a distant relative but were unaware of being at risk themselves, and for the other twelve, it was either presented to them “out of the blue” or there were hints that something was wrong for several years before they received a diagnosis.

No such research has been conducted into this aspect of Australian HD families' experience. However, in my research, identical themes were prominent in interviews with a range of people familiar with HD (affected family members, social workers, psychiatrists, and staff of HD Associations). Although many people grew up being aware of the disease, a common story was the shock of discovering that they were at risk of HD only when a close relative was diagnosed. Secrecy was the norm rather than the exception. Many individuals had no idea that HD was in their own family or in the family that they had married into. Another variant of this was a kind of half-knowledge. Some kind of disease was alluded to but never spoken of openly – clues were given at pivotal moments, but often recognised decades later once full disclosure had occurred. A recurrent theme was the shame and sometimes guilt individuals felt at having this disease in the family. Another spoke of the humiliation of

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<sup>18</sup> H Etchegary, "Discovering the Family History of Huntington Disease," *Journal of Genetic Counselling* (2006): 105-17.

being aggressively condemned by a medical specialist, when she told him that she had two children despite the fact that her husband was at risk of the disease.<sup>19</sup>

Further evidence of the stigma around HD in Australia comes from a recent publication. In 2010, the Queensland HD Association published the stories of 20 individuals affected by HD. The story of “Sandra” was typical. It began as follows: “Many families kept the presence of Huntington’s disease a secret. They did not tell other family members for various reasons. It might have been because of the stigma attached to any type of mental illness.”<sup>20</sup> (p 14) In the case of “Barry”, he knew that “Huntington’s” was in his wife’s family but did not understand it: “his wife was told that she should not have children, but the hereditary factor was never really explained.”<sup>21</sup> (p 28) Another woman whose husband and two children went on to develop HD described her situation as follows: “My journey into family secrets and genetic disease started when I was seven months pregnant.”<sup>22</sup> (p 32) A doctor who was researching her husband’s family tree had found that her husband was a descendant of Brothers’ Tasmanian family. As a result of the stigma and the associated shame and secrecy, even today, there are individuals who are only discovering that they are at risk of the disease when they reach middle age, with dramatic and life-altering ramifications for themselves, their children and grandchildren.<sup>23</sup>

These stories indicate that in Australia too, HD had become a deeply stigmatised disease.

While in the nineteenth century families had to contend with the challenging range of

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<sup>19</sup> Interview wife of person at risk of HD, 26 Nov, 2013.

<sup>20</sup> Christine Gordon, *Sharing and Caring: Connecting Queensland Families* (Huntington's Queensland, 2010).

<sup>21</sup> Ibid.

<sup>22</sup> Ibid.

<sup>23</sup> Two people who contacted me about this research found out about the disease in middle age through the diagnosis of an elderly parent.

biological symptoms, something had happened in the twentieth century which resulted in additional burdens for HD families. When they were aware of it, many felt ashamed of the disease. For many reasons, including protection of their other family members, the existence of this disease was kept a secret. The following evidence will show how eugenic thinking played a significant role in the exacerbation of this stigma.

## **5.2 Galton, Eugenics and the Promotion of Stigma**

Prior to arguing that one of the primary goals of eugenics was the creation of stigma towards the “unfit”, a brief review of the history of eugenics and its main themes will follow. For a range of complex reasons, including the impact of Darwin’s theory of evolution and advances in genetics, the eugenics movement flourished in many countries in the first half of the twentieth century. Beginning in the UK with Galton, the founder of eugenics, the movement was particularly successful in the US. Kevles wrote one of the earlier histories of eugenics, and estimated that 65,000 people were sterilized on eugenic grounds in 33 US states.<sup>24</sup> Many countries had active eugenics movements, as attested to by a recent history which studied the movement in scores of countries.<sup>25</sup> Although it took diverse forms, at its essence, the goal of eugenics was to “improve the human race,” based on insights gained from plant and animal breeding, utilising the emerging fields of genetics, statistics and the examination of family pedigrees, especially “problem families.” A series of studies of families who allegedly displayed socially undesirable traits, such as the “Jukes” and “Kallikaks” entered both academic literature and the popular culture.<sup>26</sup>

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<sup>24</sup>Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity*.

<sup>25</sup> Alison Bashford and Philippa Levine, eds., *The Oxford Handbook of the History of Eugenics* (Oxford ; New York: Oxford University Press, 2010), 586.

<sup>26</sup> Nicole Hahn Rafter, *White Trash : The Eugenic Family Studies, 1877-1919* (Boston: Northeastern University Press, 1988).

Many suggestions for achieving the goal of race betterment involved environmental and social improvements such as improved child welfare. However, Galton and the major proponents of eugenics insisted that heredity was the crucial determinant of an individual's destiny, an idea which had major consequences for public policy. The programme to improve the race involved encouraging the "fit" to have more children (positive eugenics) and the "unfit" to produce fewer or, preferably, none at all (negative eugenics). Despite these common goals, at the heart of the movement, there was a question which plagued its proponents and led to internal divisions and external criticisms. Who were the "unfit", and how were they to be identified?

Issues of race and class featured prominently in eugenic ideologies. The prime targets of eugenic intervention were the "feeble-minded and mental defectives," which, in today's language, would encompass individuals with intellectual disabilities or mental retardation, though many other groups were targeted as well, in particular those with hereditary diseases. People were encouraged to consider the financial cost of "the unfit" to society - the economic burden of supporting "the unfit" was a common eugenic theme. In 1925, the US eugenicist Harry Laughlin gave the following description of the "unfit" in an address to the British Eugenics Society. The speech was published in an article where he described the state of eugenics in the US, outlined its main goals and stressed the need to initiate studies of particular families. His description of the "unfit" is worth quoting in full:

Then there is the submerged tenth, the socially inadequate persons who must be prevented from reproducing. If we try to classify them by types, we must call them the insane, the feeble-minded, the paupers, the epileptic, the criminals, and so on.



These people, and the family stocks that produce them most frequently, must be cut off and prevented from reproducing at all.<sup>27</sup> (p 32)

In the next paragraph, he specifically described HD as an example of such a condition. Despite not being a common disease, the simplicity of the genetic transmission and its dramatic mental and physical features made it an obvious eugenic target, as we will see throughout this chapter.

Scholars of eugenics have regularly acknowledged the role of eugenic thinking in relation to “insanity” more broadly, but not hereditary disease specifically. Ian Dowbiggin noted that “one of the most distinctive trends in Progressive Era America was the use of hereditarian explanations of mental disease to justify eugenic approaches to the treatment of insanity.”<sup>28</sup> (p 379) Regarding the eugenic goal of reducing the numbers of the “unfit”, historians have drawn attention to many of the methods advocated: extermination in a lethal chamber, sterilization, segregation, marriage restrictions, and medical advice not to have children. Legislation was used in a number countries to enforce eugenic ideas; however a key stream of eugenic thinking advocated using propaganda and education to instil a “eugenic conscience” in the population.

I argue that the “encouragement of disdain for the unfit,” is equivalent to “creation of stigma towards people with disabilities,” and that this has not been recognised in relation to hereditary disease. Little attention has been paid to the fact that the creation of stigma towards the “unfit” was one of the primary means advocated by eugenicists to achieve their

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<sup>27</sup> Harry Hamilton Laughlin, "Eugenics in America," *The Eugenics Review* 17, no. 1 (1925): 28-35.

<sup>28</sup> Ian Dowbiggin, "'An Exodus of Enthusiasm': G. Alder Blumer, Eugenics, and Us Psychiatry, 1890-1920," *Medical History* 36, no. 04 (1992): 379-402.

goals. The following examples will show how at its core, eugenics aimed to create rigid boundaries between “normal” and “abnormal” members of society and encouraged the former to shun the latter. Eugenacists knew that in order to make their eugenic dreams a reality, they had to convince a sufficiently large proportion of the public to endorse their philosophy and live their lives according to eugenic principles. The hardening of attitudes towards “the unfit,” including those with hereditary diseases such as HD, was one of eugenics’ main intentions. In the words of the geneticist and historian of eugenics, Elof Carlson, “perception of the failures in American society shifted from one of pity and charity to one of fear, disgust and rejection, in less than one generation.”<sup>29</sup> (p 91) The primary goal of the eugenacists was to encourage the public to internalise eugenic ideas to such an extent that they became unaware of this “secular religion” in their everyday decision-making. Beginning with the work of Galton, I will outline the importance placed by eugenacists on dissemination of eugenic values throughout the community.

Galton was an extraordinary man: he was a polymath in the mould of the independently wealthy, well-connected, educated Victorian man. Judging from his wide range of interests and studies in diverse areas, he had a highly curious mind coupled with a great capacity for painstaking work. In addition to his work on eugenics, he laid the foundation for a range of emerging disciplines, including the use of statistics in the social sciences, weather charts and fingerprinting, amongst multiple other pursuits.<sup>30</sup> In his youth, Galton had been highly religious, but doubts began to emerge in the 1860s. His intellectual journey, including meetings with Huxley and Spencer, had undermined his faith in religious orthodoxies.

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<sup>29</sup> Elof Axel Carlson, *The Unfit : A History of a Bad Idea* (Cold Spring Harbor, N.Y.: Cold Spring Harbor Laboratory Press, 2001).

<sup>30</sup> Nicholas W. Gillham, *A Life of Sir Francis Galton : From African Exploration to the Birth of Eugenics* (New York, N.Y.: Oxford University Press, 2001).

Resolution apparently came when he read his half-cousin Charles Darwin's *On the Origin of Species* - he later wrote to him describing the liberating effect reading it had on his world view.<sup>31</sup> Galton is acknowledged as the father of eugenics – he coined the term in 1883 - though his engagement in the movement was intermittent. His contribution, alongside the British eugenics movement as a whole, is often characterised as focussing on “positive” rather than “negative” eugenics. It is true that Galton's interest in the topic began with his early works on “hereditary genius” – his own family included.

As the following examples show, however, running through his writing on eugenics, a primary goal was the creation of a “eugenic conscience” in the general public. This would include encouraging the “fit” to have more children, but it would also encourage a distaste of “unfit” matings. He repeatedly emphasized the pivotal role of education and public opinion in spreading eugenic ideas. Others were in agreement as to the importance of eugenic education: the name of the main organisation in the UK, which also had a branch in the Australian state of New South Wales, was the Eugenics Education Society. In his preface to his 1909 collection of essays, he stated in the preface “The power by which Eugenic reform must chiefly be effected is that of Popular Opinion.”<sup>32</sup> In 1904, he gave an address to the Sociological Society, where he outlined ways of improving the human race through eugenics. Two of the five themes involved eugenics in relation to marriage and the importance of popularising eugenics. Regarding the first, he reflected on how the promotion of eugenic ideas could affect the behaviour of individuals. “If unsuitable marriages from the eugenics

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<sup>31</sup> Raymond Fancher, "Scientific Cousins: The Relationship between Charles Darwin and Francis Galton," *American Psychologist* 64, no. 2 (2009): 84-92.

<sup>32</sup> Francis Galton, *Essays in Eugenics* (London: Eugenics Education Society, 1909).

point of view were banned socially ... very few would be made.”<sup>33</sup> (p 42) Next, he reiterated how this would be achieved: “It must be introduced into the national conscience, like a new religion.”<sup>34</sup> (p 42) Firstly, eugenics would be understood and accepted at an intellectual level, then “let its principles work into the heart of the nation.”<sup>35</sup> (p 43) In the final essay of the series, dating from 1908, Galton concludes:

a strong local eugenic opinion might easily be formed. It would be silently assisted by local object lessons, in which the benefits derived through following eugenic rules and the bad effects of disregarding them were plainly to be discerned. The power of social opinion is apt to be underrated rather than overrated. Like the atmosphere which we breathe and in which we move, social opinion operates powerfully without our being conscious of its weight ... In circumscribed communities especially, social approval and disapproval exert a potent force.<sup>36</sup> (p 107-108)

Galton looked forward to a time when “public opinion in favour of eugenics has once taken sure hold of such communities and been accepted by them as a quasi-religion.”<sup>37</sup> (p 107-108)

The statistician Ronald A. Fisher, usually considered to be one of the more moderate proponents of eugenics, argued along identical lines as Galton: “when we speak of ‘Practical Eugenics’ I hope that we shall always mean practical action in the legislative sphere, based on and prepared by educational propaganda appealing directly to the eugenic conscience of the nation.”<sup>38</sup> (p 99) In this era, the term propaganda had not acquired its pejorative sense which resulted from its use by totalitarian regimes. It simply referred to a method of convincing

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<sup>33</sup> Ibid.

<sup>34</sup> Ibid.

<sup>35</sup> Ibid.

<sup>36</sup> Galton, *Essays in Eugenics*.

<sup>37</sup> Ibid.

<sup>38</sup> Ronald Aylmer Fisher, "Eugenics, Academic and Practical," *The Eugenics review* 27, no. 2 (1935): 95.

others of the argument. In an article published in the *Eugenics Review* in 1935, British psychiatrist Eliot Slater commented on the eugenic measures being conducted in Germany, specifically on the 50,000 compulsory sterilizations which had taken place in the first year of the operation of Nazi laws. Noting German public opposition to the compulsory nature of the procedure, he argued that “in fact one would get as good results by propaganda as by compulsion.”<sup>39</sup> (p 285)

Other popularizers of eugenics continued this theme. The American author Albert Wiggam, who wrote a popular book on eugenics,<sup>40</sup> was one of its more messianic proponents. In a 1939 paper he claimed that “the objectives we have in view are the loftiest and most inclusive that have ever stirred the creative imaginations of men.”<sup>41</sup> He urged those in favour of eugenics to utilise the arts to spread the eugenic message: “in my belief the most effective way to write about eugenics is not to write about eugenics at all.”<sup>42</sup> (p 280) In support, he cited recent articles published in popular magazines on questions such as “Should I marry?”<sup>43</sup> (p 280), which while not using the word eugenics, contained eugenic themes. In explaining how to achieve this, he encouraged authors to write not on eugenics specifically, but on related matters, then bring “the eugenical significance either consciously or unconsciously into the conscious – at least subconsciousness – of their readers.”<sup>44</sup> Similarly, another prominent eugenicist, neurologist Alfred Frank Tredgold (1870-1952), in an article on “Eugenics and Mental Disease” argued that the only way to “stem degeneracy and advance racial progress” was by an educational campaign which would develop an emotional

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<sup>39</sup> Eliot Slater, "German Eugenics in Practice," *The Eugenics review* 27, no. 4 (1936): 285.

<sup>40</sup> Albert Edward Wiggam, *The New Decalogue of Science* (Indianapolis,: The Bobbs-Merrill Company, 1923).

<sup>41</sup> Albert Edward Wiggam, "Giving Publicity to Eugenics," *Journal of Heredity* 30, no. 6 (1939): 279-82.

<sup>42</sup> Ibid.

<sup>43</sup> Ibid.

<sup>44</sup> Ibid.

attachment to the “Eugenic ideal” which would rely not just on “intellectual recognition” of the facts of eugenics, but which would also inculcate “a sense of shame and repugnance” at non-eugenic practices.<sup>45</sup> (p 11)

This concept of spreading eugenic ideology so that it permeated the consciousness was also a major theme of the leaders of the US movement. Harry Laughlin, who the prominent eugenicist Charles Davenport appointed as the director at the Eugenics Record Office, painted a picture of the future when eugenic forces “are all working without conscious social control.”<sup>46</sup> (p 30) As early as 1913, the suggestion that the “unfit” would be shunned as potential partners was outlined in an article in the *American Breeders Magazine* (later called the *Journal of Heredity*), where it was claimed that “the establishing and recording of potentially weak strains will result in genetic ostracism.”<sup>47</sup> (p 7)

These few selected examples show how the education of the public in eugenic ideals was a primary goal of the movement, in order to achieve a “eugenic conscience” which would encourage the shunning of those deemed to be “unfit.” What has not been adequately emphasized in the academic literature is the equivalence between these eugenic goals and the creation of stigma towards people with a disability. Galton and many of his followers attempted to frame eugenics as “a new religion.” This “eugenic conscience” would encourage the examination of potential marriage partners in terms of their fitness. While Galton did not specifically mention HD in his writings, his legacy in encouraging the scrutiny of potential partners in terms of “fit or unfit matings” was carried on by those who

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<sup>45</sup> Tredgold, "Eugenics and Mental Disease. The Galton Lecture," *Eugenics review* 19 (1927): 1-11.

<sup>46</sup> Laughlin, "Eugenics in America," 28-35.

<sup>47</sup> A Gartley, "A Study in Eugenic Genealogy," *American Breeders Magazine* 4, no. 1 (1913): 4-11.

took an active interest in HD. They singled out the disease as a prime example of “the unfit,” who should never marry or have children, and therefore be a target of the broader programme to exacerbate stigmatisation of the “unfit.” Against the back-drop of this stigmatisation, in the next section the specific interest of early eugenicists into HD will be described.

### **5.3 Davenport and Eugenicists Notice HD**

“If you do not believe in heredity, look at a clean-cut pedigree of Huntington’s chorea.”<sup>48</sup>

Harry Laughlin. (p 32)

Harper and Wexler have begun to examine early links between HD and eugenics, primarily by drawing attention to the role of Charles Davenport. Despite its relative rarity, HD became a well-known condition to both eugenicists and geneticists in the first few decades of the twentieth century, as one of the few diseases with mental symptoms due to uncontested hereditary transmission. While vigorous debates took place over the heritability of a wide range of conditions, with HD the opinions were unanimous and the evidence unequivocal. In describing the interest shown by these early eugenicists in the disease, the following draws from the work of Wexler and Harper, while adding new information from other primary sources.

Davenport’s studies of the disease were outlined in the literature review – in this chapter, aspects of his work specifically relating to eugenics will be explored in more detail.

Davenport was an experimental biologist originally working in animal genetics, who went on

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<sup>48</sup> Laughlin, "Eugenics in America," 28-35.

to become America's leading proponent of eugenics. According to Wexler, Davenport was made aware of HD by Smith Ely Jelliffe (1866-1945), an American psychiatrist/neurologist<sup>49</sup> who had first written about the history of the disease in the 1908 volume of the journal *Neurographs*.<sup>50</sup> Beginning around 1911, Davenport and field officer Elizabeth Muncey conducted the first large scale study of HD, and the publications on the results of this research were hugely influential. Even before embarking on this study, Davenport made his position clear that there were obvious eugenic lessons to learn from HD. In 1909, he gave an address to the American Academy of Medicine entitled "Fit and Unfit Matings" where he laid out his eugenic programme of discouraging the "unfit" from procreating. After describing aspects of Huntington's chorea, he specifically stated that "the mating of two parents with chorea is obviously highly unfit and should not be permitted."<sup>51</sup> (p 426) In 1912 he published an extremely influential textbook, which was used in classrooms throughout the US in the coming decades.<sup>52</sup> Once again, Huntington's chorea was singled out as an example of a typical dominant trait: "The eugenic lesson is that persons with this dire disease *should not have children*."<sup>53</sup> (p 102)

In 1916, the main paper on the results of Davenport and Muncey's extensive research on HD was published. Muncey had recorded 962 people who were assumed to have had HD, with her charts comprising 4,370 separate individuals.<sup>54</sup> In addition to their other findings, the eugenic lessons were made clear. Noting how "new choreic stock has come in with the

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<sup>49</sup> Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven: Yale University Press, 2008).

<sup>50</sup> Smith Ely Jelliffe, "A Contribution to the History of Huntington's Chorea. - a Preliminary Report," *Neurographs* 2, no. 1 (1908): 116-24.

<sup>51</sup> Charles Davenport, "Fit and Unfit Matings," *Journal of Heredity* 6, no. 1 (1911): 419-31.

<sup>52</sup> Charles Benedict Davenport, *Heredity in Relation to Eugenics* (London: Williams and Norgate, 1912).

<sup>53</sup> Ibid.

<sup>54</sup> Charles B. Davenport and Elizabeth B. Muncey, "Huntington's Chorea in Relation to Heredity and Eugenics," *American Journal of Insanity* 73, no. 2 (1916): 195-222.



immense immigration of recent years”<sup>55</sup> (p 215) Davenport and Muncy draw eugenic lessons – the oft-cited text is worth noting in full:

It would be a work of far-reaching philanthropy to sterilize all those in which chronic chorea has already developed and to secure that such of their offspring as show prematurely its symptoms shall not reproduce. It is for the state to investigate every case of Huntington’s chorea that appears and to concern itself with all of the progeny of such. ... A state that knows who are its choreics ... and does not do the obvious thing to prevent the spread of this dire inheritable disease is impotent, stupid and blind and invites disaster.”<sup>56</sup> (p 215)

Furthermore, they invoked another theme central to eugenic thinking: the societal cost of the “unfit”. Drawing attention to the effects of immigration from the UK of people carrying the HD gene, they argued:

All these evils in our study trace back to some half-dozen individuals, including three brothers, who migrated to this country during the 17<sup>th</sup> century. Had these half-dozen individuals been kept out of this country much of misery might have been saved.<sup>57</sup> (p 215)

The fact that these people would nevertheless still have the disease, only in another country, implies that Davenport was concerned about the costs to American society, not to the families themselves.

Davenport’s ambiguous use of the word “misery” was followed by detailed accounts of the costs governments incurred supporting HD families. American physician Charles Stone’s paper on the disease many years later followed this theme of emphasizing the financial

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<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

<sup>57</sup> Ibid.

burden of HD families. He argued that “The economic problem presented by this family should be of interest to the community and to the State.”<sup>58</sup> (p 362) Critchley, expanding on the work of Vessie on families emigrating from the UK to the US was quick to publicise this finding in his 1934 inaugural paper on the disease, stating:

Sooner or later, most if not all the victims become a public charge. Stone has estimated the cost to the community of each patient as at least \$400 a year. One wonders just how many million dollars that gay lady of Bures with her three emigrant sons must have cost the State, or rather, the States!<sup>59</sup> (p 587)

Davenport’s influence was profound: his widely cited paper made clear the eugenic message which was to dominate discussions of HD for the next six decades. The actual needs of HD families in dealing with the disease were not even considered – the only message to them was that if they refused to do so themselves, the state needed to step in to stop them from having children and being a burden on their community. The very title of their article showed the inexorable link: “Huntington’s Chorea in Relation to Heredity and Eugenics.” The work has been cited in the medical literature on HD from as early as 1924<sup>60</sup> to as recently as 2011.<sup>61</sup> In an article in the *Journal of Heredity* in 1917, the editor once again summarised Davenport’s and Muncey’s conclusions regarding the disease, noting that: “It does not seem to be dying out through marriage selection; moreover new sources are

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<sup>58</sup> C.S. Stone, "Huntington's Chorea: A Sociological and Genealogical Study of a New Family," *Mental Hygiene* 15 (1931): 350-63.

<sup>59</sup> Macdonald Critchley, "Huntington's Chorea and East Anglia," *Journal of State Medicine* 42 (1934): 575-87.

<sup>60</sup> C K Clarke and J W MacArthur, "Four Generations of Hereditary Chorea," *Journal of Heredity* 15, no. 7 (1924): 303-06.

<sup>61</sup> Oliver Quarrell et al., "The Prevalence of Juvenile Huntington's Disease: A Review of the Literature and Meta-Analysis," *PLoS currents* 4 (2011): <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3426104>.

coming into the United States at present through immigration. State and federal action to prevent the increase of this serious taint appears to be justified.”<sup>62</sup> (p 12)

Despite the obvious consequences of this negative framing of the disease, inexorably linking the disease with eugenics, for most of the twentieth century, almost all authors (with the obvious exceptions of Harper and Wexler) writing on the history of HD have ignored Davenport’s eugenic orientation, focusing solely on his medical contributions in studying the disease. The eugenicists in the decades following Davenport’s publication, however, repeated the mantra. Whereas Davenport had only specifically referred to the prohibition of procreation of those with signs of the disease, most later authors also included those at risk. HD was frequently identified in the eugenic literature as a template of a disease where, without question, those at risk should not have children. Between 1909 and 1968, the UK journal the *Eugenics Review* published 26 articles mentioning HD, indicating that although HD was not a major preoccupation, it was certainly referred to more than most other diseases, and often given as a clear-cut example of the need for the eugenic control of the “unfit”.

The noted statistician and eugenicist Fisher indicated his awareness of the disease in the 1935 annual address of the Eugenics Society in Britain. While reporting more broadly on the state of eugenics in the UK, he detailed the genetics studies being conducted. Citing the work of Julia Bell, he made specific mention of “that terrible, though fortunately rare type of hereditary insanity known as Huntington’s chorea.”<sup>63</sup> (p 97) As late as 1962, Julian Huxley was arguing in the *Eugenics Review* that “when defects result from a single dominant gene, as

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<sup>62</sup> Anonymous, "Huntington's Chorea and Heredity," *The Journal of Heredity* 8, no. 1 (1917): 12.

<sup>63</sup> Fisher, "Eugenics, Academic and Practical," 95.

with Huntington's chorea, transmission can of course be readily prevented by persuading the patient to refrain from reproducing himself."<sup>64</sup> (p 134)

HD was mentioned not just in academic journals, but also in popular books on eugenics. Dr Carlos Blacker (1895-1975), General Secretary of the Eugenics Society in the UK from 1931-1952, specifically mentioned the disease as an example of cases where there was no grey area regarding whether or not to have children in his 1934 book *The Chances of Morbid Inheritance*.<sup>65</sup> He stated that: "In general terms it may be said that no person with a transmissible mental disorder should procreate ... few disorders permit so simple and straight-forward a decision as do Huntington's chorea."<sup>66</sup> (p 126) Appeals were made to the medical profession to take a more active role in spreading eugenic advice, noting that they were in a much better position than eugenicists and sociologists to advance the eugenic cause. One professor of physics at the University of Cambridge in 1938, citing the example of HD, urged general practitioners to delve into the family history and discuss the undesirability of marriage of those "with certain types of heritable defect."<sup>67</sup> (p 13)

In the US, as in the UK, HD was frequently discussed in the eugenics literature, especially in the *Journal of Heredity*. Beginning with Davenport, HD was mentioned in numerous articles, repeating the familiar themes. In 1914, there was a description of an article which had appeared in the *Boston Medical and Surgical Journal* on HD, where it was referred to as "one of

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<sup>64</sup> Julian Huxley, "Eugenics in Evolutionary Perspective," *The Eugenics review* 54, no. 3 (1962): 123.

<sup>65</sup> C. P. Blacker, *The Chances of Morbid Inheritance*. Edited by C. P. Blacker (London: H. K. Lewis & Co., 1934)

<sup>66</sup> Ibid.

<sup>67</sup> John A. Ryle, "Medicine and Eugenics," *The Eugenics Review* 30, no. 1 (1938): 9-19.

the most clearly marked and indisputable of the disease-factors in cacogenics.”<sup>68</sup> (p 91) As noted above, in Britain, Fisher had reported on the role of the Julia Bell’s research in the UK on HD. Similarly, Laughlin reported on Davenport’s study of HD in his outline of the work of the Eugenics Record Office.<sup>69</sup> Having shown how these early eugenicists showed an interest in the disease, I will outline the eugenic policies in Germany, as it was here that legislation directed specifically towards people with HD was not only passed, but also implemented.

#### 5.4 Germany and HD

Although the primary focus of this study is the history of the disease in Australia, as a small country, it has been strongly influenced by overseas developments. It was therefore important to consider the relationship between eugenics and HD in the US and Britain, the two countries which in the last century most influenced Australian medical and social thought. One other country, Germany, has also been important, and any history of the relationship between eugenics and HD would be incomplete without a consideration of this era. Whereas in many countries the recommendations for dealing with the “unfit” were hypothetical, the full range of measures were put into practice in Nazi Germany, including eugenic propaganda, segregation, sterilization, marriage restrictions and finally the “lethal chamber.” In relation to HD, the geneticist Peter Harper first drew attention to this link in 1992<sup>70</sup> and Alice Wexler has also described this connection.<sup>71 72</sup> They both note how people with HD were one of the groups specifically targeted by Nazi eugenic laws.

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<sup>68</sup> Anonymous, "Hereditary Chorea," *American Breeders Magazine* 5, no. 2 (1914): 91.

<sup>69</sup> Harry Hamilton Laughlin, "An Account of the Work of the Eugenics Record Office," *American Breeders Magazine* 3, no. 2 (1912): 119-24.

<sup>70</sup> Peter Harper, "Huntington Disease and the Abuse of Genetics," *American Journal of Human Genetics* 50 (1992): 460-64.

What has been less well known is the fact that details of the German programme which specifically named HD were widely circulated in eugenic circles in the US and in the UK. A 1939 article in the British *Eugenics Review* set out to explain the laws which had been enacted in Germany.<sup>73</sup> The article described how the first law was the *Law for the Prevention of Hereditary Disease of July 14<sup>th</sup>, 1933*, which allowed for the “sterilization of the hereditary ailing.”<sup>74</sup> This law specifically mentioned “inherited St Vitus dance (Huntington’s chorea)” as one of the conditions.<sup>75</sup> Another piece of legislation was the *Law for the Protection of the Hereditary Health of the German Nation (Marriage Health Law) of October 18<sup>th</sup>, 1935*, which stated that “marriage must not be contracted” of individuals suffering from “hereditary disease” and that prior to marriage, a certificate from the health office would need to be produced confirming that they were not subject to such a disease.<sup>76</sup> Another important component of the Nazi laws was the mandatory notification of disease required from doctors – all people suffering from hereditary disease were to be notified to the relevant authority.<sup>77</sup>

The mechanism for deciding who would be sterilised included “Hereditary Courts” composed of a lawyer, medical officer and physician, with the doctor’s role being to both initiate and rule on cases. It is estimated that around 350,000 people were sterilized under this programme,<sup>78</sup> and although impossible to gauge figures, there is evidence that people

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<sup>71</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

<sup>72</sup> Alice Wexler, "Eugenics, Heredity and Huntington's Disease - a Brief Historical Perspective," *Journal of Huntington's Disease* 1, no. 2 (2012): 139-41.

<sup>73</sup> Felix Tietze, "Eugenic Measures in the Third Reich," *The Eugenics Review* 31, no. 2 (1939): 105.

<sup>74</sup> Ibid.

<sup>75</sup> Ibid.

<sup>76</sup> Tietze, "Eugenic Measures in the Third Reich," 105.

<sup>77</sup> Slater, "German Eugenics in Practice," 285.

<sup>78</sup> Joachim-Ernst Meyer, "The Fate of the Mentally Ill in Germany During the Third Reich," *Psychological Medicine* 18 (1988): 575-81.

with HD were included in that number.<sup>79</sup> The number of sterilizations fell towards the end of the decade, making way for the infamous Aktion T4 programme, which involved the state-sponsored murder of people who were deemed by the regime to have “life unworthy of life.” The programme was in operation from 1939-1941, with a less formal continuation in subsequent years. Meyer stated that an estimated 70,000 patients were killed in mental institutions, in gas chambers which were disguised as shower rooms, and that Huntington’s chorea was once again one of the conditions targeted for this programme.<sup>80</sup>

Furthermore, both Wexler and Harper have noted the participation of leading psychiatrists in this process. Wexler noted that the German psychiatrist Freidrich Panse, who was the author of the first book length study of HD, had “helped authorise the sterilization and subsequently the murder of thousands of psychiatric patients and persons with disabilities.”<sup>81</sup> (p 140) It was also in Germany that the case was made most explicitly that the eradication of disability was for the good of the society and not the good of the person themselves. While it is clear that the most extreme measures by far were enacted in Nazi Germany, there were close links between the eugenics movement internationally, and the common ground they shared prior to WWII has been the subject of significant academic attention.<sup>82 83 84</sup> Whereas Britain was the birthplace of eugenics, the world’s first eugenic organisation was founded in

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<sup>79</sup> Harper, "Huntington Disease and the Abuse of Genetics," 460-64.

<sup>80</sup> Meyer, "The Fate of the Mentally Ill in Germany During the Third Reich," 575-81.

<sup>81</sup> Wexler, "Eugenics, Heredity and Huntington's Disease - a Brief Historical Perspective," 139-41.

<sup>82</sup> Mitchell and Snyder, "The Eugenic Atlantic: Race, Disability, and the Making of an International Eugenic Science, 1800-1945," 843-864.

<sup>83</sup> Mark B. Adams, E. Allen Garland, and Sheila Faith Weiss, "Human Heredity and Politics: A Comparative Institutional Study of the Eugenics Record Office at Cold Spring Harbor (United States), the Kaiser Wilhelm Institute for Anthropology, Human Heredity, and Eugenics (Germany), and the Maxim Gorky Medical Genetics Institute (Ussr)," *Osiris* 20 (2005): 232-62.

<sup>84</sup> Kevles, *In the Name of Eugenics : Genetics and the Uses of Human Heredity*.

Berlin.<sup>85</sup> The abuses which later occurred in Nazi Germany certainly differed in scale in comparison to what occurred in other countries. There were, however, many similarities in the ideas and philosophies behind them. As we saw previously, HD also received significant attention from the Anglo-US eugenics movement, and eugenics influenced the framing of HD in the medical literature, as we shall see in the following section.

### 5.5 HD Physicians and Eugenics – US and UK

The nexus between eugenics and HD was two-way: just as eugenicists found the disease a model example of the need for eugenic policies, many of the physicians who studied and attended to families with HD expressed eugenic ideas in their medical publications on the disease. While many studies maintained an academic distance from the social aspects of the disease, focusing solely on biomedical subjects, many others felt the need to comment on wider issues. Many papers on the disease followed a similar format. After describing the particular contributions of their study, for example case studies or prevalence rates, authors then used the final section of their paper to describe the “Eugenic Significance” of HD. In 1924, Clarke and McArthur followed this route, noting how “eugenic propaganda might be of greatest racial value” in relation to HD.<sup>86</sup> Stone concludes his article on the disease by stating: “There is no doubt that the facts here presented would be considered by many as positive evidence in favour of the legalization of birth control and the sterilization of mental defectives.”<sup>87</sup> The inclusion of people with HD as *mental*

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<sup>85</sup> Paul Weindling, "German Eugenics and the Wider World: Beyond the Racial State," in *The Oxford Handbook of the History of Eugenics*, ed. Alison Bashford and Philippa Levine, (New York ; Oxford: Oxford University Press, 2010), 315-31.

<sup>86</sup> Clarke and MacArthur, "Four Generations of Hereditary Chorea," 303-06.

<sup>87</sup> Stone, "Huntington's Chorea: A Sociological and Genealogical Study of a New Family," 350-63.



*defectives* is a prime example of how eugenics sought to aggregate people with a range of conditions into the single class of the “unfit”.

In both the US and UK, the assumption that people from HD families should not marry or have children was repeated frequently in the medical literature. Wexler cited three early US publications from 1908, 1914 and 1923 giving the advice not to marry.<sup>88</sup> In 1925, psychiatric social worker Estella Hughes in the US at least went beyond such blanket advice and considered the options. Despite stating boldly in her paper on the disease in Michigan that “Those of affected stock should not have children”<sup>89</sup> (p 566), she also noted that:

For the control of this disease, sterilization has been suggested. This would be compulsory or voluntary. The former is a stringent measure of doubtful extension, which in the case of this disease, society would be loath to employ because there is always the chance that the individual will not develop chorea.<sup>90</sup> (p568)

Several years later, Paul Popenoe and Kate Brousseau went even further, arguing on moral grounds that if people at risk of HD did not refrain from having children, then the state had a responsibility to step in: “It is doubtful whether any human being has the right to give the genes of Huntington’s Chorea ... circulation; and for its’ own protection society has certainly the right to prevent such perpetuation of undesirable genes.”<sup>91</sup> (p 117) These views were also expressed in medical journal articles in the UK, as noted by Harper.<sup>92 93</sup> In 1937,

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<sup>88</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

<sup>89</sup> Estella Hughes, "Social Significance of Huntington's Chorea," *The American Journal of Psychiatry* 4 (1925): 537-74.

<sup>90</sup> Ibid.

<sup>91</sup> Paul Popenoe and Kate Brousseau, "Huntington’s Chorea," *Journal of Heredity* 21 (1930): 113-18.

<sup>92</sup> Harper, "Huntington Disease and the Abuse of Genetics," 460-64.

<sup>93</sup> Peter Harper, Gary Houlihan, and Audrey Tyler, "Genetic Counselling in Huntington's Disease," in *Huntington's Disease*, ed. Peter Harper, (London: W.B. Saunders, 1996), 359-94.

in a major review of the disease in South Wales, two physicians began their article on HD with reference to eugenics.<sup>94</sup> Their opening lines read:

The chronic hereditary choreas will always serve to attract attention, not only because of the pitiable state of the sufferers, but also because a knowledge of such weaknesses in certain family strains may eventually prove to be the basis of eugenic legislation.”<sup>95</sup> (p 403)

After describing the main findings of their study, they then return to the “social significance” and outline what they feel to be the obvious conclusions. Having acknowledged the difficulties faced by these families, they specifically call for eugenic legislation:

there is no effort to avoid marriage or reproduction, indeed these families are prolific and tend rather to hide the evidence of their tainted blood. ... we strongly recommend the adoption of some form of control. Voluntary restraint we hardly think likely to be effective in our class of patient at least. ... Perhaps, with repeated advice and education, some would voluntarily abstain from marriage, but the majority would no doubt be prepared to accept the even chance that nature offers them. We are thus left with the conclusion that only legislative measures will eventually succeed in eradicating the disease.”<sup>96</sup> (p 413)

Similar arguments were made in the influential and widely consulted textbook *Neurology*, edited by one of the doyens of British neurology, Kinnier Wilson (1878-1937). Stressing the

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<sup>94</sup> John Spillane and Robert Phillips, "Huntington's Chorea in South Wales," *Quarterly Journal of Medicine* 6 (1937): 403-23.

<sup>95</sup> Ibid.

<sup>96</sup> Ibid.

role of the physician rather than the state, the 1954 edition (17 years after Kinnier Wilson's death) stated that: "the sole means of prophylaxis is to ban marriage with members of Huntingtonian stocks. ... Should the chance of danger come to the knowledge of the physician, he should veto procreation of offspring."<sup>97</sup> (p 994) Exactly how the physician was to attempt this "vetoing" was not explained.

While calls for forced sterilization diminished after the Second World War, physicians were nevertheless advised to tell their patients not to have children. The previous articles were published in academic journals and books, and although HD might have been well known to some psychiatrists and neurologists, most physicians involved in primary care were unlikely to come across the disease in their practice. When dealing with rarer conditions, it was common for doctors to consult the prestigious and ubiquitous Merck Manuals. The publishers of the manuals claim on their website that in the early 1980s, they were the largest-selling medical text.<sup>98</sup> In the section on HD in the 1950 edition, after a brief summary of the main features of the disease, the following advice was given: "Individuals with a family history of Huntington's chorea should forego parenthood, perhaps by voluntarily undergoing sterilization."<sup>99</sup> The same advice, with no change in wording, was repeated for decades, up to and including the 1972 version.<sup>100</sup>

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<sup>97</sup> Samuel Alexander Kinnier Wilson and Alexander Ninian Bruce, *Neurology*, 2nd ed., vol. 2 (London: Butterworth & Co, 1954).

<sup>98</sup>[http://www.merckmanuals.com/professional/about/about\\_the\\_merck\\_manual/committed\\_to\\_providing\\_medical\\_information\\_merck\\_and\\_the\\_merck\\_manuals.html](http://www.merckmanuals.com/professional/about/about_the_merck_manual/committed_to_providing_medical_information_merck_and_the_merck_manuals.html) Retrieved 8 Nov 2014.

<sup>99</sup> Merck & Co., Merck Sharp & Dohme., and Merck Research Laboratories., "The Merck Manual of Diagnosis and Therapy," (Rahway, N.J.: Merck, 1950).

<sup>100</sup> D. N. Holvey and J. H. Taibott, *The Merck Manual of Diagnosis and Therapy*, 12th Ed. / by D.N. Holvey and J.H. Taibott. ed. ([S.l.]: Merck, 1972).

Another eugenically influenced characterisation of HD families concerned the claim that HD was part of a broader neuropathic tendency that ran in families. This issue was debated for much of the early twentieth century. Indeed, Huntington himself stated that in all family members, “the nervous temperament greatly preponderates.”<sup>101</sup> However, he made no further claims about the origins of this “temperament” leaving the door open to the fact that perhaps having the disease in the family placed a greater burden of stress upon family members, rather than the presumption that this represented a broader “neuropathic taint.” Although the idea that HD was just one manifestation of a wider “neuropathic inheritance” was prominent, specific studies did not always support this view. Spillane and Phillips reported that in their own study, “tainted families do not include a greater percentage of ineffectuals and nervously afflicted than can be reckoned normal.”<sup>102</sup> (413).

Yet another eugenic theme in relation to HD reflected broader views regarding the excessive reproduction of the “unfit”. Wexler has noted that many studies purportedly showed that those at risk of the disease produced more offspring than unaffected family members or of the broader community.<sup>103</sup> This concept that HD families bred more profusely was in evidence up until the 1970s. Evidence of this attention to the fertility of HD families is the number of references provided in the bibliography of HD published in 1974, referred to previously in the literature review. Under the heading “Fecundity”, twelve articles were published between 1951 and 1971, with an additional eleven published under the title

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<sup>101</sup> George Huntington, "On Chorea," *The Medical and Surgical Reporter* 26, no. 15 (1872): 317-20.

<sup>102</sup> Spillane and Phillips, "Huntington's Chorea in South Wales," 403-23.

<sup>103</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

“Fertility.”<sup>104</sup> Most of these articles conclude that people with HD were reproducing at a higher rate than the wider population, consistent with the broader idea of the proliferation of the “unfit.” This is another example of how the legacy of eugenic thinking lived on in relation to HD long after it was discredited by the association between the excesses of Nazi Germany and eugenics more broadly.

Eugenic thought infiltrated medical writing on HD, both overtly and covertly. Many authors specifically included the “eugenic lessons” to be learned from their studies of the disease in their publications. Less overt influence was apparent in the particular aspects of the disease which studies focused on. Eugenic concerns of the day prevailed in the portrayal of the disease. HD families were described as “problem families” who on the whole displayed “neuropathic taints” and were breeding at an alarming rate. It was pointed out that they were an economic burden on the upstanding, fit members of society, and that measures should be taken to prevent this ongoing burden, either through persuasion or legislation if necessary.

## **5.6 Eugenics in Australia**

Having outlined the origin of the links between eugenics and HD in Europe and the US, in this section the possibility that eugenics contributed to the stigma surrounding HD in Australia will be explored. In order to examine this relationship, two broad questions will be considered. Firstly, what was the role of the medical profession and how did it respond to eugenics, especially the authors who had the closest knowledge of HD. Secondly, was eugenics a topic of conversation in Australian social discourse in the early twentieth century,

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<sup>104</sup> G. W. Bruyn, F. Baro, and Ntinios C. Myrianthopoulos, eds., *A Centennial Bibliography of Huntington's Chorea 1872-1972*, *A Centennial Bibliography of Huntington's Chorea 1872-1972* (The Hague,: Leuven University Press, 1974), 314.

and if so how were eugenic ideas spread through the community. Prior to presenting the results of my research, a brief overview of the eugenics movement in this country is warranted. Over the past few decades, various scholars have examined eugenics in Australia from a range of perspectives. These include studies of mental deficiency,<sup>105 106 107</sup> the movement in the states of Queensland,<sup>108</sup> and South Australia,<sup>109</sup> psychiatry and eugenics,<sup>110</sup> broad overviews,<sup>111</sup> conference proceedings on a range of topics,<sup>112</sup> and a recent overview published in an international collection of studies of eugenics.<sup>113</sup> Although there are disagreements on many issues, there are some areas where a reasonable consensus has been established. A detailed review of this topic is beyond the scope of this dissertation, therefore only the most relevant aspects will be explored.

One important question raised in the scholarship on the eugenics movement in Australia concerns an evaluation of its relative success. Historian Rob Watts claimed that eugenics had played an extremely important role in Australian life, stating that “without hyperbole, we can

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<sup>105</sup> Ross Jones, "The Master Potter and the Rejected Pots: Eugenic Legislation in Victoria 1918-1939," *Australian Historical Studies* 113 (1999): 319-42.

<sup>106</sup> Ross Jones, "Removing Some of the Dust from the Wheels of Civilization: William Ernest Jones and the 1928 Commonwealth Survey of Mental Deficiency," *Australian Historical Studies* 40 (2009): 63-78.

<sup>107</sup> Grant Rodwell, "'If the Feeble-Minded Are to Be Preserved...' Special Education and Eugenics in Tasmania 1900-1930," *Issues in Educational Research* 8, no. 2 (1998): 131-56.

<sup>108</sup> Emily Wilson, *Prevention Is Better Than Cure : Eugenics in Queensland : 1900-1950* (North Melbourne, Vic.: Australian Scholarly Publishing, 2010).

<sup>109</sup> Susan Lemar, "Locating Adelaide Eugenics: Venereal Diseases and the South Australian Branch of the British Science Guild 1911-1914," *Journal of Australian Studies* 28, no. 83 (2004): 49-60.

<sup>110</sup> Stephen Garton, "Sound Minds and Healthy Bodies" Reconsidering Eugenics in Australia 1914-1940," *Australian Historical Studies* 26 (1994): 163-81.

<sup>111</sup> Diana Wyndham, *Eugenics in Australia: Striving for National Fitness* (London: Galton Institute, 2003)

<sup>112</sup> Martin Crotty, John Germov, and Grant Rodwell, *A Race for a Place: Eugenics, Darwinism and Social Thought and Practice in Australia* (2000).

<sup>113</sup> Stephen Garton, "Eugenics in Australia and New Zealand: Laboratories of Racial Science," in *The Oxford Handbook of the History of Eugenics*, ed. Alison Bashford, (New York ; Oxford: Oxford University Press, 2010), 243-57.

see the first half of the twentieth century as ‘the age of eugenics.’”<sup>114</sup> (p 319) Historian Diana Wyndham, who wrote a book on eugenics in Australia, contested this claim,<sup>115</sup> (p 219) though she did outline some of the legacies of the movement, noting that “eugenists have made an extraordinarily significant contribution to public health in Australia.”<sup>116</sup> (p178) Historian Stephen Garton, in his recent review of the history of eugenics in Australia, has drawn attention to the different degrees of influence in different domains, beginning his account with the enigmatic claim that eugenics was “everywhere, nowhere, and eventually somewhere.”<sup>117</sup> (p 243)

The involvement of the medical profession in eugenics has been considered by many scholars. Watts noted the rather high involvement of physicians in the movement in Victoria, stating that of the 44 founding members of the Eugenics Society of Victoria, 11 were physicians.<sup>118</sup> Wyndham’s book contains a wealth of primary source material regarding the involvement both of individual doctors and organisations like the National Health and Medical Research Council and the British Medical Association – at that time the national body representing Australian physicians.<sup>119</sup> Most recently, Garton has noted the contribution of doctors in Australia (such as Harvey Sutton, William Agar and the radical R.J.A. Berry) to the eugenics movement.<sup>120</sup> In general, although certain physicians were eugenics enthusiasts, much of the broader medical profession maintained a more conservative stance, accepting some aspects of eugenic thinking without being radical

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<sup>114</sup> Rob Watts, "Beyond Nature and Nurture: Eugenics in Twentieth Century Australian History," *Australian Journal of Politics & History* 40, no. 3 (1994): 318-34.

<sup>115</sup> Wyndham, *Eugenics in Australia: Striving for National Fitness*.

<sup>116</sup> Diana Wyndham, "Striving for National Fitness : Eugenics in Australia 1910s to 1930s" (Thesis (Ph. D.), University of Sydney, 1997., 1996).

<sup>117</sup> Garton, "Eugenics in Australia and New Zealand: Laboratories of Racial Science," 243-57.

<sup>118</sup> Watts, "Beyond Nature and Nurture: Eugenics in Twentieth Century Australian History," 318-34.

<sup>119</sup> Wyndham, *Eugenics in Australia: Striving for National Fitness*.

<sup>120</sup> Garton, "Eugenics in Australia and New Zealand: Laboratories of Racial Science," 243-257.

advocates for its more controversial proposals. This issue has not been the subject of specific detailed examination. I would suggest that the situation reflected what Michael Roe described in his work on influential eugenicists<sup>121</sup> – that there was an enormous range in responses to eugenics from the medical profession, ranging from ardent enthusiasm (for example R.J.A. Berry) to deep scepticism. One example of the enthusiasts was a physician called Dr Addison, who proposed seven resolutions to the 1929 conference of the Racial Hygiene Association, all of which were passed. The first stated:

That the general public should be educated to the fact that it is in the interests of the common weal and posterity that those individuals who come from hereditary defective families should be sterilised.<sup>122</sup> (p 65)

One prime example of the latter was the Chief Medical Officer of NSW, John Smith Purdy, who claimed in 1929 that deliberate eugenic marriages produced mentally defective offspring.<sup>123</sup> (p 218)

It has been widely asserted that eugenics failed in two main arenas in Australia: the legislative sphere and in eugenics organisations. There were many attempts by eugenics enthusiasts to put legislation before the houses of several state parliaments, but these efforts proved essentially fruitless. The lack of success of eugenics organisations has been outlined by Wyndham.<sup>124</sup> The two most successful examples, Victoria and NSW, had spectacular feuds,

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<sup>121</sup> Michael Roe, *Nine Australian Progressives : Vitalism in Bourgeois Social Thought, 1890-1960*, University of Queensland Press Scholars' Library (St. Lucia, Qld.: University of Queensland Press, 1984).

<sup>122</sup> P Addison, "Australian Racial Hygiene Congress: Report" (Sydney, 1929).

<sup>123</sup> Wyndham, *Eugenics in Australia: Striving for National Fitness*.

<sup>124</sup> Ibid.



and on the whole memberships were low, and some states, such as Queensland<sup>125</sup> and South Australia,<sup>126</sup> had no formal eugenics organisations.

One area on which all writers on eugenics in Australia seem to agree is that eugenic ideas were widely disseminated throughout the society, which is relevant in considering the question of whether eugenics contributed to the exacerbation of stigma towards those with HD. Historian of eugenics Ross Jones claimed there was general public interest in eugenics, covering the period from the 1880s to the Second World War.<sup>127</sup> Garton stated that eugenics was “much discussed” and “an influential discourse in colonial societies.”<sup>128</sup> Wyndham has explored this question most extensively in her study of various forms of archival material, and found evidence of an interest in eugenics from a range of organisations and individuals, including the Racial Hygiene Association and the Workers Educational Association.

## **5.7 HD and Eugenics in Australia: Medical Response**

Four physicians made significant contributions to the study of HD in Australia - Charles Hogg, Charles Brothers, Neville Parker and David Wallace. Their engagement with eugenics will now be outlined. In the medical literature, one other medical publication on HD mentions eugenics. Writing in the *Medical Journal of Australia*, in 1966 Edmonds claimed in the opening paragraph of his article that since Huntington’s description of the disease in 1872, “interest has been centred on the possible methods of prevention of the disease by

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<sup>125</sup> Emily Wilson, *Prevention Is Better Than Cure: Eugenics in Queensland 1900-1950* (Melbourne: Australian Scholarly publishing, 2010).

<sup>126</sup> Lemar, "Locating Adelaide Eugenics: Venereal Diseases and the South Australian Branch of the British Science Guild 1911-1914," 49-60.

<sup>127</sup> Jones, "Removing Some of the Dust from the Wheels of Civilization: William Ernest Jones and the 1928 Commonwealth Survey of Mental Deficiency," 63-78.

<sup>128</sup> Garton, "Eugenics in Australia and New Zealand: Laboratories of Racial Science," 243-257.

eugenic counselling.”<sup>129</sup> (p 274) Taking this statement at face value, this would indicate that Australian physicians were certainly aware of this eugenic approach to the disease.

### 5.7.1 Charles Hogg

As we saw in Chapter 3, Charles Hogg was the first person to identify the disease in the Australian medical literature. From his youth living in an area with a relatively high proportion of people affected by HD, and coming from a medical family, his interest extended at least to 1917 when he wrote a letter to one of the psychiatric hospitals enquiring about a patient with HD.<sup>130</sup> As discussed previously, his single published work on HD did not refer to social aspects of the disease, nor methods of prevention. Beginning as a Junior Medical Officer, over the subsequent decades he gained extensive experience of NSW mental hospitals from 1896-1925,<sup>131</sup> moving on to the positions of Senior Medical Officer and then Medical Superintendent. In 1926 he was appointed Inspector General of Mental Hospitals of NSW, a position he held throughout the Great Depression, until his retirement in 1935.<sup>132</sup> This covered the period when eugenics was widely discussed in the community, as we shall see in the next section.

Hogg was better known for his enthusiasm for cricket<sup>133 134 135</sup> than for being a proponent of eugenics. This lack of enthusiasm for the eugenic enterprise was a stark contrast with his

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<sup>129</sup> C. Edmonds, "Huntington's Chorea, Dysphagia and Death," *The Medical Journal of Australia* 2, no. 6 (1966): 273.

<sup>130</sup> State Records of New South Wales, Callan Park Mental Hospital: Series 4984: Admission Files 1878-1962.

<sup>131</sup> Richard Hogg, "A Short Biography of Charles Alfred Hogg," (1986).

<sup>132</sup> C J Cummins, *A History of Medical Administration in New South Wales 1788-1973* (2nd) (NSW Health, 2003).

<sup>133</sup> Ibid.

<sup>134</sup> Oliver Latham, "Obituary Charles Alfred Hogg," *Medical Journal of Australia* June 2 (1951): 813-15.

fellow psychiatrists in other states. Dr William Ernest-Jones (1867-1957), for example, who served as Inspector General of the Insane in Victoria from 1905-1937, was a prominent advocate of eugenics.<sup>136</sup> Alongside the more extreme R.J.A. Berry, Ernest-Jones introduced three bills into the Victorian parliament to deal with “mental deficiency” (1926, 1929 and 1939).<sup>137</sup>

In 1929, during Hogg’s tenure in NSW, the Racial Hygiene Association held a National Congress in Sydney which promoted many eugenic measures. The Director General of Public Health opened the conference - Hogg sent his apologies.<sup>138</sup> There was no indication that he was a member of either the Racial Hygiene Association<sup>139</sup> or of the Eugenics Education Society<sup>140</sup> from perusal of the remaining archives. His role of Inspector-General would have afforded him the opportunity to advance the eugenic cause. His publications reveal that he was interested in a range of other issues – he published papers on the encephalitis lethargica epidemic,<sup>141</sup> Aboriginal mental health,<sup>142</sup> and the training of psychiatrists,<sup>143</sup> but none on eugenics. Searching the newspaper archives, there are few occasions when he touched on this subject – those which did concerned “mental

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<sup>135</sup> Alfred Theophilus Edwards, *Patients Are People* (Sydney: Currawong Pub. Co., 1968).

<sup>136</sup> Jones, "Removing Some of the Dust from the Wheels of Civilization: William Ernest Jones and the 1928 Commonwealth Survey of Mental Deficiency," 63-78.

<sup>137</sup> Jones, "The Master Potter and the Rejected Pots:Eugenic Legislation in Victoria 1918-1939," 319-42.

<sup>138</sup> Racial Hygiene Association of New South Wales., *Australian Racial Hygiene Congress, 1929 : Report, September 15th, 16th, 17th & 18th* (Sydney: Racial Hygiene Association of New South Wales, 1929).

<sup>139</sup> Family Planning Association Records, 1926-1977, ML MSS 3838, Mitchell Library, State Library of NSW.

<sup>140</sup> Wellcome Institute for the History of Medicine, London - Contemporary Medical Archives Centre - Eugenics Society - Records, c.1910-1961 M2565, State Library of NSW. On microfilm, Australian Joint Copying Project.

<sup>141</sup> Charles Hogg and Oliver Latham, "Encephalitis Lethargica," *Medical Journal of Australia* 2 (1923): 90-95.

<sup>142</sup> Charles Hogg, "Twelve Cases of Insanity in Australian Aboriginals with a Commentary," *Medical Journal of Australia* (1924): 455-58.

<sup>143</sup> Charles Hogg, "University Teaching of Psychiatry," *Medical Journal of Australia* Supplement (1927): 290-95.

deficiency.” He was one of the vice presidents of the NSW Council for Mental Hygiene in 1933, which proposed legislation to deal with criminal “mental defectives,”<sup>144</sup> though his involvement in this organisation was limited, in comparison to his more active colleagues, Professor Harvey Sutton and Judge Bevan. Following extensive research, I found only one occasion when he advocated eugenic measures. As part of the Health Week activities in 1927, he is reported in the metropolitan newspaper as pointing out the “problem ... of the mentally deficient” and recommending “their segregation ... in colonies or institutions.”<sup>145</sup>

The only other insight into Hogg’s views on eugenics was perhaps revealed in an anecdote told about him by one of his fellow psychiatrists in his memoirs. A. T. Edwards was a psychiatrist who worked for much of his life in the NSW asylum/mental hospital system. In 1968, he published his memoirs.<sup>146</sup> In addition to the ubiquitous mentions of cricket, Edwards noted Hogg’s “very strict code of sexual morality for his patients.”<sup>147</sup> (p 51) He was apparently most concerned about the potential negative publicity which might result from pregnancies in patients, though whether there were any eugenic concerns was not explicitly stated.

Overall, Hogg was in a prime position to influence medical and public opinion on eugenics. His role as the Inspector General of Mental Hospitals in NSW gave him the authority, prestige and power to argue for eugenic proposals. In addition, he would have been one of the most knowledgeable physicians on HD in Australia in the first few decades of the

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<sup>144</sup> “Mental Hygiene. Proposed Measure for Defectives.” *The Sydney Morning Herald* (NSW: 1842-1954) 1 Dec, 1933. p 10.

<sup>145</sup> Health Week. *The Sydney Morning Herald* (NSW: 1842-1954) 11 Oct, 1927. p 12.

<sup>146</sup> Edwards, *Patients Are People*.

<sup>147</sup> *Ibid*.

twentieth century. By contrast, his counterpart in Victoria, Sir William Ernest-Jones, was a prominent supporter of eugenics.<sup>148</sup> Hogg's relative silence on the issue is evidence that he was not a eugenics enthusiast – he chose not to highlight the eugenic message or to use his knowledge of HD to argue in favour of the eugenic cause. Just why this was the case remains unknown.

### 5.7.2 Charles Brothers

While we need to infer attitudes from Hogg's eugenic inactivity, the most prominent researcher of HD in Australia, Charles Brothers, engaged actively with eugenic philosophy. There are several indications of his views from 1940 to 1950 – he actively discussed eugenics in a range of professional and lay forums. Interestingly, there is no record of him discussing eugenics after 1950. As discussed in Chapter 4, just like Hogg, Brothers began his career in mental hospitals. Working firstly in Victoria where he had undertaken his medical training, he returned to his native Tasmania in 1936 when he took up the post of Medical Superintendent of Lachlan Park Hospital. From 1946 to 1951 he was the Director of Mental Hygiene in Tasmania, and from 1951 to 1963 he was the Deputy Director of the State Mental Hygiene Authority in Victoria, both positions of considerable power in the medical profession and administration.

The first record of Brothers discussing eugenics is a 1941 paper which he gave to the Royal Society of Tasmania.<sup>149</sup> The paper was not printed in its entirety – the only surviving record I was able to locate was an abstract. In summarising his views, the abstract stated that

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<sup>148</sup> Jones, "Removing Some of the Dust from the Wheels of Civilization: William Ernest Jones and the 1928 Commonwealth Survey of Mental Deficiency," 63-78.

<sup>149</sup> CR Brothers, "Eugenics: The Medical Aspect," *Papers and Proceedings of the Royal Society of Tasmania* (1941): 78.

although his support for eugenics was “lukewarm,” it also claimed that he agreed with its primary aims. In brief, the author stated that Brothers argued against the oft-stated claim that feeble-mindedness was on the rise, outlined the major goals of eugenics and the means of achieving them, and expressed his objections to the more extreme claims made. In the abstract, specific mention was made of Brothers’ presentation of pedigrees which he had collected to date. A local newspaper article reported on Brothers’ address, and by contrast, drew more attention to Brothers’ criticisms of sterilization.<sup>150</sup> In particular, they note his concerns about “Who were to be sterilised and who were to be the arbiters of such steps.”<sup>151</sup> (p 2) Finally, in both accounts, he pointed to the current haphazard nature of the research to date, suggested Tasmania was an ideal state for such a study and called for the establishment of a committee and medical director to more thoroughly examine the questions raised.

Brothers gave lectures to the public on many topics throughout his career. In 1939, he criticised the drinking of cocktails by young women at a conference on child health,<sup>152</sup> and in 1946 voiced his concerns about extra leisure creating neurosis to a meeting at the Launceston Trades Hall.<sup>153</sup> However, in newspaper articles covering his addresses, the subject of eugenics was the most frequent. In 1944 he gave a talk to the Workers Educational Association entitled the “Medical Aspects of Eugenics”<sup>154</sup> and in 1947, while reviewing the state of psychological medicine, to a joint State Library/WEA camp, a

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<sup>150</sup> “Improvement of Race: Doctor Discusses Problem of Tasmanian Hill Billies.” *The Mercury* (Hobart, Tas.:1860-1954), 15 July, 1941, p 2.

<sup>151</sup> *Ibid.*

<sup>152</sup> “Cocktails and Flats: Condemned by Dr CRD Brothers.” *The Mercury* (Hobart, Tas.:1860-1954, 23 Sep 1939, p 16.

<sup>153</sup> “Thinks Extra Leisure Will Create Neurosis.” *Advocate* (Burnie, Tas:1890-1954). 3 May, 1949, p 5.

<sup>154</sup> “Address on Eugenics.” *The Mercury* (Hobart, Tas.:1860-1954), 13 Apr 1944, p 5.

newspaper account of his work stated that “more work would have to be done in the field of eugenics.”<sup>155</sup>

1949 and 1950 saw Brothers’ most extensive forays into eugenics. Following his election as Federal President of the Australian Association of Psychiatrists, Brothers gave the Presidential speech to the annual conference. This meeting was the largest ever gathering of psychiatrists in Australia.<sup>156</sup> Brothers chose the topic Psychiatry and Eugenics for his presidential speech. The address was given significant attention in the three main Tasmanian newspapers, and at least two on the Australian mainland. The Tasmanian coverage of the speech used the familiar language of eugenics in discussing the need to tackle racial decline,<sup>157</sup> <sup>158</sup> another taking a more parochial line in advocating Tasmania as a study site.<sup>159</sup> The two articles from the mainland focussed on the question of birth control.<sup>160</sup> <sup>161</sup> The presidential address was reproduced in full in the *Medical Journal of Australia*,<sup>162</sup> and this represents one of the few comprehensive considerations of the topic of eugenics by any Australian psychiatrist or other physician. Brothers’ paper warrants particular attention in that in addition to discussing eugenic views more broadly, he ventures on to the subject of eugenics in relation to HD. Interestingly, he refrained from making any references to eugenics in his specific publications on HD.

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<sup>155</sup> “Big Improvement in Mental Treatment.” *The Mercury* (Hobart, Tas.:1860-1954), 15 Jan 1947, p 5.

<sup>156</sup> W. D. Rubinstein and Hilary L. Rubinstein, *Menders of the Mind : A History of the Royal Australian & New Zealand College of Psychiatrists, 1946-96* (Melbourne: Oxford University Press, 1996).

<sup>157</sup> “Suggests Steps to Check Racial Decline.” *Advocate* (Burnie, Tas:1890-1954). 30 Nov 1949, p 3.

<sup>158</sup> “Should Combat Racial Decline.” *Examiner* (Launceston, Tas.: 1900-1954) 30 Nov, 1949, p 8.

<sup>159</sup> Tasmania Ideal State for Research on Psychiatry. *The Mercury* (Hobart, Tas.:1860-1954). 30 Nov 1939, p 2.

<sup>160</sup> Birth Control Rarely Used by Unfit.” *Newcastle Morning Herald and Miner’s Advocate* (NSW:1876-1954). 30 Nov, 1949, p 3.

<sup>161</sup> “Psychiatrists Views on Birth Control.” *The West Australian* (Perth, WA: 1879-1954). 30 Nov, 1949, p 9.

<sup>162</sup> C R D Brothers, “Psychiatry and Eugenics,” *Medical Journal of Australia*, no. 5 August (1950): 211-15.

Brothers' presidential address struck the same tone as his first foray in 1941. Across the decade, Brothers maintained a consistent position, which was probably representative of the mainstream medical opinion at the time. He railed against the class-biases of the more extreme eugenicists, mocking their "sweeping statements"<sup>163</sup> (p 211) and wilder claims on the grounds that their proposals were ill-thought out, impractical and lacked popular support. Despite these misgivings, though, he did see a role for a selected range of eugenic measures. After outlining the major methods advocated for achieving eugenic goals, Brothers came out in support of two specific proposals. In the first, he advocated the extension of the role of Marriage Guidance Councils. He suggested that before marriage, couples should submit themselves to a council, which would examine the health of the family as well as the individual concerned, and in the case of "any defect with hereditary significance"<sup>164</sup> (p 213), the doctor should advise against marriage, or at least the bearing of children. Furthermore, he devoted a large part of the paper to the question of sterilization. While not advocating the procedure for schizophrenia, manic-depressive insanity, congenital mental deficiency, epilepsy, crime or other neurological diseases, regarding HD he stated:

Nevertheless, to prevent effectively all likelihood that the disease would be transmitted, all children of known victims should be required to be sterilized, even though half of them would be free of the taint and would not pass it on to future generations.<sup>165</sup> (p 214)

This language is open to interpretation, and it is not possible to know whether Brothers was saying that "if one wanted to stop the disease being transmitted, this is what one would have

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<sup>163</sup> Ibid.

<sup>164</sup> Ibid.

<sup>165</sup> Ibid.



to do” or whether he meant that “this is what we should do.” This issue seems to be resolved by his conclusions in the discussion section of this paper, where he stated:

In view of the limitations in our existing knowledge, sterilization of normal people is not justified in order to prevent the appearance in their descendants of such mental diseases as those considered above. The only probable exception would be in cases of apparently normal parents who might eventually become victims of Huntington’s chorea.<sup>166</sup> (p 215)

In spite of this supposed support for sterilization of people with HD, Brothers made no suggestions about how this could be achieved, did not mention it in any of his later articles on the disease and indeed there is no indication that he attempted to advocate for this position in his professional role. In judging his legacy regarding HD and eugenics, like Hogg, his lack of pro-active advocacy of the goals of eugenics is the factor that would have had the most influence. Throughout the 1940s, he published his thoughts on eugenics and talked on the subject, though there is no indication that he argued for legislative measures. In his roles as the head and deputy of mental health services in Tasmania and Victoria, I was unable to find evidence that he argued the eugenic cause. After examining the records of the Eugenics Society of Victoria, I was unable to find any record of him being a member,<sup>167</sup> further evidence that he was not a eugenics enthusiast.

The clinical practice of physicians in the past is mostly impossible to reconstruct, though my research has revealed one insight into his everyday practice. I was able to find one person who had met Charles Brothers in his role of physician.<sup>168</sup> This woman met Brothers on

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<sup>166</sup> Ibid.

<sup>167</sup> Victor Hugo Wallace Collection. Melbourne University Archives, Baillieu Library. A1977.0065. Contains many papers of the Eugenics Society of Victoria, including membership lists.

<sup>168</sup> Interview with HD family member, 13 Jun, 2011.

several occasions in the 1950s. She was caring for her mother-in-law, who had HD and was living in her home. Surprisingly as it seems, at this time, specialists seemed to pay home visits. On several occasions, she reported that Brothers visited the house, and as she recalls it, dispensed medications but barely exchanged a word with her. Of particular note, there was no advice from him about whether or not she should have children, or what she should tell her own children about the disease.

### 5.7.3 Neville Parker

As described in the previous chapter, Dr Neville Parker (1929-1993) conducted a survey of the disease in Queensland, publishing his first paper in 1958. He also co-wrote a paper for the 1972 Centennial Huntington's conference with David Wallace. While Hogg's and Brothers' careers followed similar courses, Parker was primarily engaged in clinical practice, teaching and research rather than administration. There are three sources of information about Parkers' views and activities regarding eugenics – his 1958 paper itself, his membership of a eugenic organisation and another paper he wrote on a related topic. Although there was no formal eugenics association in Queensland, the state nevertheless had its eugenics enthusiasts.<sup>169</sup> Parker was, however, listed as a Fellow of the UK Eugenics Society in the 1963 edition of *Eugenics Review*.<sup>170</sup> (p 36) He also wrote an article entitled "Segregation: The Case for" in 1972, though his argument was directed towards the "mentally retarded."<sup>171</sup>

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<sup>169</sup> Wilson, *Prevention Is Better Than Cure : Eugenics in Queensland : 1900-1950*.

<sup>170</sup> Anonymous, "Notes and Memoranda," *Eugenics review* 55, no. 1 (1963): 36.

<sup>171</sup> Neville Parker, "Segregation: The Case For," *Australian Journal of Mental Retardation* 2 (1972): 16-18.

His article on HD<sup>172</sup> was one of the earlier Australian articles to deviate from a purely biomedical approach to the disease, and he was obviously well aware of the arguments surrounding eugenics in previous publications. Regarding his clinical practice, in at least one case, he indicated that he had persuaded a woman to undergo sterilization: after describing aspects of her circumstances, he stated “she has submitted to sterilization.”<sup>173</sup> (p 355) Later in the article, he addressed the question of eugenics head on, beginning with the caution that: “Bias is obvious in any discussion on eugenics, and in the literature on Huntington’s chorea emotionally charged words creep in when this aspect is considered.”<sup>174</sup> (p 358) Parker is clearly disturbed by the fact that people with HD continued to have children, noting: “These people will not be stopped from producing potential choreics by education alone” and that “the only successful method of eradicating this untreatable chronic disease is by legislative measures.”<sup>175</sup> (p 358)

Parker echoed Davenport’s concern about the possibility of allowing people affected by HD into the US from Britain 50 years earlier. Noting their “restless, wandering disposition”, he cited the “alarming rate” of the descendants of Brothers’ Tasmania family, and bemoaned the possibility of them being allowed to “multiply with democratic freedom.”<sup>176</sup> (p 358) In summary, he urged public health departments to take an active interest in the disease. On one issue, Parker went against the narrative which claimed that people with HD were reproducing at a disproportionately larger rate – he refuted such claims based on his own

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<sup>172</sup> Neville Parker, "Observations on Huntington's Chorea Based on a Queensland Survey," *Medical Journal of Australia* 45 (1958): 351-59.

<sup>173</sup> Ibid.

<sup>174</sup> Ibid.

<sup>175</sup> Ibid.

<sup>176</sup> Ibid.

study and in identifying methodological difficulties in previous accounts. Overall, Parker showed a much greater propensity to advocate for eugenic measures than his predecessors.

#### **5.7.4 David Wallace**

An extension of Parker's Queensland study was made by David Wallace (1925-1979) from 1969-1970, and although there is little information about his views on eugenics it is interesting to note his family history. He was born in Newcastle in 1926 and came from a family with many medical connections. His father was the Government Medical Officer in NSW. His father's cousin was Victor Hugo Wallace, who was a founding member of the Eugenics Society of Victoria in 1936. Victor Hugo Wallace remained active in the organisation until its demise in 1961, when he wrote a history of the organisation in the *Eugenics Review*.<sup>177</sup> In his writings on the disease, Wallace himself did not endorse eugenic propositions, but still maintained the stance that it was in the physician's remit to advise patients regarding their reproductive decisions. In 1972, he indicated that he advised family members not to have children as the disease was "so terrible in its social consequences."<sup>178</sup> (p 304) While maintaining the paternalistic attitude of previous generations, this was a far cry from the calls for sterilisation of decades past, and reflected the changing views of the times.

#### **5.7.5. Overview of Eugenics and Medical Response**

The four leading Australian physicians who engaged with HD families did not adopt the more strident views of some eugenics advocates. They reflected the medical views on

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<sup>177</sup> Victor Hugo Wallace, "The Eugenics Society of Victoria (1936-1961)," *The Eugenics Review* 53, no. 4 (1962): 215-18.

<sup>178</sup> D C Wallace, "Huntington's Chorea in Queensland: A Not Uncommon Disease," *Medical Journal of Australia* 1 (1972): 299-307.

eugenics of the day, remaining in the mainstream rather than being the crusading enthusiasts such as Davenport. In particular, Hogg and Brothers both held positions of power in mental health administration which would have allowed them to advance the eugenic cause. They had the opportunity to set HD up as a poster child of eugenics, as Davenport had done, but they did not follow this path. Parker's work echoed eugenic themes, but as noted in the previous chapter, he also attempted to help these families by providing information on the disease. Nevertheless, eugenic thinking from other sources in the medical profession must have had a significant effect on HD families. Many general practitioners would have consulted medical textbooks, such as the Merck manuals, and followed the advice to tell people with the disease in their family not to have children. In the following section, I will argue that another source of information would likely have had an even more profound effect on families. That is, the popularisation of eugenics in the wider society, through newspapers and magazine articles, home encyclopaedias and adult education.

## **5.8 Popularisation of Eugenics**

Regarding Stephen Garton's description of eugenics in Australia, as "everywhere, nowhere, and somewhere,"<sup>179</sup> noted previously in this chapter, it will be argued that the popularisation of eugenics created one of these "somewheres" – that is, in the minds of the population, including families with HD who were faced with the challenges of managing this mysterious and worrying disease. While various historians of eugenics have described some of the ways eugenics was popularised in Australia, there has been no systematic overview of the material in relation to the methods proposed to reduce numbers of the "unfit," and in spreading the eugenic message more broadly. The main source materials I will describe in attempting to fill

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<sup>179</sup> Garton, "Eugenics in Australia and New Zealand: Laboratories of Racial Science," 243-57.

this gap include adult further education, popular books, and newspaper and magazine articles from 1900 to 1960 which included hundreds of references to eugenics. An exposition of the commonness of eugenic ideas is presented in order to recreate a part of the social environment in which people with HD lived in the last century. I propose that the extremely common references to eugenics in the newspapers both reflected the popular concerns of the day and also exposed the wider public, including people with HD, to eugenic messages.

### 5.8.1 Encyclopaedias, Magazines, Popular Books, Films and Adult Education

Eugenics entered the home through a number of routes. During the early part of the twentieth century, numerous popular science magazines such as *Harmsworth Popular Science*, *Home University Library*, and *Armchair Science* brought the subject to a wider audience.<sup>180</sup>

Historian Grant Rodwell has noted how Arthur Mee's *Children's Encyclopaedia* had strong eugenic themes running through it.<sup>181</sup> This was a multi-volume work which was found in the libraries and homes of millions of people internationally from the 1910s through the 1960s, including in Australia. Rodwell stated that it was used in teacher training schools and was encouraged by the New South Wales Director of Education. One of the contributors was C. W. Saleeby, one of the stalwarts of the eugenics movement in the UK.

In addition to the many books on eugenics published in the United States and Britain, there were original contributions from New Zealand and Australia. Early in the century, the

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<sup>180</sup> Peter J. Bowler, *Science for All : The Popularization of Science in Early Twentieth-Century Britain* (Chicago: University of Chicago Press, 2009).

<sup>181</sup> Grant Rodwell, "Lessons in Eugenics from Arthur Mee's 'Children's Encyclopedia'," *Education and Research Perspectives* 24, no. 1 (1997): 94-110.

psychiatrist John Bostock and psychologist Lesley Nye published a book, *Whither Away?*<sup>182</sup> which was mentioned and reviewed in the popular press in four different Australian states, most frequently in their native Queensland.<sup>183</sup> <sup>184</sup> One review noted how its publication had stimulated discussion, was so popular it quickly went to a second edition and “made many people sit up and take notice.”<sup>185</sup> This book, according to Wyndham, praised Hitler and Mussolini’s “triumph of autocracy” and advocated the sterilisation “of those individuals who possess such serious transmissible diseases as would make their progeny a burden to themselves and to the state.”<sup>186</sup> (p 312) Brisbane’s leading newspaper took the issue so seriously that the book was reviewed by the Archbishop of Brisbane. He noted their claim that “Nature’s own plans for getting rid of the “unfit” are frustrated by our modern relief measures, and that the result has been an accelerating rate of degeneracy.”<sup>187</sup> (p 8)

Pamphlets and magazines were also produced which argued the eugenic cause. Millicent Preston-Stanley, who was the Women’s Editor of the *Daily Telegraph* and later a Member of the Legislative Assembly in NSW wrote a book called *The Production of Human Degeneracy* where she bemoaned “the propagation of degenerate human stocks.”<sup>188</sup> (p 3) Literary magazines such as *Stead’s Review* ran articles on eugenics, such as “Eugenic Reform and the Unfit” by Jean Devanny.<sup>189</sup>

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<sup>182</sup> John Bostock and L. J. J. Nye, *Whither Away? : A Study of Race Psychology and the Factors Leading to Australia’s National Decline*, 2nd ed. (Sydney: Angus & Robertson, 1936).

<sup>183</sup> “Queensland Doctors Forecast Racial Decline for Australia.” *The Queenslander* (Brisbane, Qld:1866-1939)3 Jan 1935, p 3.

<sup>184</sup> In Brisbane Churches: Modern Problems. *The Courier-Mail* (Brisbane, Qld: 1933-1954). 31 Dec 1934, p 15.

<sup>185</sup> *Whither Away*. *Maryborough Chronicle* (Qld.: 1860-1947), 28 Nov 1936, p 4.

<sup>186</sup> Wyndham, *Eugenics in Australia: Striving for National Fitness*.

<sup>187</sup> J.W.C. Wand, “Whither Australia?: The Price of Posterity,” *The Courier-Mail* (Brisbane, Qld: 1933-1954), 29 Dec 1934, p 15.

<sup>188</sup> Millicent Preston-Stanley, *The Production of Human Degeneracy* (HH Watson Printing Co, 1917).

<sup>189</sup> Jean Devanny, "Eugenic Reform and the Unfit," *Stead's Review* 1930.

The Worker's Educational Association, which still exists today, was formed to provide higher education to working class men and women. Begun by Albert Mansbridge in the UK in 1903, Australian branches were established in 1913 following a trip by Mansbridge.<sup>190</sup> Diana Wyndham, in her study of eugenics in Australia, outlined aspects of the relationship between this organisation and the eugenics movement. She noted that the director of the WEA had promoted eugenics in 1916, that "Eugenics Circles" had run in Sydney from 1922-1924, and that the association's magazine, the *Australian Highway*, had given publicity to eugenics.<sup>191</sup>

The following information about WEA activities provides further evidence that eugenic ideas were widespread in the community. The WEA branches in various Australian cities warmly embraced the eugenics movement through a range of activities. In Hobart, Tasmania, public lectures on eugenics were publicised in 1915<sup>192</sup> and in 1944.<sup>193</sup> In Brisbane, Queensland, the question "Will the Practice of Eugenics Benefit the Human Race?" was the topic of the WEA Literary and Debating Society in 1926.<sup>194</sup> "Eugenics Study Circles" were established in both Sydney and Newcastle. The *Newcastle Morning Herald* began an article with the phrase, "The subject of eugenics exercises the minds of many thoughtful persons", before describing how the local WEA study circle had been meeting monthly for more than a year, using Major Leonard Darwin's *What is Eugenics?* as the textbook.<sup>195</sup> A month later, the same newspaper reported on the month's talk on the topic of Mendelian inheritance, which

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<sup>190</sup> [www.weasydney.com.au/historywea.html](http://www.weasydney.com.au/historywea.html). Accessed 12 Jan, 2014.

<sup>191</sup> Wyndham, *Eugenics in Australia: Striving for National Fitness*.

<sup>192</sup> "Meetings." *The Mercury (Hobart, Tas.:1860-1954)*, 18 Sept, 1915, p 7.

<sup>193</sup> "Address on Eugenics." *The Mercury (Hobart, Tas.:1860-1954)*, 13 Apr, 1944, p 5.

<sup>194</sup> "W.E.A. Debaters." *The Brisbane Courier* (Qld: 1864-1933) 10 Nov 1926, p 8.

<sup>195</sup> "Eugenics Class – W.E.A.," *Newcastle Morning Herald and Miner's Advocate* (NSW: 1876-1954), 3 May 1930, p 3.



concluded that “Several diseases had been traced in numerous families and tended to confirm the impression that they were inherited as a simple dominant.”<sup>196</sup>

In Sydney, a series of five public lectures was announced in 1922<sup>197</sup>, with topics including “The Trinity of Racial Evils”, “The Future of the Race”, “The Segregation of the Unfit”, and “Heredity.”<sup>198</sup> The most detailed written summary of the contents of these eugenics lectures was published over three issues in the *Australian Highway*. One of the organisers of the Study Circles, Miss Ellice P. Hamilton, provided a written version of her lectures, entitled “Heredity in Relation to Eugenics.”<sup>199</sup> The subject matter dealt mostly with technical descriptions of Mendelian inheritance, though she also ventured into public policy and her interpretation of the social implications of eugenics in the final paragraphs. After arguing for the permanent segregation of the “unfit”, she implored:

It is then, for us who are aware of these evils which are ever increasing and threatening our race with ruin and degeneration, mental, moral and physical, to do our “bit” in the great wars being waged throughout the civilised world at this very hour, against the spread of criminality, insanity, and feeble-mindedness.<sup>200</sup> (p 213)

The direct impact of these courses which brought eugenic thinking to the general public has not been explored. In terms of the numbers of people involved, an online history of Tasmania stated that 540 students attended the WEA in Hobart in 1929.<sup>201</sup> Regardless of exact numbers, the existence of these courses reflected the fact that eugenics had attained some prominence in the minds of the general public. The discussion of eugenic ideas in the

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<sup>196</sup> “W.E.A Eugenics Study Circle.” *Newcastle Morning Herald and Miner’s Advocate* (NSW: 1876-1954), 3 June 1930, p 6.

<sup>197</sup> D Stewart, “Series of Public Lectures on Eugenics,” *Australian Highway* (1922): 151.

<sup>198</sup> *Ibid.*

<sup>199</sup> Ellice E Hamilton, “Heredity in Relation to Eugenics,” *The Australian Highway* (1923): 211-13.

<sup>200</sup> *Ibid.*

<sup>201</sup> Stefan Petrow, *The Workers Educational Association* (Centre for Tasmanian Historical Studies, 2006).

wider community must have served as a continual reminder to those with hereditary diseases such as HD that eugenic thinking was respectable, and that the goals of eugenics, such as segregation and marriage restriction, and even sterilization, were real possibilities.

Another educational organisation also enthusiastically encouraged discussion of eugenic ideas. The Australian Army Education Service (AAES) was highly active in the 1940s, and, like the WEA, was established to provide non-university-based adult education. With the goal of improving morale and readying the soldiers for civilian life after the war, a large range of activities was offered.<sup>202</sup> The hundreds of thousands of soldiers in the army were given the chance to attend lectures, watch films, enrol in correspondence courses and join discussion groups.<sup>203</sup> As with the WEA, a magazine was produced. *SALT*, which was widely distributed to the troops, contained information about the courses available and summarised aspects of the different discussion groups.

The AAES also produced additional written material for the discussion groups, and one of the most popular was the course “Man’s Place in Nature.”<sup>204</sup> After discussing topics such as biology, evolution, “man’s relationship to animals” and evolution more broadly, the final chapter was subtitled “Mental characteristics in man are inherited: The science of eugenics.”<sup>205</sup> What followed in the paper reflected typical eugenic themes. From the utopian goals: “It is for us in this present age to lay the foundations of a ‘new heaven and a new

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<sup>202</sup> Darryl Dymock and Australian Association of Adult and Community Education., *A Sweet Use of Adversity : The Australian Army Education Service in World War II and Its Impact on Australian Adult Education* (Armidale, N.S.W.: University of New England Press in association with AAACE, 1995).

<sup>203</sup> Ibid.

<sup>204</sup> Anonymous, *Man's Place in Nature, Discussion Group Scheme Course* (Sydney: Australian Army Education Service, 1945).

<sup>205</sup> Ibid.

earth,”<sup>206</sup> (p 92) the eugenic family studies of the Nams, Jukes and Kallikaks were retold, leading to the question of “Eugenics and Sterilization.”<sup>207</sup> The paper accepted the proposition that sterilization is warranted, while acknowledging the difficulty in deciding who should be sterilized. Nonetheless, the author goes on to argue that:

It seems highly probable that negative Eugenics will be practiced by the State, and that all those whose ancestry shows the presence of definitely undesirable characters, will be required to present a certificate of sterilization before they will be permitted to get married.<sup>208</sup> (p 96)

The author even seriously considers the question of killing the “unfit”, stating “I feel, personally, that it would be a terrible denial of our humanity to destroy these “unfit” members of the community.”<sup>209</sup> (p 99) The series ends with discussion points: “Should the mentally and physically unfit be sterilized?” and “Should the state rely on the present marriage laws for the continuance of the race.”<sup>210</sup> (p 99) An example of the kind of debate these discussion groups evoked was described in another article in *SALT*. The author reported on a discussion group in Canberra, where the participants “wrangled” with the issues brought up – “Highlights of this were the battles between the medical section and the Padre about human breeding and mental cases.”<sup>211</sup> (p 37)

The prominence of eugenic ideas in these educational societies provides further evidence of the success of the eugenics movement in spreading their ideas throughout different sectors

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<sup>206</sup> Ibid.

<sup>207</sup> Ibid.

<sup>208</sup> Ibid.

<sup>209</sup> Ibid.

<sup>210</sup> Ibid.

<sup>211</sup> Anonymous, “RAAF “Discussers” Eat Ideas and Biscuits,” *SALT* 1, no. 29th Nov (1941): 36-37.

in society. The role of the popular press in presenting and disseminating eugenic ideas will follow.

### **5.8.2 Newspaper References: 1900-1955**

The exposure given to eugenic ideas in Australian newspapers is another potential indication of their role in popular culture. This search was conducted using the National Library of Australia online newspaper archive,<sup>212</sup> entering combinations of the search terms “hereditary disease”, “eugenics”, “sterilisation” “unfit” “lethal chamber” “marriage certificates” “compulsory” and “Huntington’s Chorea.” There are some drawbacks to this use of this database. The scanning technology results in enormous numbers of results, most of them bearing no relation to the topics investigated. Using specific search terms results in a vast number of false hits – for example searching the term chorea produces 11,078 hits,<sup>213</sup> but the vast majority of these are errors and refer to similar words like “church.” Therefore, this tool cannot be used easily to ascertain numerically accurate data such as numbers of references to particular themes. The information presented here reflects only the sources that I could identify by reading the original newspaper articles. Another limitation is that the archive of most newspapers stops in the mid-1950s.

Nevertheless, hundreds of relevant articles were found using these search terms. These included short articles, reports on developments overseas, reports of legislation introduced to parliament and letters to the editor. There were two peaks. The majority of the articles were from the 1930s, with another peak from 1910-1920, however apart from this they were spread fairly evenly across the first five decades of the twentieth century. These eugenic

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<sup>212</sup> This online newspaper database is operated by the National Library of Australia and can be found at: <http://trove.nla.gov.au/> .

<sup>213</sup> Accessed 20 Jan 2015.

themes were common in mainstream newspapers in all of the major cities, but were not confined to them: a large number of references to these topics were found in the scores of smaller newspapers across regional Australia. The usual pattern was that a particular event resulted in coverage. A report on a public lecture, the publication of a book or a report in an overseas newspaper (usually British) prompted activity on a particular topic, with gaps of a few months or years until the next major “news event” encouraged coverage once again. Out of the many possible themes covered in these articles, I will firstly describe those referring to developments in the UK, the US and other countries. Next, there were many articles arguing for and against sterilization, and also proposals regarding the introduction of “health certificates” prior to marriage. There were dozens of references to the Nazi German laws, and in newspapers we can even find use of the phrase “lethal chamber” in relation to the “unfit”, well before 1939. Lastly, the anti-eugenic voices expressed in the newspapers will be outlined, followed by the few specific references to Huntington’s chorea. I have quoted liberally from these texts to give an idea of the kind of language to which people with HD, and the wider community, were exposed.

### **5.8.3 References to Eugenics in US, UK and Other Countries**

Australian readers were kept aware of developments regarding eugenics in the UK, the US and other countries of less influence and significance. An article in the Melbourne *Argus* reiterated the eugenic goal of creating stigma against the unfit. In 1910, it stated that the goal of the British eugenics society “is to create a public opinion which will frown down the mating and the reproduction of the “unfit”, even if it is found impossible to control or forbid it by law.”<sup>214</sup> Arguing against more drastic measures, the article goes on to say that: “The marriage of epileptics, lunatics, consumptives, and others suffering from hereditary

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<sup>214</sup> “Physical Deterioration.” *The Argus* (Melbourne, Vic: 1848-1957), 3 Feb 1910, p 6.

taints may be forbidden, but that is as far as legal restraint in British communities can be expected to go.”<sup>215</sup>

In 1914, newspapers reported on a major meeting of the Eugenics Education Society in London marking Galton’s birthday. One article referred specifically to a speech by Major Leonard Darwin, (one of Charles Darwin’s sons who was Galton’s successor in the role of Chairman of the Eugenics society in Britain) who stated that Galton’s goal was the creation of “a semi-religious horror of non-eugenic marriages.”<sup>216</sup> Further reports in 1928 of the Eugenics Education Society in Britain reiterated its commitment to “modify public opinion and create a sense of responsibility in respect of bringing all matters pertaining to human parenthood under the domination of eugenic ideals.”<sup>217</sup> Scholars of eugenics have described the popularisation of eugenics which took place in the US, such as Better Babies competitions at State Fairs.<sup>218</sup> Knowledge of these reached Australia. In 1912, an Adelaide article reported on one such fair in Iowa, and noted how “The American woman is the leader of the awakened social conscience in a country-wide crusade that is cooperating to build a better race.”<sup>219</sup> Later in the article the author stated: “social ostracism will be meted out to fathers and mothers who bring into the world any other kind.” That is, those who do not “measure up.”<sup>220</sup>

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<sup>215</sup> Ibid.

<sup>216</sup> “Galton and Eugenics: Anniversary of His Birth,” *Western Mail* (Perth, WA: 1885-1954), 3 Apr 1914, p 24.

<sup>217</sup> “Marriage of the Unfit,” *The Advertiser* (Adelaide, SA: 1889-1931), 29 Dec 1928, p 16.

<sup>218</sup> Kevles, *In the Name of Eugenics : Genetics and the Uses of Human Heredity*.

<sup>219</sup> Mabel Potter Daggett, “Women: Building a Better Race,” *The Advertiser* (Adelaide, SA: 1889-1931), 28 Dec 1912, p 6.

<sup>220</sup> Ibid.

Even developments in less traditional locations were reported. A small newspaper in the NSW town of Singleton saw fit to report on its front page the fact that an Indian parliamentarian had introduced a bill calling for the compulsory sterilisation of the “unfit”.<sup>221</sup> Similar coverage was given to an Egyptian doctor promoting the provision of birth control in Egypt, adding that the “physically or mentally unfit should be sterilised.”<sup>222</sup> In 1943, there was a report on the sterilization of the “unfit” in those with hereditary disease in Norway.<sup>223</sup> The fact that a marriage had been dissolved when one of the couple was discovered to have had a hereditary disease in Germany, was reported in 1937.<sup>224</sup> The story noted that both parties were imprisoned.

Australian newspapers reported on developments in eugenics organisations, such as the founding of the “Human Heredity Bureau” in London, which had the highly ambitious goal of becoming an “international clearing house” for studies of human heredity, which would allow it to provide a service “for persons wishing advice as to their fitness for marriage.”<sup>225</sup> The *Sydney Morning Herald* reported on the work of the bureau.<sup>226</sup> Davenport’s work at the Eugenics Record Office in the United States was also described. In a 1913 article titled “Social Problems and Eugenics” the work of the office in encouraging “eugenic principles” in marriage so as to minimise “insanity, the hereditary degenerations, pauperism and crime” was reported.<sup>227</sup>

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<sup>221</sup> “Sterilisation Move in India.” *Singleton Argus* (NSW: 1880-1954), 1 Aug 1952, p 1.

<sup>222</sup> “Egypt Has Controversy Over Birth Control.” *Chronicle* (Adelaide, SA: 1895-1954), 5 Nov 1953, p 10.

<sup>223</sup> “The Sterilisation of the Unfit.” *The Mercury* (Hobart, Tas.:1860-1954), 1 Jan 1943, p 2.

<sup>224</sup> “Disease Leads Two to Prison.” *The Argus* (Melbourne, Vic: 1848-1957), 30 Oct 1937, p 9.

<sup>225</sup> Ruggles-Gates, “Bureau of Human Heredity,” *British Medical Journal* 1, no. 3932 (1936): 1018.

<sup>226</sup> “Human Heredity: Bureau Collecting Data.” *The Sydney Morning Herald* (NSW: 1842-1954), 17 Jun 1936, p 16.

<sup>227</sup> “Social Problems and Eugenics.” *The Queenslander* (Brisbane, Qld: 1866-1939), 12 Jul 1913, p 41.

#### 5.8.4 Arguments for and Against Sterilisation

Examination of the database from 1900-1950 revealed that dozens of newspapers contained references to the “sterilisation of the unfit” (searching this phrase gives 988 hits, with an additional 45 using the spelling “sterilization.”)<sup>228</sup> This issue was a complex one for most journalists writing on the idea. Many articles outlined a range of arguments for and against, however many simply reported on developments overseas without comment. Beginning in 1904, several newspapers reviewed *The Fertility of the Unfit*,<sup>229</sup> an influential book by the New Zealand eugenicist W.A. Chapple. The *Adelaide Register*, for example, summarized Chapple’s argument that “the only treatment for the hereditary taint is sterility”<sup>230</sup> though the article presciently cautioned that the “risk with heroic cures is that they are often worse than the disease.”<sup>231</sup>

As Wyndham has pointed out, numerous women’s groups were enthusiastic proponents of some eugenic measures.<sup>232</sup> In 1927 newspapers reported on the pro-eugenic views of a delegate to the National Council of Women’s Conference. A Mrs Weldon put a motion to the meeting and “said prevention was better than cure, and that a great part of the work of gaols, hospitals, asylums and clinics could be eliminated by improving the human stock.”<sup>233</sup> This included “weak people, criminals, sufferers from hereditary disease” who should not carry on the race. Her motion was approved.<sup>234</sup> A newspaper reported in 1930 that the Country Women’s Association’s annual conference “passed a resolution urging the

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<sup>228</sup> Accessed 21 Jan 2015.

<sup>229</sup> William Agar Chapple, *The Fertility of the Unfit* (Melbourne: Whitcombe and Tombs, 1903).

<sup>230</sup> “Fertility of the Unfit.” *Register* (Adelaide, SA:1901-1929), 23 Jan 1904, p 9.

<sup>231</sup> *Ibid.*

<sup>232</sup> Wyndham, *Eugenics in Australia: Striving for National Fitness*.

<sup>233</sup> “Eugenics Urged.” *The Queenslander* (Brisbane, Qld: 1866-1939), 29 Sep 1927, p 47.

<sup>234</sup> *Ibid.*



sterilisation of the mentally unfit in the interests of the Australian race.”<sup>235</sup> In 1934, a Melbourne newspaper reported how the “Victorian Women Citizens’ Movement and the Victorian Federation of Mothers’ Clubs had organised a meeting on ‘the sterilisation of the unfit.’”<sup>236</sup> The majority of the articles were published in 1933 and 1934, prompted by discussion of the Nazi legislation. In 1934, Brisbane’s *Courier Mail* included a long article on “Sterilisation: Its Pros and Cons,” which argued in favour of “selective sterilisation,” dismissing opposition as “emotionalism.”<sup>237</sup>

Although many scholars of Australian eugenics point to its failures in terms of legislation, the press nevertheless regularly reported on the eugenics-related bills introduced into the various State parliaments. In 1934, the introduction of legislation for the sterilisation of the “unfit” in Victoria was reported.<sup>238</sup> In 1938, Brisbane’s *Courier Mail* reported on a parliamentary debate where the leader of the Opposition had stated: “We will have to take the plunge sooner or later and provide for the sterilization of the unfit.”<sup>239</sup> Others reported on public meetings held to discuss the question and the Catholic churches’ opposition was frequently noted. Opposing views were also reported, such as that of J.B.S. Haldane who argued that “Physicians Should be Healers.”<sup>240</sup> The article quoted him as speaking against the idea that “sufferers from certain incurable disease should be killed” and against compulsory sterilisation more broadly.<sup>241</sup>

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<sup>235</sup> “The Mentally Unfit.” *The Argus* (Melbourne, Vic: 1848-1957), 22 Aug 1930, p 5.

<sup>236</sup> “Sterilisation of the Unfit.” *The Argus* (Melbourne, Vic: 1848-1957), 3 Apr 1934, p 11.

<sup>237</sup> “Sterilisation: Its Pros and Cons.” *The Courier-Mail* (Brisbane, Qld: 1933-1954), 27 Jan 1934, p 18.

<sup>238</sup> “Sterilising the ‘Unfit’: Will Britain Follow Germany?” *The Catholic Press*, (Sydney, NSW:1895-1942), 25 Jan 1934, p 20.

<sup>239</sup> “‘Must Take Plunge’: Sterilisation of Unfit Urged.” *The Courier-Mail* (Brisbane, Qld: 1933-1954), 17 Nov 1938, p 9.

<sup>240</sup> “Right to Take Life: Physicians Should Be Healers.” *Examiner* (Launceston, Tas: 1900-1954), 19 Jan 1935, p 8.

<sup>241</sup> *Ibid.*

While the topics discussed above were most active in the period prior to World War II, occasional references were made to eugenic goals in the 1950s. “Housewife” Mrs M. Moore, in one of the earlier examples of vox pops in the media, stated: “degenerates should not be permitted to reproduce their kind. Fit people were kept working to maintain the “unfit” throughout their lives. Moreover, such types tended to raise the largest families.”<sup>242</sup> This survey, where “four out of five agree with Bishop Barnes”, referred to a British Anglican minister who was an outspoken advocate of eugenics. Over several decades Barnes argued the eugenic case, and this article commented on Barnes’ controversial address to the British Association for the Advancement of Science. Barnes’s speeches to various institutions in the UK were widely reported in the Australian Press, with titles such as “A Eugenic England: Bishop on “Blind Humanitarianism”<sup>243</sup> From 1933 to his death in 1953, there were at least 150 articles mentioning his pro-eugenic views in Australian newspapers, according to a search of the database.

### **5.8.5 Proposals re Marriage**

Eugenic proposals regarding marriage varied in the same way as other recommendations for reducing the number of the “unfit.” At the one end was the goal to instil the eugenic message so that it became the natural thing to do: couples were encouraged to look into their prospective partner’s family history to unearth potential reasons why they should not marry. Next, marriage guidance bureaus were encouraged which would provide a similar service. At the more authoritarian extreme, many called for state intervention in marriage: it was

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<sup>242</sup> “Four out of Five People Agree with Bishop Barnes.” *The Daily News* (Perth, WA: 1882-1950), 7 Sep 1950, p 9.

<sup>243</sup> “A Eugenic England: Bishop on ‘Blind Humanitarianism.’” *Chronicle* (Adelaide, SA: 1895), 26 Oct 1933, p 27.

proposed that couples should be required to have a health certificate before they were allowed to marry. All three of these proposals were likely to drive knowledge of any hereditary disease underground. For example, if children were kept in the dark about family illness, there was less chance of them being rejected as potential marriage partners. Examples of all of these suggestions appeared commonly in the newspapers from the 1900s through to the 1950s.

In 1935, it was reported that the Racial Hygiene Association (now known as the Family Planning Association) was arguing the case for sterilization.<sup>244</sup> It was also noted that “Compulsory health examination before marriage may be sought from the State Government as a result of the health week campaign ... (and that) ... The need of a health certificate before marriage and greater use generally of the science of eugenics will be discussed at a special meeting.”<sup>245</sup> References to the restriction of marriage to check the propagation of the “unfit” appeared regularly. In 1928, an Adelaide newspaper described a proposal of the British Eugenics Society: After stating the society’s goal of furthering “eugenic teaching at home, in the schools, and elsewhere,” the article stated that:

The society denounces parenthood on the part of the diseased, the insane and the alcoholic -when these conditions promise to be transmitted - as “a crime against the future”, and it stands for active legislation.<sup>246</sup>

The control of marriage joined sterilisation as a salient issue even in women’s magazines. For example, in a wide-ranging discussion on eugenics in 1935, the medical reporter for the

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<sup>244</sup> “Sterilisation in Sydney.” *The Courier Mail* (Brisbane, Qld), 10 Oct 1935, p 13.

<sup>245</sup> *Ibid.*

<sup>246</sup> “Marriage of the Unfit.” *The Advertiser* (Adelaide, SA), 29 Dec 1928, p 16.

*Australian Women's Weekly* claimed that “Not so many years ago eugenics was scoffed at and made fun of” but now “it is better understood.”<sup>247</sup> The article decried the fact that there are people “who are absolutely unfit to mate because of disease” who still continue to marry and bear children. For these reasons, the physician supported laws restricting marriage which had been enacted in other countries.<sup>248</sup> One of the reasons was because “such laws aim to promote a more healthy and vigorous stock for the nation as well as protect the ignorant and the uninformed.”<sup>249</sup> (p 43)

A year later, “Health Certificates before Marriage: Lovers’ Schedule of Fitness” was the headline greeting readers of the same magazine.<sup>250</sup> The article referred to a form provided by the Eugenics Education Society in London which would be sent to doctors, enabling them to scrutinise prospective marriages for eugenic fitness.<sup>251</sup> In 1936, the *Rockhampton Morning Bulletin* too reported on this activity, citing the credentials of the proponents of the examination, many of them holding high office.<sup>252</sup> In 1937, the Perth *Daily News* reported that Sydney was to have one of the first marriage clinics in the world under the auspices of the Racial Hygiene Association, “launched with the blessing of Government Officials.”<sup>253</sup> A letter to the editor in 1940 advocated that those with “hereditary taints or diseases” should not be allowed to marry unless they “submit themselves to curative or preventive treatment.

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<sup>247</sup> “What My Patients Ask Me.” *The Australian Women's Weekly* (1933-1982), 16 Mar 1935, p 43.

<sup>248</sup> Ibid.

<sup>249</sup> Ibid.

<sup>250</sup> “Health Certificates Before Marriage: Lovers’ Schedule of Fitness.” *The Australian Women's Weekly* (1933-1982), 11 Apr 1936, p 48.

<sup>251</sup> Ibid.

<sup>252</sup> “Pre-marriage Examination: Eugenics Society Proposal.” *Morning Bulletin* (Rockhampton, Qld:1878-1954), 10 Feb 1936, p 2.

<sup>253</sup> “Practical Eugenics in Sydney.” *The Daily News* (Perth, WA: 1882-1950), 2 Feb 1937, p 5.

Otherwise the prolific breeding of the unfit will impose an increasing burden on the community and the State.”<sup>254</sup> This presumably meant sterilisation for at least some.

### 5.8.6 References to Nazi Eugenics Laws

The sheer volume of references to the Nazi legislation on the sterilisation of the “unfit” in Australian newspapers was surprising. Combinations of the search terms “eugenics, sterilisation, unfit, Germany” revealed hundreds of references to the drafting and implementation of the German sterilization and marriage restriction programmes. Even before laws passed federally in Germany, the West Australian newspaper commented on the “Sterilization of the Unfit in Prussia.”<sup>255</sup> From June to December 1933, various aspects of the Nazi legislation were discussed in detail, including a popular women’s magazine stating that Germany was set to sterilise “2,000,000 unfit citizens”<sup>256</sup> whereas another newspaper article referred to the more often quoted figure of 400,000.<sup>257</sup>

Many of the articles specifically linked the German policies with the broader eugenic movement. One striking feature of the reports is the absence of commentary. The Townsville *Daily Bulletin* in June 1933 reported on a statements by “Herr Frick,” (presumably the German Interior Minister Wilhelm Frick) that “worn out dogmas must not permit the transmission of hereditary disease.”<sup>258</sup> The Adelaide *Mail* of October 1933 was titled “The Big Problem of Degenerates” and referred to the fact that “the unfit members of the community” had engaged attention because of “Germany’s bold decision to sterilize the

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<sup>254</sup> H.J. Gardener, “Eugenics.” *The Argus* (Melbourne, Vic: 1848-1957), 24 Feb 1940, p 4.

<sup>255</sup> “Sterilisation of the Unfit: German Legislation.” *The West Australian* (29 Apr 1933), p 15.

<sup>256</sup> “Points of View: Values of Extremes.” *The Australian Women’s Weekly* (1933-1982), 4 Nov 1933, p 10.

<sup>257</sup> “Eugenics in Germany: 400,000 Likely to be Sterilised.” *The Daily News* (Perth, WA: 1882-1950), 21 Dec 1933, p 5.

<sup>258</sup> “Sterilisation of Unfit: German Proposal.” *Townsville Daily Bulletin* (Qld: 1885-1954), 30 Jun 1933, p 5.

unfit,” including sufferers of St Vitus Dance (which was specifically subtitled Huntington’s chorea in the German legislation).<sup>259</sup> The fact that whole families were involved was emphasized in a headline of a Queensland newspaper, which read: “Family Life. Sterilising Unfit. German Legislation.”<sup>260</sup> Most articles were news articles, not commentaries, and simply reported on these stories.

Some articles focussed on the resulting conflict between German authorities and the Catholic “Holy See.”<sup>261</sup> Many also specifically described the hereditary courts – the headline of the *Cairns Post* article of December, 1933 was “Courts Established: Hereditary Disease Cases: German View.”<sup>262</sup> One article from 1934 questioned whether Britain would follow Germany in the “Sterilization of the Unfit.”<sup>263</sup> The Medical Correspondent of the *Adelaide Advertiser* began the column on “Sterilisation for Hereditary Diseases” praising Germany, “which has ever been to the fore in scientific circles.”<sup>264</sup>

The experience in Germany was given prominence in an article about a plan by the Eugenics Society of Victoria to establish a “Marriage Advisory Bureau” in Melbourne. It mentioned the compulsory nature of health certificates in Germany, and the fact that those deemed “unfit” could not marry without undergoing sterilization.<sup>265</sup> It was not until the 1940s that the German proposals were seriously criticised. The *Adelaide Chronicle* of 1941 reported on

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<sup>259</sup> “The Big Problem of Degenerates.” *The Mail* (Adelaide, SA: 1912-1954), 28 Oct 1933, p 6.

<sup>260</sup> “Family Life: Sterilising Unfit. German Legislation.” *Cairns Post* (Qld: 1909-1954), 30 Jun 1933, p 4.

<sup>261</sup> “Serious Tension: Germany and Holy See Sterilisation Law,” *Examiner* (Launceston, Tas: 1900-1954), 29 Nov 1933, p 6.

<sup>262</sup> “Courts Established: Hereditary Disease Cases. German View,” *Cairns Post* (Qld: 1909-1954), 23 Dec 1933, p 8.

<sup>263</sup> “Sterilising the ‘Unfit’: Will Britain Follow Germany?” *The Catholic Press* (Sydney, NSW 1895-1942), 25 Jan 1934, p 20.

<sup>264</sup> “Sterilisation for Hereditary Diseases.” *The Advertiser* (Adelaide, SA 1931-1954), 12 Apr 1934, p 8.

<sup>265</sup> “Advice About Eugenics: Proposal to Establish a Bureau in Melbourne.” *News* (Adelaide, SA: 1923-1954), 26 Nov 1937, p 8.

“Hitler’s Greatest Crime: Opponents Mutilated at Will”<sup>266</sup> and in 1942 one headline read “Germans Slaughter Sick and Insane.”<sup>267</sup> These references to the fact that eugenic proposals had moved from a theoretical possibility to reality in Germany must have added enormously to the worries of people who either knew of or suspected a hereditary disease in their families.

### **5.8.7 Use of the Phrase “lethal chamber”**

The murder of millions of people, mostly, but not exclusively Jewish, in “gas chambers” is one of the horrifying legacies of World War II, and a defining feature of twentieth century history. What is less known is that well before this, the term “lethal chamber” was used frequently in British, North American and Australian discourse, as attested to in the following example from Australian newspapers. The term had multiple meanings, most commonly referred to as a method of euthanizing dogs. The next most common usage referred to it as a means of carrying out the Death Penalty. A less common but in hindsight disturbing use was discussed in respect of the “unfit.” The difficulties referred to above in using this newspaper database to gauge frequency of newspaper reports are particularly apparent in this case due to the varied meanings of the term. In order to give some idea of the frequency of this term, the exclusion terms “dogs, cats, RSPCA and animals” were used, and the additional terms of “unfit”, “mental”, “mental deficient” and “insanity” were included for the period 1920-1930. A similar search using the period 1910-1920 yielded similar results. This yielded at least 50 references to these groups in this decade, and a brief sampling of the references in the early twentieth century will follow.

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<sup>266</sup> “Hitler’s Greatest Crime: Opponents Mutilated at Dictator’s Whim.” *Chronicle* (Adelaide, SA: 1895-1954), 28 Aug 1941, p 33.

<sup>267</sup> “Germans Slaughter Sick and Insane.” *The World’s News* (Sydney, NSW 1901-1955), 24 Jan 1942, p 2.

In 1907 a Tasmanian newspaper reported on a doctor advocating the lethal chamber for “weakly children,”<sup>268</sup> followed by another call in 1908 including tramps, criminals and “all useless and worthless lives.”<sup>269</sup> 1909 saw an article titled “Wasted Millions: Lethal Chamber Suggested” involving a proposal for dealing with the “feeble-minded,” as medical science was now so advanced that “it is possible to submit these idiots to a painless death.”<sup>270</sup> The use of the “lethal chamber” to deal with “the unfit” was referred to in scores of articles in newspapers in the following decades. While acknowledging the fact that the advocates of this course of action were a minority, articles such as this from the *Adelaide Advertiser* in 1923 kept the issue alive in the minds of readers. In describing “backward children” the author referred to those who believe “that the problem of the unfit will best be solved by sterilisation or the lethal chamber.”<sup>271</sup> Two years later, the same newspaper reported on another advocate asking whether “lethal chambers ought not to be instituted for hopeless mental patients who live in misery, a burden to themselves and an agony to their friends.”<sup>272</sup>

The views of the R.J.A. Berry, former Professor of Anatomy at the University of Melbourne and ardent eugenicist were reported in several newspapers, including one in Broken Hill, in 1930. Berry was reported as saying that “it would be kind to put some of the more chronic mental derelicts out of their misery, and out of the way of harming others, in a national lethal chamber.”<sup>273</sup> Given what was to come in Nazi Germany, these references to the killing of

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<sup>268</sup> “The Lethal Chamber: For Weakly Children. Doctors Startling Scheme.” *Examiner* (Launceston, Tas: 1900-1954), 10 Sep 1907, p 3.

<sup>269</sup> “Lethal Chamber for Criminals.” *Examiner* (Launceston, Tas: 1900-1954), 7 Mar 1908, p 3.

<sup>270</sup> “Wasted Millions: Lethal Chamber Suggested.” *Examiner* (Launceston, Tas: 1900-1954), 24 Dec 1909, p 2.

<sup>271</sup> “Backward Children,” *The Advertiser* (Adelaide, SA: 1889-1931), 14 Feb 1923, p 2.

<sup>272</sup> “Hopeless Cases of Insanity: Lethal Chamber Suggestion.” *The Advertiser* (Adelaide, SA: 1889-1931), 26 Jun 1925, p 17.

<sup>273</sup> “National Lethal Chamber for Mental Derelicts,” *Barrier Miner* (Broken Hill, NSW: 1888-1954), 7 Feb 1930, p 1.



the “unfit” must once again have reinforced the importance of hiding any potential evidence of a hereditary disease.

### 5.8.8 Anti-eugenic Voices

In addition to the neutral voices reporting the news, and those advocating for eugenic proposals, there were also a range of anti-eugenic views expressed. The most notable opponent was the Catholic Church. Some journalists ridiculed eugenic arguments, while taking other aspects of it seriously. In 1934, two local newspapers ran an article entitled “Eugenics Explained.”<sup>274</sup> Curiously, this article was first published in 1913, later to be re-published when there was a resurgence of interest in eugenics in the 1930s. This article explained eugenics in blunt vernacular terms, with not a little sarcasm: “The Eugenists are on the war-path, and, being very ‘fit’ themselves, they are going to eliminate ‘the unfit.’ We must not pooh pooh these excellent people. Eugenics is the coming science; it may soon be a practical issue in politics.”<sup>275</sup> Later, the author states: “So, for a whole generation, the ‘unfit’ shall not be allowed to marry. Hereditary diseases would then be stamped out.”<sup>276</sup>

In 1940, the local Launceston newspaper reported that opinion was “sharply divided” on the question of compulsory marriage certificates, with the churches, women’s groups and medical profession holding “widely differing views.”<sup>277</sup> The Perth *Daily News* reported the views of the Government Pathologist and Bacteriologist, who argued against compulsory health certificates before marriage. In his view, the “responsibility for an unhealthy marriage

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<sup>274</sup> “Eugenics Explained,” *Mullumbimby Star* (NSW: 1906-1936), 3 Jan 1913, p 5.

<sup>275</sup> “Eugenics Explained,” *The Carcoar Chronicle* (NSW, 1878-1943), 20 Apr 1934, p 3.

<sup>276</sup> *Ibid.*

<sup>277</sup> “Certificates of Health: Views on Marriage Problem,” *Examiner* (Launceston, Tas: 1900-1954), 3 Jul 1940, p 4.

thus rests on the couples themselves.”<sup>278</sup> It would be a long time before this position was officially adopted in recommendations for the genetic counselling of hereditary diseases in the 1980s.

Alexandra Minna Stern has stated that from the 1940s, eugenicists such as Paul Popenoe turned their attention “away from public and legislative arenas and into the intimate domain of domesticity and the family.”<sup>279</sup> (p 114) In this brief overview of eugenics in popular culture, we have seen how eugenic ideas in Australia had already entered the home, well before the 1940s. All of the suggestions for eugenic improvement of the race which were expounded in Britain, the US and Germany were subjects of conversation in Australian society.

## 5.9 HD as Exception

Eugenics had always had its critics, and questions, such as exactly who constituted the “unfit”, also caused fractious internal divisions. Many disapproved of the class and racial biases which dominated certain strands of eugenic thinking. However, as Wexler has pointed out, for many eugenicists, amongst the many targets of eugenic reform, HD was the exception.<sup>280 281</sup> While debate ensued about the heritability of conditions such as epilepsy, feeble-mindedness and alcoholism, HD was one disease all could agree on partly because of the impact of the disease and partly because it followed a straightforward, Mendelian pattern

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<sup>278</sup> “Pre-Marriage Examinations ‘Not Advisable’ Says Doctor,” *The Daily News* (Perth, WA: 1882-1950), p 1.

<sup>279</sup> Alexandra Minna Stern, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America* (Berkeley: University of California Press, 2005).

<sup>280</sup> Alice Wexler, "Chorea and Community in a Nineteenth-Century Town," *Bulletin of the History of Medicine* 76, no. 3 (2002): 495-527.

<sup>281</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

of inheritance. It was argued that at least in the case of this condition, eugenic action in the form of the prevention of procreation, was warranted. This view prevailed well into the 1970s, much longer than the overt support of many for eugenics in Australia, which diminished rapidly after WWII. The reasons for this will be explored in the remainder of the chapter.

In the developed world in the first decades of the 21<sup>st</sup> century, mainstream public opinion would agree that the state should have a limited role in controlling the reproductive choices of its population (exceptions including surrogacy, adoption and abortion). However, myriad moral and ethical questions remain regarding reproductive choices in relation to “disability.” In this chapter, the paternalistic attitudes expressed towards HD families in the twentieth century were stated bluntly. In part due to the absence of knowledge about the real problems of HD families, it was assumed by many medical professionals that people with this hereditary disease did not have the right to make their own choices about reproduction for themselves. If they could not be persuaded to conform to this view (and many studies showed that individuals from HD families continued to have children), then the state was justified in controlling their choices through a range of eugenic measures.

Throughout the twentieth century, critics of eugenics argued against these measures in relation to a range of other conditions, but it was often specifically stated that HD was an exception. The certainty of the heredity nature of the condition, the severity of the disease, the financial costs to society and the possibility of eradicating the disease all played their part in defining HD as the ideal target for eugenic control. Wexler has explored this issue in detail. The most notable historical example is the hugely influential examination of eugenics

which was conducted in the US in 1936, titled “Eugenical Sterilization: A Re-orientation of the Problem.”<sup>282</sup> Wexler has pointed out how a committee of the American Association of Neurologists had examined eugenic proposals and practices, and while critical of many aspects, “the authors defended a policy of sterilization for Huntington’s chorea (along with several other disorders).”<sup>283</sup> The fact that eugenic measures were thought acceptable for HD up until the 1970s is apparent from the pronouncement of physicians and the recommendations of the Merck Manuals, which, as described above, repeatedly advised doctors to tell their HD families not to have children. This advice was also given in newspaper articles. In 1953, a reader wrote to the *Adelaide Chronicle* with the question: “Very worried asks if Huntington’s Chorea is inherited and would it affect her children.” The reply described the pattern of hereditary transmission, then stated: “With the help of a psychologist she should start now to reconcile the children to the necessity for making plans not to pass on the complaint to children of their own.”<sup>284</sup>

This paternalistic viewpoint, whether expressed on behalf of the broader society, or on the part of particular physicians giving advice to individual family members, was problematic because of the exclusion of “the patients’ voice.” It was assumed by many that HD families were not qualified to make these decisions themselves. It was repeatedly noted by HD scholars that even when the disease was known in the family, many chose to still have children. That was the case in the past, and continues to be the case today. Many will use the opportunities offered by new technologies to avoid giving birth to child who carries the

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<sup>282</sup> American Neurological Association. Committee for the investigation of eugenical sterilization. et al., *Eugenical Sterilization* (New York,: The Macmillan company, 1936).

<sup>283</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*.

<sup>284</sup> “Readers Questions Answered: Hereditary.” *The Chronicle* (Adelaide, SA:1895-1954), 26 Nov 1953, p 37.

altered HD gene, whereas others choose to take their chances. The negation of their right to choose by those who wished to impose their moral and ethical viewpoints was one of the last vestiges of eugenic thinking, which presupposed that life with this particular disability was a life not worth living. While this question is now seen as a matter for the individual, the ethics of various positions are now debated, rather than imposed on HD families. This raises questions of disability rights more broadly, and the question of disability in relation to HD will be discussed in more detail in the following chapter. A related question is whether new reproductive technologies which are available to HD families represent a form of “new eugenics”. This is an important question for both HD families and the wider society to consider, but is beyond the scope of this dissertation.

## **5.10 Conclusion**

Despite a significant reduction in the stigma experienced by HD families over the past few decades, even in the present day, many families currently living with HD are still bearing the consequences of the intense stigmatisation of the disease, which resulted in family secrets and feelings of shame and guilt. In the past, many people who were already facing the challenges of coping with the disease in one or more family members also had to also contend with the fact that information had been hidden from them, increasing the strains on family relationships. In this chapter, some of the factors which contributed to this stigma in the past have been unearthed. Although there are many biological features of the disease which raise the likelihood of stigmatisation, the degree to which HD has been stigmatised has varied significantly over time, indicating that social forces play a major role in stigma creation. The primary focus of this chapter has been the influence of one social movement. Eugenic thinking was found to have played a significant role in the development of

unhelpful characterisations of HD, associating it with a range of other conditions like criminality and focusing on disease prevention rather than the needs of individuals already affected by the disease. Communities were encouraged to shun those with hereditary diseases and other conditions grouped under the rubric of the “unfit.”

Paradoxically, eugenics, too, became stigmatised, and it is still not widely known just how mainstream eugenic thinking was in the past. It is rare for eugenics to be mentioned in the obituaries and biographies of people who earlier in the century supported eugenic causes. A prime example of this is Charles Davenport’s own paper on HD, which has the word eugenics in the title, yet no historians of HD apart from Harper and Wexler have thought fit to examine the potential influence of eugenics on HD families. Eugenics’ well-hidden past has necessitated the use of novel source material, which in this chapter involved the eugenics journals, medical papers written about HD, educational journals and newspaper articles which reported on eugenics in the first half of the twentieth century.

In this chapter, I presented evidence that the stigma described by Wexler in the US was also an issue in Australia. I then went on to argue that the very core of eugenic philosophy was the creation of stigma towards the “unfit,” which in current terminology would be translated as the “disabled.” A distaste of “dysgenic” marriages was encouraged, and people were prompted to enquire into the family background of potential partners to scrutinise their genetic legacy. This was uncovered by researching the early pronouncements of Galton and other early eugenicists. The major eugenics journals were then searched for references to HD – this led to the discovery that Charles Davenport was not the only early eugenicist who was interested in the disease. Prominent eugenics proponents Ronald Fisher and Harry

Laughlin both indicated their awareness of HD as a model example of a human hereditary disease. This search also revealed that eugenicists were aware of the Nazi programmes requiring compulsory notifications of hereditary diseases and their sterilization policies, as they too were reported on in the major eugenics journals.

HD and hereditary diseases in general were grouped alongside other stigmatised conditions, such as alcoholism, insanity, criminality and feeble-mindedness, and placed into one entire undesirable category called the “unfit.” Proponents of eugenics found in HD unequivocal evidence that some diseases with mental symptoms could be inherited, giving support for their broader goals. Physicians studying the disease in turn were influenced by eugenic ideas. The previous chapter noted how therapeutic nihilism was one response to the disease. In this chapter, it was not just neglect of the needs of families, but advice telling them that they should not have children, which was repeated in popular medical books such as the Merck Manuals. All of these forces contributed to HD families feeling they needed to hide this disease away.

Moving to the situation in Australia, I have argued that although eugenic thought contributed to the stigmatisation of people with HD, the situation might well have been worse. At least in this country, HD was not specifically targeted as it was in Nazi Germany, nor did it attract the interest of the more ardent eugenicists in Australia, who were more concerned with the “feeble-minded.” The medical response to the disease in Australia was influenced but not dominated by eugenic thinking. In the first half century, Hogg and Brothers, the two physicians who studied the disease and worked most closely with HD families, did not adopt the kind of eugenic rhetoric seen in the US, Germany and to a lesser

extent Great Britain. Both had considerable power, and had the potential to make HD a eugenic target, particularly in their positions as the head and deputy head of mental health services in their respective states, but they chose not to do so. Nevertheless, eugenic proposals were widely discussed in mainstream society, as evidenced by my examination of newspaper articles and organisations providing adult education.

In the absence of any cures or treatments to improve symptoms of the disease, it is an understandable response that physicians considered how to prevent this obviously distressing disease. However, the voices of HD family members themselves were omitted from these considerations. The assumption was that if people chose to take the risk to have children, then they must be mistaken. Medical paternalism was the dominant paradigm: the most dramatic example being advice for physicians to “veto” their HD patients from having children. The concept that individual rights, including the right to have children, was best placed in the hands of professionals rather than lay people, was first seen in the pronouncements of Davenport, who questioned why people with HD were not being “selected against” in marriage, later arguing for immigration restrictions and other state restrictions. When families at risk of the disease chose to have children (as many continue to do) their decisions were viewed as flawed, ignoring the fact that those with experiential knowledge of the disease sometimes did consciously make this choice. It was not until “patient voices” began to be heard that life for HD families began to change. Rather than the therapeutic nihilism which dominated medical responses to the disease, physicians and other medical staff began to see that they did have a role in the lives of HD families, even when there was no medical treatment. This emergence “out of the closet” first internationally, and then in Australia, will be the primary subject of the following chapter.



## Chapter 6: From Secrecy and “Problem Families” to Raising Awareness

*The understanding that I was not alone and was in no way responsible for the devastation it causes came as a great relief to me.*<sup>1</sup>

Joyce Abblitt. President of the Australian Huntington's Disease Association, Tasmania.  
1998.

While shame and stigma still figure in the lives of many HD families, these additional burdens have lessened in the last few decades. The next era for HD families, which I will examine in this chapter, coincided with the social movements of the 1960s and 1970s, when previously stigmatised or marginalised groups began to argue their case for greater social acceptance. The campaigning singer-songwriter Woody Guthrie had been diagnosed with HD, and his former wife Marjorie adopted the methods of social activism in her pioneering work to bring HD out into the open. Physicians began to find out what they could do for HD families to improve life with this harrowing disease. Researchers began to search for the genetic basis of HD, with the cooperation of family members who volunteered as research subjects. This collaboration eventually resulted in the identification of the marker for the gene in 1983, the gene itself in 1993, and the ongoing search for disease-modifying treatments. Directly and openly facing the some of the problems caused by the disease was a large change from the deep secrecy and shame which permeated the disease for the previous decades.

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<sup>1</sup> Joyce Abblitt, "Introduction," in *Out of the Darkness*, ed. Elsie Targett, (King's Meadow: Huntington's Disease Association (Tas.) Inc, 1998).

In this chapter I will provide an account of this era, emphasising the following questions. First, in addition to the previous descriptions, how was HD depicted in medical publications and what influence did this have on HD families? Previous chapters have considered the framing of the disease in terms of witchcraft allegations and dancing manias. One aspect of this question is the eugenically-inspired “problem family” genre, which further stigmatised the disease in the post-war period. Second, what was life like for HD families in Australia in the 1960s, and how did the situation begin to improve? I will then describe the consequences of the negative framing of HD, primarily by reference to the work of a Victorian Social Worker, Betty Teltscher, who had first-hand knowledge of the challenges faced by HD families in the past. In the US, an alternative to the previously stigmatising narratives emerged, and therefore a brief overview of how this occurred will follow.

I will then describe the circumstances and events in the late 1960s and early 1970s in the Australian state of Victoria which led to the development of an HD clinic and a reorientation of the potential role of medical professionals in their response to HD. This led to the formation of the first patient advocacy organisation in Australia. Unlike the US, the UK and Canada, where family members took the lead in the formation of patient support groups, in Australia this happened through a collaboration between medical professionals and HD families. As with many episodes described in this dissertation, the Tasmanian kindred once again played an important part in HD’s history. A research project searching for genetic markers of the disease at the Department of Psychiatry at the University of Melbourne was the catalyst for these significant changes which then became nationwide. The activities of physicians, other professionals and lay activists in improving the situation for HD families will then briefly be described. The difficulties faced by Aboriginal Australians

with HD in South Australia, and in particular the creation of services to educate people about the disease and provide services in that state will then be outlined.

Third, I will attempt to place these developments in the context of other social movements which have argued for minority rights and questioned aspects of the medical response to disease. The language used by the HD community is in many cases identical with the language of other stigmatised identities, most notably in the use of the phrase “out of the closet.” After noting these similarities, the relationship between HD activism, the anti-psychiatry movement of the last century and more recent disability scholarship will be examined. The underpinnings of the anti-psychiatry movement which flourished in the 1970s will be examined in relation to HD and the reasons why this movement did not resonate with the HD community will be explored.

More contemporaneously, aspects of the disability studies and disability rights movement which has emerged will then be analysed. I will argue that this movement has more common ground with HD activism, though also some major differences. HD is rarely mentioned in academic disability studies, nor by the various lay disability organisations – I will discuss the exceptions. Next, I will consider the points of difference and similarities between the influential branch of disability activism characterised as the “strong social model” and HD advocacy and activism. HD never fitted into this major disability model, but recent scholarship focussing on the concept of “biological citizens” more closely reflects the activism engaged in by HD families and professionals over this period.

## 6.1 “Problem Families” or “Families with Problems?”

The previous chapter showed how eugenic thinking was influential in shaping both medical responses and public opinion towards those deemed “unfit,” including those with hereditary disease. This section will examine the adoption of the notion of “problem families” in the depiction of HD, including in the post-war period. From the late nineteenth century, extensive genealogical investigations of various families considered to exhibit “social problems” were undertaken, and these studies were promoted for eugenic purposes. The names of the “Jukes,” “Kallikaks” and “Nams” entered popular discourse from the 1930s. In 1988 Nicole Hahn Rafter analysed and reproduced the original versions of many of these studies due to their importance but inaccessibility.<sup>2</sup> She stated that half of these studies in the US emanated from the Eugenics Record Office.<sup>3</sup> She noted that Charles Davenport contributed to the genre in his study of the “Hill Folk: Report on a rural community of hereditary defectives.”<sup>4</sup> The lesson to be learned was that heredity was paramount in the creation of problem families which were a financial burden on the rest of society and accounted for a large proportion of criminality and other social problems. As noted by Wexler, Vessie’s representation of HD families neatly fitted into this wider eugenic paradigm of problem families.<sup>5</sup> As further evidence of this linkage, she also noted that in Vermont, one of the families singled out for study was specifically selected because of Huntington’s disease.<sup>6</sup> In Australia, too, there was awareness of the concept of “problem families” many decades later. As late as 1976, in an article which mentions the surveys of families with HD,

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<sup>2</sup> Nicole Hahn Rafter, *White Trash : The Eugenic Family Studies, 1877-1919* (Boston: Northeastern University Press, 1988).

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> Alice Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (New Haven: Yale University Press, 2008).

<sup>6</sup> Ibid.

a Tasmanian GP wrote about such families in an article titled *The Jukes of Van Diemen's Land? Or, a Tasmanian Problem Family*.<sup>7</sup> Further evidence of the use of this framework is the fact that Charles Brothers' superior, Eric Cunningham Dax, the Director of the Victorian Mental Hygiene Authority, produced a paper on "multiproblem families" in 1977.<sup>8</sup>

While the influence of eugenics waned in other domains, in the 1960s, emphasis on the social problems of people with HD was apparent in the medical literature, and the links between these "problem families" and the eugenic lessons to be adopted in the case of HD were explicitly made. Prior to describing a selection of these studies, it is important to acknowledge the fact that HD is an extremely burdensome disease for the families concerned, as all chronic diseases have significant financial and personal ramifications. Lost income, the burden of care-giving on family members, and the physical, psychiatric and behavioural features of the disease necessarily impact enormously on the individuals concerned and their family.<sup>9</sup> However, the following studies painted an almost completely hopeless picture of HD, in some senses blaming the families themselves for the disease, and in several instances the reports were used to justify eugenic goals.

Several studies produced by British psychiatrists John Oliver and Kenneth Dewhurst are a case in point. The title of one of their papers is telling - *Six generations of Ill-Used Children in a Huntington's Pedigree*.<sup>10</sup> Published in 1969, this paper described six generations of a family

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<sup>7</sup> G. N. Flaherty, "The Jukes of Van Diemen's Land? Or, a Tasmanian Problem Family," *Australian Family Physician* 5, no. June (1976): 707-12.

<sup>8</sup> E. Cunningham Dax and Rona Hagger, "Multiproblem Families and Their Psychiatric Significance," *Australasian Psychiatry* 11, no. 4 (1977): 227-32.

<sup>9</sup> Betty Teltscher and Brian Davies, "Medical and Social Problems of Huntington's Disease," *Medical Journal of Australia*, no. 1 (1972): 307-10.

<sup>10</sup> J.E. Oliver and K.E. Dewhurst, "Six Generations of Ill-Used Children in a Huntington's Pedigree," *Postgraduate Medical Journal* 45 (1969): 757-60.

which the authors claimed was representative of HD families as a whole. They stated that “The pedigree described here is typical of twenty five others involving at least 425 families,”<sup>11</sup> (p 759) that “children reared in these families later manifest subtle anti-social tendencies”<sup>12</sup> (p 757) and that the third generation “is almost invariably crippled by alcoholism, chronic neurosis or psychopathy, initiating ‘problem families’ in subsequent generations.”<sup>13</sup> (p 757) They go on to portray the individuals in these families as “vicious and cruel,” “brutal,” a “pathological liar” and one is described as leading “a feckless existence in London with casual prostitution, starting a line of problem families, delinquents and gaolbirds.”<sup>14</sup> (p 758) The final paragraph states that there have also been examples of “infanticide, brain injury, incest, incestuous sodomy, sadism and other perversions.”<sup>15</sup> (p760) Under the heading “Eugenic Aspects,” Oliver bemoans the fact that “eugenic control of the illness is not possible whilst the present record systems are relied upon.”<sup>16</sup> (p 253) Dewhurst, Oliver and Mc Knight state that “eugenic measures are still of importance” and conclude with the comment: “we believe that the illness carries a responsibility of preventive medicine which at present is not being fulfilled.”<sup>17</sup> (p 258)

Social worker Mary Hans and psychiatrist Hans Gilmore painted a similar picture of the disease in their study published in 1968 of a group of HD patients in the US.<sup>18</sup> While describing what seems like an excellent service for the families they assisted in their clinic in

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<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> Ibid.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

<sup>16</sup> J.E. Oliver, "Huntington's Chorea in Northamptonshire," *British Journal of Psychiatry* 116 (1970): 241-53.

<sup>17</sup> K.E. Dewhurst, J.E. Oliver, and A.I McKnight, "Socio-Psychiatric Consequences of Huntington's Disease," *British Journal of Psychiatry* 116 (1970): 255-58.

<sup>18</sup> Mary Hans and Thomas H Gilmore, "Social Aspects of Huntington's Chorea," *British Journal of Psychiatry* 114 (1968): 93-98.

Albany, New York, they nevertheless go on to paint a monochrome view of life with the disease, emphasizing the “low class” nature of the disease, where “few of the patients or their families were active in social, fraternal, political or civil affairs” with “few cultural interests.”<sup>19</sup> They conclude that “The disease bears within itself the seeds of desocialization and cultural alienation.”<sup>20</sup> (p 97) This sentence is particularly telling, in its failure to acknowledge the social forces which may have contributed to the difficulties these families faced, laying all blame for stigma on the biological features of the disease. It is ironic that one of the cultural icons of the twentieth century, Woody Guthrie, his dancer wife Marjorie Guthrie and Milton Wexler, psychoanalyst with prominent connections within artistic circles, were simultaneously acting as the catalysts of HD activism.

What both sets of researchers failed to emphasize was that both studies were based on patients admitted to institutional care, without considering that this might not be representative of the HD population on the whole. Hans and Gilmore clearly state that their sample was based on those admitted to their hospital. Oliver and Dewhurst also do not take into account their reliance on the experience of those with HD who were admitted to asylums. Their 1970 paper reports that of the 102 patients that they studied, 80 were admitted to mental hospitals.<sup>21</sup> At that time, many earlier studies had found that the majority of people with HD had not been admitted to mental hospitals.<sup>22 2324</sup> Therefore, by definition, those that did were not representative of the people living with the disease as a whole. They

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<sup>19</sup> Ibid.

<sup>20</sup> Ibid.

<sup>21</sup> Dewhurst, Oliver, and McKnight, "Socio-Psychiatric Consequences of Huntington's Disease," .

<sup>22</sup> Julia Bell, *Huntington's Chorea* (London: Cambridge University Press, 1934).

<sup>23</sup> J A R Bickford and R.M. Ellison, "The High Incidence of Huntington's Chorea in the Duchy of Cornwall," *Journal of Mental Science* 99 (1953): 291-94.

<sup>24</sup> C R D Brothers, "The History and Incidence of Huntington's Chorea in Tasmania," *Proceedings of the Royal Australian College of Physicians* 4 (1949): 46-50.

were admitted to these institutions because the families were struggling. This leaves unaccounted for the large numbers of people living with the disease in the community who did not require institutional care.

In the Australian literature, both Parker and Wallace tended towards the same depictions of their families. In discussing the clinical features, they note the “well documented social problems – the alcoholism, the broken families, the sexual promiscuity, the brushes with the law.”<sup>25</sup> (p 231) They also describe the personalities as “inordinately egocentric, highly irascible, violent.”<sup>26</sup> (p 231) Even when admitting that some people had obtained status and wealth, this was apparently due to “possession of the ruthless, driving personality of the pre-morbid carrier of the disease.”<sup>27</sup> (p 231) In fairness, they also admit that many with the disease manage to live without the need for institutional care, that many people come from “the professions” and that “by no means all carriers of the disease go raving mad.”<sup>28</sup> (p 230)

It is of interest to note the absence of this narrative in Brothers’ work on the Tasmanian families. He was clearly aware of the “problem family” genre. In 1941, a newspaper article headed “Improvement of Race: Doctor Discusses Problem of Tasmanian ‘Hill Billies’”<sup>29</sup> cited Brothers as noting that “hill-billies” existed not only in America - Tasmania had “its quota of them.”<sup>30</sup> (p 2) By contrast, as outlined previously, he characterised HD families as being from “industrious yeoman stock” resisting the temptation to characterise the families

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<sup>25</sup> D C Wallace and N Parker, "Huntington's Chorea in Queensland: The Most Recent Story," in *Advances in Neurology: Huntington's Chorea 1872-1972*, ed. Andre Barbeau, Thomas N. Chase, and George W. Paulson, (New York: Raven's Press, 1973), 223-36.

<sup>26</sup> *Ibid.*,

<sup>27</sup> *Ibid.*,

<sup>28</sup> *Ibid.*,

<sup>29</sup> “Improvement of the Race: Doctor Discusses Problem of Tasmanian Hillbillies” *The Mercury (Hobart, Tas.:1860-1954)*, 15 Jul 1941, p 2.

<sup>30</sup> *Ibid.*



as part of the broader eugenic discourse so common at the time. His own experience of the real lives of HD family members perhaps tempered his account, allowing a more realistic appraisal of life with the disease. This was a stark contrast to the depiction of problem families as welfare-dependent drains on the public purse.

Towards the end of the 1960s, occasional voices dissenting from the dominant paradigm began to be heard. In a sensitive article from a Scottish medical journal, the authors argued against medical paternalism and the framing of the disease in a totally negative light. They stated that although families should be given sound contraceptive advice so that they could avoid unwanted pregnancies, “We feel that it is not part of the physician’s duty to patients to advise for or against having children; he cannot live their lives for them.”<sup>31</sup> (p155) They further note that while some physicians feel they have a duty to society to prevent people with potential HD being born, that:

They should remember that we know very little of the relative value of persons with Huntington’s chorea. No proper investigation has been made of this and we should not automatically assume that, from the community point of view, the condition is disastrous.<sup>32</sup> (p155)

In Australia, too, the end of the 1960s saw a switch from “problem families” to “families with problems.” The dawn of this new approach is apparent from a 1972 medical publication by social worker Betty Teltscher and psychiatrist Brian Davies<sup>33</sup> entitled “The Medical and Social Problems of Huntington’s Disease,” the paper indeed spoke of the social problems. Where their paper broke new ground was that the authors went beyond mere

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<sup>31</sup> D. Cameron and Venters G.A., "Some Problems in Huntington's Chorea," *Scottish Medical Journal* 12 (1967): 152-56.

<sup>32</sup> Ibid.

<sup>33</sup> Teltscher and Davies, "Medical and Social Problems of Huntington's Disease," 307-10.

description of the problems, in addition offering practical advice. Previously, the medical response to the disease could reasonably be characterised as therapeutic nihilism. Doctors had little to offer in the way of a cure or even treatments of the disease, and in the absence of these traditional medical roles, it was felt there was little to be done. The question of how health professionals might deal with affected families was rarely addressed in medical papers.

Teltscher and Davies approached the issue of what could be done to help these families, other than telling them not to have children. The abstract of the paper placed this emphasis firmly in the mind of the reader – the problems “are discussed from the viewpoint of total family care.”<sup>34</sup>(p 307) Under the section on genetic counselling, advice is given about sensitive issues such as disclosure of information to other family members and what to tell children at risk. Rather than simply describing the “problem families” in almost lurid detail, the paper presented the viewpoints of affected families. The misunderstandings of the disease by others, such as mistaking the movement disorder and slurred speech for drunkenness, were acknowledged. The article provided advice to physicians about management of the patient, including consideration of financial issues, and the possible need to plan for institutional care in the latter stages of the disease.

Social aspects were also specifically addressed, particularly the stigma and secrecy. They drew attention to the social dimensions of disease, noting the distinction between “popular diseases which elicit sympathy and help, and unpopular diseases”<sup>35</sup> such as epilepsy or mental retardation. As a contrast to the nihilism of the past, and hopelessness surrounding the disease, advice was given to physicians to discuss the research being done into the

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<sup>34</sup> Ibid.

<sup>35</sup> Ibid.

disease in order to give families some hope. The paper ends with a discussion of the work of Marjorie Guthrie in the US, who started the first HD patient organisation. They describe an information pamphlet produced by the unit in Melbourne and also another useful pamphlet from the US. The article ends with the rhetorical suggestion: "Perhaps the time has come for the organization of such a group of interested persons in Australia."<sup>36</sup>(p 310)

Later reflections on these earlier times were provided by Teltscher in talks given by her to various conferences.<sup>37</sup> In describing the situation for the HD families she worked with in the late 60s and 70s, she stated:

Generally, they had only sketchy information about HD, but now they wanted as much information as they could obtain about the disease, especially about the mode of inheritance. It was distressing to hear one story after another of families receiving incorrect information which they had used as a basis on which to make major decisions such as marriage and child-bearing. In some cases, doctors had deliberately kept knowledge from certain family members and whilst many people may have preferred not to contemplate their worst fears, many more wanted the truth.<sup>38</sup> (p 4)

Teltscher drew attention to the potential consequences of the negative portrayals of HD families as "problem families," silence about the disease and other stigmatising language used by many physicians in publications. She pointed to the demoralizing effects for family members looking for information about HD when they were described as alcoholics, criminals etc. She also described the effect it might have on generalist physicians who had not previously encountered the disease and were looking for information: these negative descriptions would hardly encourage the physician to get involved with these "problem families." Her description is worth noting in full:

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<sup>36</sup> Ibid.

<sup>37</sup> During a face to face interview Mrs Teltscher gave me transcripts of three conference presentations.

<sup>38</sup> Betty Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care," (1991).

Enquiring members of Huntington's disease families who searched the medical literature for guidance anticipating their probable future should they develop the disease had good reason for despair. The literature abounded in descriptions of fecklessness, alcoholism, violence and sexual promiscuity. The latter was particularly emphasized with no reference to a rate for sexual promiscuity in the general population.<sup>39</sup> (p 2)

As a general rule, prior to the 1970s, families were left to struggle with HD on their own. Few doctors took any interest in the disease and most GPs were ignorant of basic facts about HD. In this pre-internet era, even simple facts were hard to come by. Even in straightforward matters such as the pattern of transmission, which had been identified as early as George Huntington's original publication and verified in the early 1900s, mistakes were commonly made. Local doctors were not only often ignorant about the disease, but in fact provided misinformation. Teltscher reported that families had been told by their doctors that the disease only came from one sex or the other, in many cases they were told to ignore the disease, and many were diagnosed with similar conditions such as Parkinson's disease.

Even when they were aware, many doctors were reluctant to make the diagnosis "which they saw a social death sentence."<sup>40</sup> (p 2) In the absence of reliable medical knowledge to draw on, families often invented their own HD narratives, a kind of folk knowledge based on their personal stories. While some believed that only women could pass on the gene, other believed that it only went through the male line. Others thought birth order was contributory

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<sup>39</sup> Betty Teltscher, "History of Care in Huntington's Disease in Australia," in *Handbook for Caring in Huntington's Disease*, ed. Edmond Chiu and Betty Teltscher, (Melbourne: Huntington's Disease Clinic, Melbourne, 1985), 1-5.

<sup>40</sup> Betty Teltscher, "Paper by Betty Teltscher," (1998).

factor. Many people used physical appearances or similarities or differences in temperament to guess whether they would inherit the gene from their mother or father.<sup>41</sup>

## 6.2 HD Advocacy - US, UK and Canada

Having described the challenges faced by HD families, in part due to stigma and secrecy, the following section will describe how this situation began to change. The concept of “patient organisations” is now so ubiquitous that they seem a permanent part of the medical landscape; however they have only existed in the past few decades. They have had a huge influence on HD families’ experience of the disease. The isolation and belief that they were the only ones in their position began to come to an end in the 1970s. The first HD patient organisations were formed in the US by spouses of people with HD. Marjorie Guthrie (1917-1983), former wife of folk singer Woody Guthrie, formed the first group, the Committee to Combat Huntington’s Disease, (CCHD) in 1967.<sup>42</sup> Woody’s Guthrie’s neurologist, Dr John Whittier, put Marjorie Guthrie in touch with two prominent HD researchers, Dr Ntinios Myrianthopoulos and Dr Andre Barbeau, and she was invited to a meeting of HD researchers in Montreal in 1967.<sup>43</sup> Her organisation went on to become the Huntington’s Disease Society of America, and over the next decade she travelled around the world facilitating the formation of patient organisations, including in Australia.

A second organisation was formed by psychoanalyst Dr Milton Wexler, whose wife Leonore had been diagnosed with HD. In his attempts to deal with the impact of the disease and the fact that his two daughters were at risk, he met with Marjorie Guthrie and formed the

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<sup>41</sup> Interviews with HD family members.

<sup>42</sup> G. P. Bates, "The Molecular Genetics of Huntington Disease - a History," *Nature Reviews Genetics* 6, no. 10 (2005): 766-73.

<sup>43</sup> Wexler, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*

California Chapter of the CCHD in 1968.<sup>44</sup> Differences between Guthrie and Wexler emerged over the coming years. These primarily concerned whether the funds raised should be used for the support of families dealing with HD or spent on finding treatments or cures. Wexler's organisation had been very successful at fund-raising and had considerable financial resources. In 1974 Wexler formed a separate organisation, the Hereditary Disease Foundation.<sup>45</sup> This organisation, which also still exists, was highly influential in the discovery of the marker for the gene in 1983 and the gene itself in 1993. Nancy Wexler now serves as the President. Alice Wexler has provided a detailed account of this organisation and its relationship with the CCHD in her autobiographical *Mapping Fate*.<sup>46</sup> In other countries, too, family members formed organisations - in the UK, Mauveen Jones and in Canada Ralph Walker.<sup>47</sup> The attendance of these two groups (UK and Canada) at the 1974 American Huntington's Disease Association marked the beginnings of the International Huntington's Association.<sup>48</sup>

### 6.3 The Victorian HD Experience

The engagement of Australian HD families with professionals interested in their plight marked the beginning of their emergence from the secrecy of the past.<sup>49</sup> The paucity of research into HD was highlighted by the neurologist Myrianthopoulos in his extensive 1966

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<sup>44</sup> Alice Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (Berkeley: University of California Press, 1996)

<sup>45</sup> Ibid.

<sup>46</sup> Ibid.

<sup>47</sup> <http://www.huntington-assoc.com/purpose-and-history-of-iha.aspx> Accessed 7-1-2014.

<sup>48</sup> Ibid.

<sup>49</sup> The information presented in the following section was provided in interviews with Dr Edmund Chiu and Ms Betty Teltscher, papers written for conferences by Ms Teltscher as described above and academic literature published by this group.

review of the disease.<sup>50</sup> When Canadian researcher Barbeau planned to organise a meeting of HD researchers in 1967, he found only 12 medical scientists actively working on the condition.<sup>51</sup> (p 99) However, at this meeting in Montreal, the seeds of interest into the disease were sown. In addition, the discovery of an effective treatment for Parkinson's Disease in the form of leva-dopa offered hope for the treatment of other movement disorders. The 1960s also saw increased interest in the biological aspects of mental diseases in general. Scientists joined physicians in utilising new technologies and the developments occurring in genetics. However, in order to utilise these new tools, they needed diseases to research - Huntington's Disease, with its known autosomal dominant mode of transmission, was an obvious choice.

Colin Brackenridge (1932-1981) was an Australian biochemist whose interests moved from basic research to the application of new biomedical techniques in patient populations. In the late 1960s, he was employed by the newly founded Department of Psychiatry at the University of Melbourne to head up the "scientific research section."<sup>52</sup> Working initially with children with psychosis,<sup>53</sup> Brackenridge had become interested in HD while doing postgraduate study in London.<sup>54</sup> He obtained a three-year National Health and Medical Research Council grant to study the genetics and biochemistry of HD. This research was to

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<sup>50</sup> Myrianthopoulos, "Huntington's Chorea," *Journal of Medical Genetics* 3 (1966): 298-314.

<sup>51</sup> Alice Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (New York: Times Books, 1995)

<sup>52</sup> Sylvia Fraser, "Chapter 2 Sylvia Fraser," in *The Department of Psychiatry at the University of Melbourne 1969-2009*, ed. Edmond Chiu and Joy Preston, (Melbourne: Department of Psychiatry, University of Melbourne, 2010), 12-15.

<sup>53</sup> Elizabeth Horton, "Chapter 25 Elizabeth Horton," in *The Department of Psychiatry at the University of Melbourne 1969-2009*, ed. Edmond Chiu and Joy Preston, (Melbourne: Department of Psychiatry, University of Melbourne, 2010), 153-67.

<sup>54</sup> Teltscher, "Paper by Betty Teltscher."

prove the catalyst for a whole new phase in the history of the disease in Australia, resulting in monumental changes for HD families.

The Tasmanian kindred once again played a pivotal role in the history of the disease in Australia. Brackenridge became aware of Brothers' records of HD families from Tasmania and Victoria.<sup>55</sup> From 1970 until his death in 1981, judging from his prodigious output, Brackenridge dedicated himself wholeheartedly to the study of HD. Over this 11-year period, he published 22 articles on the disease, many in influential journals such as *Clinical Genetics: The Journal of Medical Genetics and Human Heredity*. The primary goal was to find genetic markers for the disease, but he also engaged in studies of other aspects of HD. Initially, he used already published studies which he subjected to complex statistical analysis.<sup>56</sup> Another of his interests was the potential contribution of sex-linked factors, including the finding that juvenile HD was mostly associated with paternal transmission.<sup>57</sup> Although he never succeeded in finding any genetic markers, he was part of an international community of researchers who stimulated renewed interest in the disease. He was one of only two Australians appointed to the World Federation of Neurology working group on HD.<sup>58</sup>

Brackenridge's devotion to the study of HD was to have important consequences for families living with the disease. Given that many people with HD had been admitted to the

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<sup>55</sup> Edmond Chiu and Betty Teltscher, "Huntington's Disease in the Department of Psychiatry," in *The Department of Psychiatry at the University of Melbourne 1969-2009*, ed. Edmond Chiu and Joy Preston, (Melbourne: University of Melbourne, 2010), 176-79.

<sup>56</sup> Brackenridge, "A Genetic and Statistical Study of Some Sex-Related Factors in Huntington's Disease," *Clinical genetics* 2, no. 5 (1971): 267-86.

<sup>57</sup> C. J. Brackenridge, "The Relation of Sex of Affected Parent to the Age at Onset of Huntington's Disease," *Journal of medical genetics* 10, no. 4 (1973): 333-36.

<sup>58</sup> Teltscher, "Paper by Betty Teltscher."



state's asylums, Brackenridge initially thought that he would be able to recruit patients himself, but after much effort, he had only a handful of suitable candidates.<sup>59</sup> He needed only 20 subjects, but according to Teltscher "it became obvious to him that families were not willing to come forward, even to hear about the research."<sup>60</sup> The Head of the Department of Psychiatry, Dr Brian Davies, set out to remedy this situation. Teltscher had joined the department in the 1960s, and was involved in several research projects, one of which involved working with family members.<sup>61</sup> When Davies became aware of the difficulties Brackenridge was having recruiting subjects, he approached Teltscher to see if she would get involved. Soon afterwards, he appointed a psychiatrist, Dr Edmond Chiu, who, in 1972 had returned from studying in London. It was initially envisaged that Teltscher would find subjects and Chiu would conduct the clinical examination. When Chiu pointed out that he knew little of HD, Davies presciently replied: "If you don't know anything about HD now, you will by the time you've finished."<sup>62</sup> (p 177). Chiu was to become a world leader in the care of HD patients and their families.

Using some of Brothers' records as their starting point, Teltscher searched the mental hospitals<sup>63</sup> and launched an extensive media campaign, putting advertisements and stories about the research into city and suburban newspapers and organising TV interviews.<sup>64</sup> Teltscher and Chiu discussed the project widely with medical colleagues and, gradually, the research programme took off. By 1972 they had located 192 people with HD and a further

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<sup>59</sup> Ibid.

<sup>60</sup> Ibid.

<sup>61</sup> Brian Davies, "Chapter 1 Brian Davies," in *The Department of Psychiatry at the University of Melbourne 1969-2009*, ed. Edmond Chiu and Joy Preston, (Melbourne: Department of Psychiatry, University of Melbourne, 2010), 3-11.

<sup>62</sup> Chiu and Teltscher, "Huntington's Disease in the Department of Psychiatry," 169-79.

<sup>63</sup> Ibid.

<sup>64</sup> Interview with Betty Teltscher, 12 Jun, 2011.

370 with a 50/50 risk of developing it.<sup>65</sup> Once they began to hear the stories of these families, the entire team all felt that they could not use the families as research subjects without doing something to assist in their plight. In the words of Chiu, the idea “offended their ethical souls.”<sup>66</sup> (p 176) Thus the provision of coordinated, specialist care for families with HD began – the service offered “diagnosis, clinical care and genetic counseling.”<sup>67</sup> (p 3) The initial period involved listening to the family members to find out what it was that they needed. Over time, the team was “building up a picture of the fate of people who developed the symptoms of the disease” and they “tried to understand the social situation.”<sup>68</sup> (p 7) This approach, which was revolutionary at the time in respect to HD, was to have major consequences for the way the medical profession more broadly approached the disease. One highly influential event came in 1973 when Brackenridge’s funding was not renewed by the NH&MRC. This was a devastating time for all concerned: families’ hopes had been raised, and the possibility emerged that the research and all it involved would end.

In response, Davies suggested a meeting with all of the family members who had been involved, to give them a full report of the progress their collaborative efforts had made to date. Towards the end of 1973, 80-90 individuals came to the meeting room at the Royal Melbourne Hospital.<sup>69</sup> After giving their report, Teltscher and Chiu opened the meeting for questions and comments. Teltscher has reported on the high emotion which ran through this first meeting. She described how “Branches of families who had lost touch and some

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<sup>65</sup> Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care."

<sup>66</sup> Chiu and Teltscher, "Huntington's Disease in the Department of Psychiatry,"

<sup>67</sup> Teltscher, "History of Care in Huntington's Disease in Australia,"

<sup>68</sup> Teltscher, "Paper by Betty Teltscher."

<sup>69</sup> Chiu and Teltscher, "Huntington's Disease in the Department of Psychiatry,"

who had deliberately cut themselves adrift confronted one another.”<sup>70</sup> At the end of the meeting, a few volunteered to call another meeting where it would be formally resolved to create an Australian HD Association.<sup>71</sup> This association flourished in the years to come and there were strong connections between this patient group and the HD service.

In addition to meeting family members, Teltscher had travelled to the US where she met with Marjorie Guthrie. Teltscher described one of their early meetings: “We talked and talked and agreed, that at this stage our first priority was to give all families access to reliable information, both directly as a right to know and also through the medium of better-informed physicians.”<sup>72</sup> (p 5) Initially, the Melbourne service relied on brochures given to them by Guthrie which they modified for local relevance.<sup>73</sup> Teltscher traveled to the other side of the country where she met “the urbane” Milton Wexler, the other family member activist. In contrast to the efforts by Marjorie Guthrie’s efforts on meeting the needs of the families with HD, Wexler’s efforts were directed towards finding innovative ways of stimulating research into the disease.<sup>74</sup> Back in Australia, Chiu and Teltscher fused these two approaches into their service, working on research while looking for ways to help families manage the disease.

Teltscher recounted how as a response to listening to the needs of the families, the next two goals of the newly-formed HD service were the provision of accommodation and good

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<sup>70</sup> Ibid.

<sup>71</sup> Teltscher, "Paper by Betty Teltscher."

<sup>72</sup> Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care."

<sup>73</sup> Betty Teltscher, "Hd in Victoria: Personal Historical Overview," in *Australian Huntington's Disease Association* (Melbourne: 1997).

<sup>74</sup> Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care."

medical care. Families were extremely unhappy about the fact that the primary option for care outside the home was in mental institutions. Nursing home owners often rejected people with HD as a matter of course. In order to encourage them to take HD patients, Chiu promised to be available whenever needed. Chiu also opened a small specialist unit which was a converted part of a building in the grounds of one of the psychiatric hospitals, and it was here that staff members, including nurses and therapists, began to develop the “special skills they had to develop appropriate care”<sup>75</sup> (p 10) of HD patients.

Over the coming years, the HD clinic at the University of Melbourne expanded in its provision of services. The awareness-raising efforts of the team had a range of successful outcomes. After watching an interview on the current affairs show *This Day Tonight* in 1972, the philanthropist Jack Tomasetti became interested in the disease.<sup>76</sup> He funded a bus service for the Association, and many years later when he died, he made a substantial bequest which allowed the service to run a four bed residential facility for people with HD. Some years later, an Australian documentary film on HD, entitled *Something in the Family*<sup>77</sup> screened on national television, which resulted in even more interest in this disease.<sup>78</sup> The publicity attracted another benefactor: the Wesley Central Mission. This resulted in the funding of day and holiday programmes, the provision of respite and residential care and many other activities. Thanks to the efforts of many, but especially Chiu and the superintendent of

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<sup>75</sup> Ibid.

<sup>76</sup> Donna Robson, "Benchmark of Citizenship: Jack Tomasetti and the Huntington's Disease Community," *Philanthropy* (1995): 4-6.

<sup>77</sup> *Something in the Family*, Gordon Bick, Peter Dawes Smith, Producers, Yorkshire TV, Australian Broadcasting Corporation.

<sup>78</sup> Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care."

Wesley Central Mission Arthur Preston, an HD-specific residential home was eventually opened in 1981.<sup>79</sup>

In order to overcome the ignorance about the disease in medical circles, Chiu and Teltscher also set about increasing knowledge of HD in physicians. They firstly educated the GPs of their affected family members – giving information about the disease and also ideas on how to provide the best care.<sup>80</sup> They also introduced programmes in the Royal Melbourne and St Vincent's Hospitals where they “arranged for all undergraduates to meet someone with HD symptoms and the chance to hear people at risk “talking about their concerns.”<sup>81</sup> (p 12)

Teltscher reported how mutually beneficial this exercise was. The students began to understand their possible role in working with families with diseases for which there was no cure, and the families were keen to describe their experiences which had been hidden for so long. Another important development was the organisation of the first Australian HD conference, which took place in 1979. In keeping with the collaborative framework set up by the Melbourne group, the conference included contributions from the medical, allied health, scientific and lay organisations.<sup>82</sup>

The contribution of this group to the care of families with HD was not restricted to Australia. News of the workings of the Melbourne clinic reached the US, and Chiu was invited to assist in the development of a clinic at the Cardinal Cooke Hospital in New

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<sup>79</sup> Teltscher, "Paper by Betty Teltscher."

<sup>80</sup> Ibid.

<sup>81</sup> Ibid.

<sup>82</sup> AHDA, "Report on 1st Australian Huntington's Disease Conference" (paper presented at the 1st Australian Huntington's Disease Conference, Melbourne, 1979).

York.<sup>83</sup> Brackenridge died in 1981,<sup>84</sup> two years before a marker for the HD gene was identified. Recognition of the work of Teltscher and Chiu has come from multiple sources. Teltscher was appointed the President of the International Huntington's Association and was made a member of the Order of Australia (OAM) in 1980.<sup>85</sup> Chiu was given the same honour in 1988.<sup>86</sup>

Once the Victorian HD Association was established, the Melbourne group, especially Teltscher, traveled to other states to assist in the formation of Associations there. She also facilitated trips by Marjorie Guthrie who gave talks around the country. Other states followed in forming associations of their own: Western Australia in 1974, New South Wales in 1975, Queensland in 1976, Tasmania and South Australia in 1978. Some of these organizations have written brief accounts of their histories, though there has been no formal study of the early history of these organisations.

Teltscher described features she felt were unique to the Australian experience. She compared the origins of the patient organizations in different countries, contrasting the Victorian and Canadian experience. She reported that in Canada, it was mostly the work of one man, Ralph Walker, whereas "Here in Victoria our experience was very different. It was not as a result of one person's drive but a coming together of over 60 people united in their determination to change the way they were experiencing HD"<sup>87</sup> The decades of shame and isolation were coming to an end. As the rise in support groups for specific diseases over the past few

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<sup>83</sup> Teltscher, "Paper by Betty Teltscher."

<sup>84</sup> Chiu and Teltscher, "Huntington's Disease in the Department of Psychiatry,"

<sup>85</sup> Betty Teltscher, "Huntington's Disease. Some Recent Developments," *Australian Social Work* 34, no. 1 (1981): 33.

<sup>86</sup> Anonymous, "Lifeline. Edmond Chiu," *The Lancet* 355, no. 9212 (2000): 1378.

<sup>87</sup> Teltscher, "Paper by Betty Teltscher."

decades has shown, many people derive considerable consolation from the support of other people who are living with the same condition and experiencing similar problems. The stigma which characterised the condition, which had previously prevented them from receiving the support of others with similar concerns, was finally receding.

Although the Melbourne group was the first one to organize the provision of comprehensive care, other professionals working with HD families had sought to help in earlier times in previous decades. Teltscher noted Neville Parker's contributions in Queensland. In describing his 1958 journal article, she noted: "For the first time in Australia a paper touched on the need to help affected persons and their families."<sup>88</sup> (p 1) Parker also noted in his paper that he had sent all living relatives a letter from him and a pamphlet from the Minnesota Genetic Research Unit entitled "Huntington's Chorea and Your Family." While this would be viewed as an unethical breach of privacy by today's ethical standards, Parker was at least trying to give the families information about the condition, which was extremely difficult to access at the time.

#### **6.4 South Australia and the Point Macleay Aboriginal group**

In South Australia, a different story unfolded, and it was the work of two women, a geographer and a social worker, who were most influential in drawing attention to the existence of HD in an Aboriginal community and in the provision of services. As noted in Chapter 4, Fay Gale, a geographer, together with Henry Bennett, Professor of Genetics at

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<sup>88</sup> Teltscher, "History of Care in Huntington's Disease in Australia."

the University of Adelaide, published the first reports of HD in an indigenous community in Australia in 1969.<sup>89</sup>

Marjorie Angas (1919-1997), a social worker, was also involved in this research, and over the coming decades she worked extensively with South Australian HD families. Her initial contact with HD was through her role as a welfare officer for the South Australian Aborigines Department, which she commenced in 1957.<sup>90</sup> This role broadened to include all families with HD in South Australia, both indigenous and non-indigenous families. In addition to supporting families, Angas placed a high priority on providing education about the disease. In 1973, she produced a six-page “Confidential” summary of the disease for the benefit of staff members working for the Department for Community Welfare.<sup>91</sup> This included a summary of the main features of the disease, a description of services for affected families in Australia, and details of the “Huntington’s Chorea project” in South Australia. The main aims as outlined in the chapter headings were eugenics education, addressing the problems of crime and HD, the maintenance of records and the distribution of information.

Angas was involved in the production of an information brochure for general public consumption under the auspices of the South Australian Department of Community Welfare which contained much the same basic information about the disease as other populations, though with the addition of information about the indigenous population and the history of

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<sup>89</sup> Fay Gale and J H Bennett, "Huntington's Chorea in a South Australian Community of Aboriginal Descent," *Medical Journal of Australia* Sept 6 (1969): 482-84.

<sup>90</sup> Marjorie Alice Angas. <http://archives.samuseum.sa.gov.au/aa676/provlist.htm>. Accessed 14-10-2013.

<sup>91</sup> M. A. Angas, "Huntington's Chorea," ed. Department for Community Welfare (South Australia Department for Community Welfare, 1973).



the disease.<sup>92</sup> Lastly, she had an article published in the Aboriginal and Torres Strait Islander Health Care Worker journal, where she outlined the specific challenges of trying to assist Aboriginal Australians with the disease.<sup>93</sup> The issue of crime in the Aboriginal HD population was especially salient because of the media publicity given to a crime committed by an Aboriginal person with HD in 1970. According to Angas, the “sensational” media coverage “adversely affected the confidence and motivations of the whole Aboriginal group.”<sup>94</sup> Angas drew attention to the fact that HD was yet another of the diseases brought to the Aboriginal population by European settlement, a point also made by another counsellor working with HD families.<sup>95</sup>

## 6.5 HD, Disability and Stigmatised Identities

The similarities between HD and a range of other stigmatized identities is apparent from the common language shared by these groups. Variations on the term “Out of the Closet,” which are most usually associated with the gay rights movement, are employed regularly in describing the process of revealing the existence of the disease. In a 1981 booklet about HD published by the NSW HD Association, Phillips wrote: “HD has come out of the closet. Fewer and fewer people are making their lot even worse by denying the presence of the disease or attempting to hide from it.”<sup>96</sup> Websites abound with stories of people “coming out.” One person describing how her family had “come out” in 2013 met with a reply

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<sup>92</sup> Marjory Angas, "Huntington's Disease," ed. South Australian Department for Community Welfare (South Australian Department for Community Welfare, 1978).

<sup>93</sup> M. A. Angas, "Huntington's Disease," *Aboriginal and Islander Health Worker Journal* 5, no. 1 (1981): 16-19.

<sup>94</sup> Ibid.

<sup>95</sup> Koolmatrice, "Huntington's Disease and Aborigines," *Aboriginal and Islander Health Worker Journal* 11, no. 1 (1987): 39-40.

<sup>96</sup> Phillips, *Huntington's Disease* (HD Association (NSW), 1981).

stating: “No one should have to cope with HD in the family as if it were a dirty secret.”<sup>97</sup> The title of another recent blog post was: “One year out of the terrible, lonely Huntington’s disease closet.”<sup>98</sup> A recent article in the prestigious British journal *The Lancet* posed the question: “HD out of the closet?” Another common description contrasts the secrecy and darkness with openness and light – as noted in the introduction, the history of the Tasmanian Huntington’s Association is actually called “Out of the Darkness,”<sup>99</sup> the title also chosen for this dissertation.

Despite these similarities, there have been few attempts to examine the stigma attached to HD in relation to other areas of study which have focused on stigmatized identities, with the exception of Wexler, details of which were outlined in the literature review and the previous chapter. Two areas of comparison are the anti-psychiatry movement and the field of Disability Studies. The anti-psychiatry movement was at its most influential in the second half of the twentieth century, with prominent proponents including Thomas S. Szasz, Ronald D. Laing and Michel Foucault. Medical historian Roy Porter proposed that the movement had three main tenets: “mental illness was not an objective behavioural or biochemical phenomenon but a label; madness had a truth of its own; and under the right circumstances, psychotic madness could be a healing process and should not be pharmacologically suppressed.”<sup>100</sup> (p 522) Given the uncontested biological features of HD and its known genetic transmission, there is little wonder that this philosophy offered little to HD families struggling to deal with the relentlessly unfolding symptoms of the disease.

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<sup>97</sup> Hdmessageboard.com Accessed 6.2.2015.

<sup>98</sup> Curehd.blogspot.com/2013/11/one-year-out-of-the-terrible-lonely.html Accessed 6-2-2015.

<sup>99</sup> Elsie Targett, *Out of the Darkness*, 2nd ed. (Huntington's Disease Association (Tas.) Inc, 1998).

<sup>100</sup> Roy Porter, *The Greatest Benefit to Mankind : A Medical History of Humanity from Antiquity to the Present* (London: HarperCollins, 1997).

HD results in multiple disabilities: the movement disorder, cognitive decline, personality changes and psychiatric features are each disabling - and in combination even more so. Over the past few decades, the disability movement has focused popular and academic attention on various aspects of disability. Common subjects include analysis of the discrimination and stigmatisation many disabled people face, the negative portrayals of disability and the exclusion of disabled people from full participation in society. Disability Studies is now a common presence in academic institutions, with its own journals.<sup>101</sup> In their review of the state of disability history, Longmore and Umansky place disability rights as “the culmination of the civil rights era.”<sup>102</sup> (p 2) HD’s emergence from its hidden past in the 1960s and 1970s can be seen as part of this wider movement of individuals arguing for their rights to information and care. A high priority of both groups was addressing the shame and stigma that was commonly experienced in past generations. The use of a disability studies framework to analyse aspects of medical history has yielded significant insights.<sup>103</sup>

Given the multiple disabilities arising in Huntington’s Disease and the difficulties faced by Huntington’s families as a result of stigma, there is a surprising dearth of references to HD in the disability literature. An extensive search of various databases and books on disability found that only two disability scholars had specifically addressed the question of disability in relation to HD. One was the prominent disability activist Baron Thomas Shakespeare, the other was sociologist Colin Goble. One possible reason for this relative silence is the

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<sup>101</sup> Examples include *Disability and Health*, *Disability Studies Quarterly* and *Disability and Society*.

<sup>102</sup> Paul K. Longmore and Lauri Umansky, "Introduction: Disability History : From the Margins to the Mainstream," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky, (New York: New York University Press, 2001), 1-32.

<sup>103</sup> C. Kudlick, "Disability History: Why We Need Another "Other", " *American Historical Review* 108, no. 3 (2003): 763-93.

dominance of what has been called the “strong social model.” This movement focuses on the societal responses to disability and the problems these responses cause for disabled people, while minimizing or even denying the difficulties caused by the impairments themselves. In order to examine how the history of HD fits within the broader category of disability activism, a consideration of the similarities and differences between the two approaches is illuminating.

One of the major themes of the “strong social model” is the rejection of the emphasis on impairment and mistrust of the medicalisation of disability. Instead, the focus is on the attitudes and social conditions which prevent disabled people from fully participating in society. The most extreme version of this theory views disability solely as the consequence of society’s refusal to make the environment disability-friendly. A straightforward example is how the absence of wheelchair-enabling ramps and lifts precludes wheelchair users from participating in the wider society. The movement is highly skeptical of the search for medical cures and treatments for disabilities. In particular, many disability scholars are critical of genetic testing. Disability activists Erik Parens and Adrian Asch stated that many in the disability movement “believe that public support for prenatal diagnosis and abortion based on disability contravenes the movement's basic philosophy and goals.”<sup>104</sup>

By contrast, from the early 1970s, HD families have contributed towards medical research and many have embraced the possibilities offered by genetic testing, though this has proven to be a more complex arena than previously thought. Prior to the possibility of testing it was

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<sup>104</sup> Erik Parens and Adrienne Asch, "Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," *Mental Retardation and Developmental Disabilities Research Reviews* 9, no. 1 (2003): 40-47.

envisaged that most people would take advantage of this technology. In fact, of those at risk, the numbers undertaking genetic testing vary considerably in different regions, with different studies reporting the take-up rate ranging from 5% to 25%.<sup>105</sup> However, even if they choose not to be tested, there is no evidence of criticism from within the HD community of the fact that genetic testing is offered. After decades of neglect by medical professionals, family members have welcomed medical interest in the search for both greater understanding of the disease and potential treatments, and large numbers of individuals actively raise funds for research. As we have seen in the case of the Australian HD experience, it was close collaborations between researchers and HD family members which resulted in the situation improving for HD families. This collaboration has continued. Joint conferences between medical, scientific and patient organisations are the norm rather than the exception, with much cross-fertilization between the groups. Questioning the medicalisation of the disorder is absent in the HD community – any criticism is more likely to stem from families wanting more involvement of informed HD physicians.

The collaboration between physicians and HD families has been mutually beneficial. The formation of the patient organisations in the US encouraged researchers to consider non-medical aspects of the disease, which in turn influenced the allocation of resources. An example occurred as early as 1975, when an important paper by Stern and Eldridge appeared in the *Journal of Medical Genetics*.<sup>106</sup> The authors stated that Marjorie Guthrie had provided them access to patients and their families, who were then surveyed about their views on topics such as the information available to them, the importance of physical versus mental

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<sup>105</sup> Rhona Macleod and Aad Tibben, "Genetic Counselling and Testing," in *Huntington's Disease*, ed. Gillian Bates, Sarah Tabrizi, and Lesley Jones, (New York: Oxford University Press, 2014), 165-81.

<sup>106</sup> R Stern and R Eldridge, "Attitudes of Patients and Their Families to Huntington's Disease," *Journal of Medical Genetics* 12 (1975): 217-23.

symptoms and their reproductive decision-making processes. Without the patient organisation, this research would not have been possible. Most clinicians only see very small numbers of patients with the disease, and with this disparate clientele, research involving large samples of people would not have been possible without the assistance of the patient organisations. In turn, this inclusion of the patients' voice enabled the researchers to gain a deeper understanding of the disease.

Peter Harper, the HD geneticist with a long history of working with HD families, who has also written on the history of the disease, has also spoken of strength of the collaboration within the HD community, where:

well-defined research communities had grown up involving intense loyalties and close friendships between laboratory scientists, clinicians, and patients and family members. Such disease-based loyalties have proved remarkably strong and enduring.<sup>107</sup> (p375)

This is not to say that there have not been criticisms of the role of various physicians in relation to the disease, especially previously paternalistic attitudes which were outlined in discussions of medical responses to the disease and eugenics. People affected by HD also express a range of views regarding HD genetic testing and reproductive decision-making, many choosing not to utilize available technologies. Despite these criticisms, every person involved with HD I have come across holds out hope for a cure or treatments which would delay the onset of the disease. This is in stark contrast to the kind of disability activism which is skeptical of the search for medical cures and treatments for disabilities. HD families

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<sup>107</sup> Peter S. Harper, *A Short History of Medical Genetics* (Oxford ; New York: Oxford University Press, 2008).

recognize “impairment” - they know all too well the impact of the disease which is not due to “society” or “culture.”

Perhaps one reason why HD is so rarely mentioned in the disability literature is the emphasis of the “strong social model” on the social forces producing disability, combined with a deliberate negation of role of impairment. A representative example is given by Anne Borsay. In her review of the special edition of *Radical History Review* devoted to “Disability and History,” she praises the editors of the volume for their move “away from the disabled body to the conditions that produce disability: the vast web of social, political, economic, medical and legal forces that create material and virtual barriers for individuals with physical or cognitive impairment.”<sup>108</sup> (p 187)

In the case of HD, the “disabled body” is indeed the cause of significant difficulties both for the person themselves and family members caring for the person with HD, especially in later stages of the disease. The biological imperatives of HD – the gradual loss of control of movement, cognitive and behavioural changes, and the fact that it is eventually fatal – have meant that amongst HD families and activists, the question of “impairment” is not contested. While many disability activists have skirted this issue, Shakespeare is one of the few to address it head on, for which he has received extensive criticism. In his 2013 review of the state of disability studies, he commented on “the prevailing disability rights activists’ unwillingness to engage with the question of impairment.”<sup>109</sup> (p 139) Again, this is not to say that social forces are irrelevant, but that both impairment and disability need to be considered in some conditions, obviously so in HD. To paraphrase Wexler’s statement about

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<sup>108</sup> Anne Borsay, “Disability and History: A Special Issue of *Radical History Review*,” *Social History of Medicine* 20, no. 1 (2007): 186-88.

<sup>109</sup> Thomas William Shakespeare, *Disability Rights and Wrongs Revisited* (London: Routledge, 2013).

social contributions to the disease which opened the previous chapter, it is equally true that not all the misery of HD comes from the surrounding culture.

Another disability trope which is rejected by the “strong social model” is the idea that disability is “tragic.” There is an extensive literature on this subject – amongst others, the authors John Swain and Sally French have written extensively on this theme.<sup>110</sup> This school of thought questions “ablest” assumptions about disability, such as the idea that disabled people might accept their disabled identity and not seek a “cure” for their condition. Once again, medical conditions such as HD have been ignored by most disability scholars proposing this view, with two recent exceptions. Goble outlined the case of a woman with HD in her family. While acknowledging the social impediments to a better life, such as better access to services for patients and families, Goble also noted how ignoring the “tragic aspect of the disease” is “to ignore people’s lived experience, and thus to alienate them and render them irrelevant.”<sup>111</sup> (p 52) Shakespeare recently reviewed seven books on disability and attempted to sum up the state of disability scholarship. He specifically singled out HD as a condition which could well be classified as a “tragedy.”<sup>112</sup>

The accounts of living with HD as provided by HD family members certainly allow aspects of the disease to be seen as a “tragedy.” One woman interviewed for this research had spent over a decade caring for her husband who had HD (finding out it was in the family only after he was symptomatic), and she then faced the prospect of caring for both of her single sons in their 30s, one who was gene positive and the other who was already showing

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<sup>110</sup> Sally French and John Swain, *Whose Tragedy?: Towards a Personal Non-Tragedy View of Disability* (Sage, 2004).

<sup>111</sup> Colin Goble, "Controlling Life?" in *Controversial Issues in a Disabling Society*.ed. John Swain, Sally French, and Colin Cameron, (Philadelphia, PA: Open University Press, 2003), 45-53.

<sup>112</sup> Tom Shakespeare, "Disability Studies Today and Tomorrow," *Sociology of health & illness* 27, no. 1 (2005): 138-48.



symptoms. Despite this, as is the case with many people living with challenging conditions, many are determined to look for the positives of the disease. People talk of the importance of living their lives to the full. As noted in the introduction, HD has a wide range of presentations. For a small number of people, the disease has a very late onset, and the symptoms are relatively mild. At the opposite end, juvenile HD is an extremely challenging disease for the child concerned and distressing and devastating for their families. For the majority in the middle of these two extremes, many families would agree that some aspects of the disease can be seen as a “tragedy,” both for carers and those directly affected, and that it is the disease itself which causes most disruption for affected families.

In all of the cases described above, the differences between the two outlooks – “social model stalwarts” vs those living with HD, have been highlighted. Despite these differences, there are also many points of commonality. Although HD families on the whole did not reject “medicalisation,” there were certainly medical practices and aspects of medical thinking which the HD community did not feel well served by. These can be grouped into four main areas. First, family members wanted correct information from physicians who had a solid knowledge base about the disease. Numerous HD family members have referred to the absence of information about even the basics of the disease. In time HD activists, though the HD Associations took it upon themselves to produce literature not only for family members but for medical professionals as well. Taking control over the information presented allowed an alternative narrative to the vilified and stigmatised coverage of HD which characterised earlier medical publications on the disease.

Second, the families wanted the information provided about the disease to be delivered in a non-directive and non-judgmental fashion. As noted previously, it was an almost universal theme prior to the 1970s that it was the duty of the physician to persuade at-risk family members not to have children. Later, the principle of “non-directiveness” became the dominant paradigm amongst genetic counsellors.<sup>113</sup> Within this framework, the role of medical professionals, such as geneticists, psychiatrists, neurologists, genetic counsellors, GPs and other specialists was to advise clients of the medical information about the disease, estimate their risks etc, but not to give direct advice about the course of action the clients should take. In the recent past, many have questioned whether non-directiveness is ever achievable in reality. Even so, these critics still reject “the paternalistic and prescriptive approaches of the preceding generation.”<sup>114</sup> (p 26)

An example of the change in medical thinking is revealed in the advice contained in the *Merck Manuals*. In the section on HD, the 1950,<sup>115</sup> 1956,<sup>116</sup> 1966<sup>117</sup> and 1972<sup>118</sup> versions bluntly state under the subheading of “Prophylaxis, Prognosis and Treatment” that “Individuals with a family history of Huntington’s chorea should forego parenthood, perhaps by voluntary sterilization.”<sup>119</sup> (p 1346) By 1977, two slightly different emphases emerged. Under the section on the disease itself, the advice had changed slightly to “all

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<sup>113</sup> Alexandra Minna Stern, *Telling Genes: The Story of Genetic Counselling in America* (Baltimore: The Johns Hopkins University Press 2013).

<sup>114</sup> *Ibid.*

<sup>115</sup> Merck & Co., Merck Sharp & Dohme., and Merck Research Laboratories., "The Merck Manual of Diagnosis and Therapy," (Rahway, N.J.: Merck, 1950).

<sup>116</sup> Charles E. Lyght, *The Merck Manual of Diagnosis and Therapy*, 9th ed. (Rahway, N.J.: Merck, 1956)

<sup>117</sup> Charles E. Lyght, *The Merck Manual of Diagnosis and Therapy*, 11th ed. (Rahway, N.J.: Merck, 1966)

<sup>118</sup> D. N. Holvey and J. H. Taibott, *The Merck Manual of Diagnosis and Therapy*, 12th Ed. / by D.N. Holvey and J.H. Taibott. ed. ([S.l.]: Merck, 1972)

<sup>119</sup> *Ibid.*

potential carriers should be urged not to have children.”<sup>120</sup> (p1451) By contrast, the section on “Genetic Counselling in Hereditary Disorders” for the first time presented a more nuanced view of the difficulties encountered by those affected. After considering the dilemmas faced by family members, the authors recommended the far more empowering view: “Most physicians feel therefore, that all individuals at risk – all children and all siblings of an affected individual – should consider the possibility of not having children.”<sup>121</sup> (p 1099)

By the 1982 edition, the same advice was given under the section on genetic counselling, with the added proviso that “These are individual decisions, however, and the physician must not allow personal biases to intervene.”<sup>122</sup> (p 409) These different editions of this influential medical reference book clearly reflect the changing role of physicians. Changes in the popular sphere were also occurring. As early as 1970, the *Australian Women's Weekly* ran a report on a visiting American physician, and chose to highlight one of his intended messages: “Don’t be afraid to seek genetic counselling: it gives you a chance to make your own decisions.”<sup>123</sup>

Third, the families wanted an end to the hopelessness which had dominated the medical response to HD for the past century. In the absence of a cure, they wanted advice on the management of the symptoms of the disease and ongoing care by experts who knew and understood their difficulties. Once again, the professionals associated with the Melbourne clinic were pioneers in this respect. In describing the effects of this programme of

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<sup>120</sup> Robert Berkow and John H Talbott, *The Merck Manual of Diagnosis and Therapy*, 13th ed. (Rahway, N.J.: Merck, 1977).

<sup>121</sup> Ibid.

<sup>122</sup> Robert editor Berkow, *The Merck Manual*, 14th ed. ed. ([S.l.]: Merck Sharp & Dohme Research Laboratories, 1982).

<sup>123</sup> Kay Keavney, "Will the Baby Inherit Good Health," *Australian Women's Weekly*, 29 Apr 1970.

engagement of clinicians and patients, Teltscher noted how difficult it was for doctors when their role did not include curing or fixing a patient, the most pessimistic response being “therapeutic nihilism.” She noted how “no condition demonstrated as well as HD that there is a role and that is one of caring based on a wide ranging knowledge of the disease and an understanding of the changing needs of the whole family of which the affected member is a part.”<sup>124</sup> (p 13) Teltscher also highlighted the fact that many families felt abandoned once HD was diagnosed in a family member. She reported how non-HD-related medical conditions were ignored – in her words: “It was as if having HD meant that a patient had no right to appropriate care for a physical ailment.”<sup>125</sup> (p 9) She gave the example of a patient who was in the extremely early stages of HD, who had been admitted to hospital for a broken leg. Once the registrar found out the patient had HD, a transfer was organised to the psychiatric ward, despite the absence of any psychiatric symptoms. Even when challenged, his justification was: “But ... he’s got HD.”<sup>126</sup>

Last, the most notable similarity between the early HD pioneers and disability activists centres around shared attempts to destigmatise the respective conditions, challenging the previous narratives and replacing them with hope for the future. Regarding HD, there were several components of this destigmatisation process which began in the 1970s. People touched by HD had felt though shame – family members often hid people with the disease, and many ended their days in the back wards of mental asylums. In her groundbreaking and influential book, *Illness as Metaphor*, Susan Sontag drew attention to the emotional and cultural meanings associated with particular diseases, and the implications of these

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<sup>124</sup> Teltscher, "Paper by Betty Teltscher."

<sup>125</sup> Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care."

<sup>126</sup> Ibid.

“metaphors” or frames for people living with stigmatised conditions. As we have seen in this and the previous chapter, a diagnosis of HD carried with it more than just the label, and in many respects it was not treated as a “normal” disease.

In the words of one of the founders of the HD Association in Tasmania, “What we really hoped for was for people to accept HD as just another illness and to talk more freely about it, so that more people would come forward and give us a louder voice to the government of the day.”<sup>127</sup> Angas, addressing the complex situation of Aboriginal Australians with HD stated: “The folklore which has been developed about Huntington’s disease has been passed down to us over hundreds of years and it is frequently based on the values, morals, and customs of a particular period in history and has no scientific basis at all.”<sup>128</sup> (p 17)

Acknowledging the challenges ahead for HD Associations in 1981, Phillips stated that “we will never return to a past of ignorance, denial, superstition and fear.”<sup>129</sup> (p 27) Beginning in the 1970s, HD families wanted to end the kind of social exclusion and self-exclusion which often came with a diagnosis of HD. Many activists publicly identified with the disease, and it was hoped that exposure and education of the broader public would result in greater understanding and acceptance of HD. In fact, greater “awareness” remains one of the primary goals of HD activist groups in Australia and around the world.

Another related issue was the devaluing of people with HD once a diagnosis was made.

Many individuals with HD felt that they were seen only in terms of their disease, not as people first. This is an extremely common theme running through disability activism. As we

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<sup>127</sup> Targett, *Out of the Darkness*.

<sup>128</sup> Angas, "Huntington's Disease."

<sup>129</sup> Phillips, *Huntington's Disease*.

saw in the previous chapter, the eugenic project, like many divisive philosophies, created the impression that human beings were divisible into two groups. On the one side were the eugenic stock - the stable, hard-working, productive, able-bodied backbone of society. On the other were the dysgenic - the wandering, alcoholic, lazy, unproductive, mentally and physically ill and those with hereditary disease. This philosophy had significant ramifications – people classified as “the unfit” were considered as of less worth and it was therefore easier to ignore their needs. To ameliorate this situation, one of the goals of the Melbourne clinic was to help individuals and their families make the best of life with a chronic disease. The pessimism which marked the medical response to the disease was challenged by Chiu and Teltscher. In a later summary of what they achieved at the time, statements which seem so obvious now were startling to hear at the time. They needed to affirm that “People with HD can continue to achieve many satisfactions long after the disease is manifest.”<sup>130</sup> (p 25) and “HD family members will maintain a more positive view of themselves and life if appropriate care is available for their affected members throughout the progress of the disease.”<sup>131</sup> (p 25)

There are too many aspects of destigmatisation to comprehensively review here, but another important part of the story is that even in relatively well-adjusted HD families, many felt responsible for the disease in their midst. Once again, eugenic thinking encouraged the broader society to blame the “unfit” for their situation. In the quote which opened this chapter, Joyce Abblitt, who comes from a HD family which was relatively open about the disease, stated that: “The understanding that I was not alone and was in no way responsible

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<sup>130</sup> Teltscher, "History of Development of Care in Huntington's Disease and the Development of Philosophies of Care."

<sup>131</sup> Ibid.

for the devastation it causes came as a great relief to me.”<sup>132</sup> In South Australia, Angas sought to address the double stigmatization of Aboriginal people with HD. In an article written for health workers, she claimed that families were previously “punished” rather than “treated” for their disease.<sup>133</sup> Phillips also described the previous situation, stating that in the past, being diagnosed with HD was “to burden all those associated with it with a sense of absolute hopelessness.”<sup>134</sup> (p 26)

The creation of patient organisations and the changes they fought for challenged this narrative. A new narrative was created - one of hope – which was particularly emphasized by Teltscher in her reminiscences of her work in the 1970s.<sup>135</sup> The emergence of HD activism has not been studied in the academic literature or within disability studies. However, while not mentioning HD, the disability activist Bill Hughes has drawn attention to similar organisations, and argued that the disability movement has “bifurcated” into “Social model stalwarts” and “biological citizens.” Utilising the framework of Paul Rabinow who used the term “biosociality” to describe the process of biologically similar people coming together, Hughes next mentions the work of Nicholas Rose and Carlos Novas, who later termed this kind of activism “genetic citizenship.” Rose has argued that these groups challenged eugenic thinking and “demand civil and human rights of those whose lives, previously, were deemed less worthy of life.”<sup>136</sup> (cited in Hughes, page 679)

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<sup>132</sup> Abblitt, "Introduction,"

<sup>133</sup> Angas, "Huntington's Disease,"

<sup>134</sup> Phillips, *Huntington's Disease*.

<sup>135</sup> Teltscher, "Paper by Betty Teltscher."

<sup>136</sup> Bill Hughes, "Disability Activisms: Social Model Stalwarts and Biological Citizens," *Disability & Society* 24, no. 6 (2009): 677-88.

In this kind of “biological citizen activism”, individuals with a common disorder or genetic marker “assume that biology is an important basis for identity and collective activism.”<sup>137</sup> (p 679) This framework much better describes the kind of activism engaged in by HD families. This is in stark contrast to the “strong social model.” At the most radical end of this viewpoint are the groups, such as elements of the deaf community, who reject the notion that their condition be viewed as an illness. They prefer to label themselves as different, and reject the “ablism” which they feel renders them as lesser people because of this difference. HD activists could well be characterised as the diametric opposite – embracing the search for cures, collaboration with the medical establishment and accepting of the biological impairments which have such a profound effect on their lives. But they are disability activists, nonetheless, who have argued and succeeded in changing social responses to HD and in the process improving the lives for recent generations of HD families.

This chapter has focused attention on the role of stigma in suppressing knowledge of the disease. However, it is also important to acknowledge that other factors also play a part, and that this is not to argue that every person with HD should declare their health status to others. Regardless of the attitudes of the surrounding culture, there are many circumstances where disclosure of information about HD involves keeping information private. Two notable examples in the domestic sphere are when and how to tell children about the disease and when to disclose information to prospective partners. In the public sphere, genetic discrimination remains an issue, and therefore individuals will choose not to disclose information which may penalize them in employment, or in relation to financial matters such as insurance policies.

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<sup>137</sup> Ibid.



## 6.6 Conclusion

Awareness-raising has become one of the mantras of patient organisations in the 21<sup>st</sup> century medical landscape, but this concept is of particular significance for HD families. The move from the deep secrecy to open acknowledgment of the disease (at least in some quarters) over the past half-century has improved the lives of HD families enormously. In part due to the stigma which was previously so central to the HD experience, people felt the need to hide any reference to the possibility of a hereditary disease in their midst. Having noted the steady stream of references to eugenic pronouncements in popular culture in Chapter 5, in this chapter, the effect of this thinking on HD families has been described more explicitly, in particular the narrative of HD “Problem Families.”

After describing the way Marjorie Guthrie and Milton Wexler founded organisations which brought HD families together, the Australian experience was explored. In the state of Victoria, Australia, in the 1970s, a serendipitous set of events brought together four people with the wherewithal to offer real help and hope to HD families. Dr Brian Davies, the Head of the Department of Psychiatry at the University of Melbourne supported research, the keen young biochemist Colin Brackenridge wanted to test new pioneering genetic technologies, and social worker Betty Teltscher and psychiatrist Dr Edmond Chiu became passionate and tireless advocates for HD families and a service was born. The inclusion of a social worker in the provision of medical care also reflected changing medical practices. The combination of research and care offered both hope and help: hope for the future, through conducting studies into the disease, and help at a practical level such as providing accurate information, social support, treatment of psychiatric symptoms, rallying for appropriate

multi-disciplinary care and accommodation and assistance in the formation of the patient groups which have become such a feature of the 21st century medical landscape.

In the introduction to this thesis, it was noted that the kind of openness about HD in the second decade of the 21<sup>st</sup> century would have been unimaginable in the 1970s. This seismic shift began when families became involved in the research project, were listened to by medical professionals and started to exchange details of their experiences. In the process, they took the opportunity to end the decades of secrecy, isolation and shame. While not necessarily recognizing themselves as “disability activists” and part of a broader social movement, HD families and some members of the medical professionals working with them helped to bring about enduring and life-altering changes not only for the families affected by HD, but for the broader community as well.

Raising awareness of HD has allowed for a closer examination of the complex disabilities of HD, which has then encouraged a range of improvements. Individuals and families now have ready access to a vast array of information about the disease. They have the support of other families dealing with the disease and a range of professionals who have expert knowledge. Families continue to be part of the numerous research projects searching for cures and treatments and research aiming to improve the lives of HD families. This chapter has told the story of some of these courageous individuals who swam against the tide, challenging the stigma of HD by “coming out of the closet.”

## 7. CONCLUSION

I had my own strong emotional reactions when I first came across a person with Huntington's disease in 1993 at the now defunct Lidcombe Hospital, which at the time was the centre of HD services in the Australian state of NSW. As a new graduate in my first job as a neuropsychologist, I was involved in a programme which offered predictive testing for people with the disease. The exact location of the HD gene had not yet been isolated, but a marker for the gene had been found. Testing based on the gene marker did not provide the level of certainty of current testing regimes, but nevertheless allowed much better prediction than had been possible in the past. This genetic testing was supplemented with a neurological examination and cognitive testing, and neuropsychologists administered a range of tasks to help determine whether there were early signs of the disease.

In one such session, a genial, tall, solid man had come in for his predictive testing session. We went through the niceties of introducing ourselves, and the assessment began. Early on, I saw that he was shaking as he performed one of the tests – moving blocks around to make patterns. Even to my untrained eye, this was not the chorea of HD - it was the trembling of anxiety. Over the years, I have become used to people having strong reactions when their cognition is being assessed, but the intensity in this man pointed to what was at stake and highlighted the seriousness of this disease. Not long after, out of the blue, I came across a television programme about the discovery of the HD gene in the large Venezuelan kindred. I have since worked clinically with several HD families. For me, the disease evoked wonder: I tried to imagine how people live with such a challenging disease. Anyone who knows HD

families sees that, in addition to those who struggle under its terrible weight, many others show the most extraordinary resilience. In looking into the history of HD, the fact that people in the past had to deal not only with the symptoms, but with the additional intense stigma and shame, seemed doubly unfair. I then wondered how HD had changed from being a deeply stigmatised and hidden condition into a disease which is now discussed so openly by at least some individuals and families - a dramatic transition that has occurred in just a few decades.

The social history of medicine is more nebulous than other forms of historical enquiry – the experiences of patients throughout history are difficult to reconstruct retrospectively.

Attitudes to disease in the past are difficult to gauge. In a condition like Huntington's disease, the challenge is especially apparent, considering the fact that it was shrouded in deep secrecy for much of the twentieth century. Medical histories frequently focus on topics such as scientific breakthroughs, the progress in our understanding of diseases, and the lives of the physicians who have researched and treated them. In this dissertation, I have utilised both kinds of historical enquiry - social history *and* medical history - to shed light on aspects of the broader history of HD, particularly in Australia, a topic which has been minimally explored in the academic literature thus far.

To answer the different kinds of questions posed in each chapter, I made use of a range of diverse historical methods and sources. Despite my dogged search, no “treasure trove” of information on HD in Australia emerged. In the absence of physicians' case books or diaries of HD family members, the history I have presented in this dissertation has gradually emerged from the myriad small details I managed to gather over many years. Family histories

in which HD played a role, in particular the Tasmanian family book (although the disease was not mentioned in it), yielded much information, which I subsequently verified and further explored by traditional genealogical sources such as online genealogy sites, birth, death and marriage certificates, and newspaper articles.

A novel technique I employed was to consult early medical publications which included initials of HD patients. I then used this scant information to search asylum and mental health archives. This yielded information on two fronts. Firstly, this was a rich source of social history, revealing details of individuals with HD who ended up in mental hospitals and also provided biographical details of their families. It also shed light on the responses of the medical profession to the disease, and the interplay between the two. The National Library of Australia online newspaper database was the cornerstone of my research on eugenics in the popular press. I explored the lives of physicians through obituaries, family histories and other records. My understanding of the issues was deepened by interviews with HD family members and the health professionals who worked with them in the 1970s, and by the early writings of the Australian HD Associations. Papers of talks given by Betty Teltscher about the birth of the Melbourne HD clinic, and interviews with her and Edmond Chiu were invaluable in describing their early, pioneering years. In this research I was also able to answer many questions about the history of the disease by consulting people who had begun to research their own family history, using this as a springboard for further genealogical studies.

In every chapter of this thesis, the Tasmanian family have figured to some extent. Brothers' work on this family was first noted because he compiled one of the early extensive surveys

of the disease in a specific geographical area. Attention was then drawn to the high prevalence of the disease in Tasmania. More recently, Brothers' research is used in genetics textbooks as example of the "founder effect." Just as Wexler used the work of Elizabeth Muncey to shed light on social aspects of the disease, I was able to find evidence of many individuals from HD families who were well accepted in their community in nineteenth century Tasmania.

I am not alone in being fascinated by the history of this disease – this searching for HD's past has proven to be a compelling quest both for family members and medical specialists writing on the disease. Despite this enthusiasm, only a limited range of subjects within its history have been explored to date, and previous historical enquiry has focussed on the northern hemisphere, primarily the United States. The symptoms of the disease frequently evoke strong reactions in people, especially when they first encounter the unexpected movements of a person with chorea. The dramatic features of the disease have probably contributed to the emphasis on dramatic historical epochs in the histories of HD - the "dancing manias" and links with "witchcraft." Usually staid medical publications have used highly emotional language in describing the disease and have linked it with these dramatic eras in human history, often with the flimsiest of evidence, or frankly incorrect information.

In reviewing the literature on the history of the disease, it was notable how many researchers have simply repeated older sources without verifying this information. This has resulted in the repetition of fallacious information. One such trivial example is the fact that so many people call George Huntington "George Sumner Huntington," who was, in fact, a contemporaneous but altogether different physician. This error was first made in 1957 by

neurologist Russell de Jong, and is being repeated to this day. The same applies to references to the dancing manias and witchcraft accusations – they are restated without scrutiny or even any acknowledgement that the evidence supporting these claims is contentious. These claims have both been found wanting when they were subjected to more detailed examination.

Another error was the often repeated claim of a prevalence rate in Tasmania of 17.4 per 100,000 – in this thesis the origins of this error was found to be the pioneering HD physician Brothers himself through personal letters he wrote to other researchers.

Parts of this thesis have built on the pioneering work of Alice Wexler and Peter Harper, using their research as a springboard for a broader analysis of some issues and a widening of their research beyond the Northern Hemisphere. Other aspects of my research are original. The early history and medical response to the disease in Australia have not been studied in the academic literature; in my research I gathered data from a wide range of sources to answer both straightforward and more complex questions about the unfolding of the disease in this country. Using information from families who have attempted to find out the source of HD in their midst and the medical publications of physicians, I have been able to demonstrate that HD has been in this country since the very early days of European settlement and that HD's history parallels that of the rest of the country. This extends to the tragic effect Europeans have had on the indigenous population – HD is yet another of the diseases introduced by Europeans to indigenous communities. One of the erroneous and often-repeated but not scrutinised claims is that the origin of the disease in Australia was the Tasmanian family which arrived in 1842, and that there were no convicts with the disease. My research has shown that this was not the case. Indeed, in Chapter 3 I present evidence of

multiple families coming to Australia with the disease from the beginning of European settlement, some from convict families who nevertheless went on to lead prosperous lives.

Based on the medical publications of physicians and family histories collected by HD family members, I have been able to trace the fate of people with the disease before it was recognised as a medical entity. In Australia in the nineteenth century, many families with individuals affected by HD were well thought of in their communities. They may well have endured stigmatisation to some extent; however this was not the most important element in the stories about them that have survived in the historical record. There were stories of convicts made good, and admittedly one who went on to commit more crimes. In the Tasmanian kindreds I traced most extensively, the many branches of the families were consistently characterised by reference to their hard work and contribution to the community. I have presented numerous examples of contemporaneous records, such as obituaries in local newspapers, indicating respect, warmth and sympathy for the families. Even when the disease must have been recognised as hereditary, this did not prevent family members from getting married and taking up responsible positions in their communities. They were elected to local offices and headed sporting organisations. The idea that the disease itself is solely responsible for the stigma, rather than being influenced by external social forces, is not supported by the stories of the families I described in Chapter 3. My findings have strong parallels with those of Wexler in her American study.

In an uncanny parallel with George Huntington in the US, the two primary writers and researchers of HD in Australia in the first half of the twentieth century, psychiatrists Charles Brothers and Charles Hogg, both grew up in areas where HD was relatively common. In



Australia, both physicians, decades apart, were born in an area of Tasmania with a high prevalence of HD. In the case of Brothers, it is acknowledged that he had numerous contacts with HD families. In the case of Hogg, the evidence is circumstantial but convincing. His grandfather and other relatives were local physicians. These men, Brothers and Hogg, were later in positions of authority, respectively as deputy-directors and director of mental health services in Victoria and NSW. Neither pushed the eugenic cause in relation to HD although they were in a position where they could have done so. This reinforces the idea that exposure to people living with potentially stigmatised conditions like HD can lead to a reduction in stigma and an absence of the vilifying narratives of others writing on the disease.

Given the emphasis on the dramatic historical eras of the “dancing manias” and “witchcraft” accusations, the ongoing silence and minimal acknowledgement of another recent significant epoch is especially surprising. In the past thirty years, only two scholars of HD’s history have written about the influence of eugenics in the early to mid twentieth century. The period between Huntington’s identification of the disease and the genetic discoveries of 1983 and 1993 has generally been described by historians of the disease as “quiescent.” Yet in the twentieth century, up to the 1970s, eugenic philosophies shaped reactions to the disease, contributing to the disease becoming deeply stigmatised, which persisted long after eugenics itself fell from favour. In Nazi legislation HD was specifically named and targeted for eugenic measures, and unknown numbers were sent to hereditary courts by their physicians, sterilized and even exterminated in the infamous T4 programme. Although the stigma surrounding HD was mentioned liberally in medical articles about the disease, the factors contributing to this stigma and secrecy have remained unexplored terrain until the work of

Harper and Wexler. These two historians have been writing about various aspects of the social history of the disease since the 1990s; however they have not been joined by other scholars in their exploration of the influence of eugenics on attitudes towards HD.

In this thesis, amongst other things, I have shown that, in Australia, a country far removed from the main eugenic centres of the USA, Britain and Germany, eugenic thinking played an important role in the exacerbation of stigma for HD families as well. In my analysis, I extended the work of Harper and Wexler in examining stigma creation amongst early eugenicists and documenting their interest in HD. I argued, by reference to the work of Sir Francis Galton and later proponents of eugenics, that the creation of stigma was one of the primary goals and in fact one of the major successes of eugenics. Early eugenicists were interested in HD because of its dramatic symptoms and because it was the first “mental disease” shown to be incontestably hereditary, making it a perfect template for the eugenic enterprise more broadly.

Building on Wexler’s work, I described how writers on HD were influenced by eugenic thinking. In particular, I described how they transferred the eugenic narratives of problem families, who needed to have their reproductive choices controlled, to HD families, both in Australia and more generally. Families with HD were characterised as consisting of drunks, vagabonds, criminals, and alcoholics. I argued that, in Australia, although there were many proponents of eugenics amongst the medical profession and eugenic arguments permeated the international HD literature, another potent influence was the widespread dissemination of eugenic ideas in the community. Talk of compulsory sterilisation, marriage restrictions, segregation and “the creation of a eugenic conscience in the population” were common in

the Australian press, bringing eugenics into the home. Diana Wyndham had already explored the role of one adult education organisation, the Workers' Educational Association (WEA), in providing a platform for eugenic ideas.<sup>1</sup> I found further evidence of the links between WEA and eugenics, and also another source, previously undiscovered, the Army Education Service, where eugenic ideas were presented to potentially hundreds of thousands of service people.

My research has also offered insights into the changing role of medical professionals in the management of chronic disease. Throughout the twentieth century, the fact that HD was incurable and untreatable made it difficult for physicians to know what they could do to help families. When they looked to the medical literature, the information they encountered on HD “problem families” likely encouraged them to turn away from these difficult patients. Consulting the *Merk Manual*, a standard reference book for general practitioners at the time, the primary suggestion on managing these patients was to tell them and their families not to have children. A common recourse was to turn away from the disease, leaving families to struggle alone with the management of the complex physical and psychological symptoms.

Into this breach stepped the founders of the Melbourne clinic, who were instrumental in bringing about enormous changes in HD care in Australia, starting in the early 1970s. Initially recruited to help find participants for a study into genetic markers for the disease, these clinicians were moved by the challenges HD families faced, and set about finding ways to help them. The first step in this process was to listen to patients to find out what their needs were, rather than expecting to have all the answers themselves. Having established

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<sup>1</sup> Diana Wyndham, *Eugenics in Australia: Striving for National Fitness* (London: Galton Institute, 2003).

what the problems were, they set about finding ways to ameliorate the situation, educating the family's GPs about the disease, educating medical students, providing families with accurate information and offering treatment of the psychological symptoms. The isolation patients felt and the enormous stigma around HD was lessened by both the engagement with health services, and the formation of patient groups, which came together as active participants who had a role to play in making life better for HD families. These groups viewed medical research into the disease as a crucial part of this process, particularly because of the hope it offered for the development of future treatments and ultimately a cure.

The relationship between disability and HD has been touched on in various ways by Wexler. In this thesis I have further explored these questions. Despite having significant points of difference to the "strong social model" branch of disability activism which shies away from notions of impairment, I have shown that HD families had much in common with other stigmatised minorities, especially those with other disabilities. The devaluing of people with stigmatised conditions, the encouragement of divisions between the normal and abnormal, the "us" versus the "them," the "fit" and the "unfit" are common threads. The common language used by stigmatised groups is a case in point. When people with HD began to emerge from the "closet," they also talked of emerging "Out of the Darkness." Rather than opposing medical involvement in their condition, HD families generally welcomed it. Having been ignored and been effectively told that nothing could be done, they welcomed the information about the disease, suggestions for management and the ability to participate in the research into the disease which was offered by the medical profession. This was in stark contrast to the kind of anti-medicine views of both the anti-psychiatry movement, and disability activists embracing the strong social model. In Australia, this point was brought

home even more starkly, as the catalyst for the beginning of care for HD families began with a research study conducted through a university psychiatry clinic.

The findings presented in this dissertation point the way to further research. My research ended in the developments of the early 1970s. It would be fascinating to find out more about the family members and health professionals who began the HD Associations in each Australian state. Many of these groups have kept records and, given the ages of these founders, interviews sooner rather than later might prevent these stories being lost forever. A comparison between the development of the HD Associations with other patient organisations might also be instructive. My research briefly explored the medical response to eugenics in Australia. While some aspects of this history have been written, a more comprehensive account of the varying responses of physicians and their professional organisations to eugenics would shed light on the movement more broadly.

Ironically, the eugenics movement itself has itself become deeply stigmatised, and, like HD, it has a history which has been actively suppressed. References to physicians' involvement in eugenics have been omitted from biographies. The fact that a history has been suppressed is a hint that it may have something to teach us about the past, and that in itself makes a deeper analysis of the history of eugenics worthy of more investigation. Regarding eugenics more broadly, and in particular its popularisation, I found references to the Army Education Service in an isolated pamphlet located in the Royal Australian College of Physicians library. This allowed further investigations of their journal, resulting in the material presented in Chapter 5. Who knows what kind of material might be present in uncatalogued library

archives across the country which might further illuminate the reach of eugenics into the popular culture?

Another potential area of enquiry is further analysis of the causes of stigma in relation to disability more broadly and HD in particular. Disability historian Baron Thomas Shakespeare has considered this question, and posited that fear of mortality is behind much of the fear of disability. I have argued that physicians frequently let their own emotional reaction to the disease colour their depiction of it in their writings on the disease. As a health professional myself, one salutary lesson from this research is the importance of considering the language we use when we describe disease and the importance of self-reflection in examining our own emotional responses. From the perspective of a different disability, in the blunt words of a father writing on his life with his son, there is a vast difference between the description of a “mongoloid idiot” and a person with Down’s syndrome.<sup>2</sup> Especially in this age, where patients and their families have ready access to medical publications, it would benefit families if professionals were more attentive to the possible effect of their words. I am not arguing for a punitive kind of self-censorship, but only for a thoughtful use of the language we choose to use. As we have seen throughout this dissertation, HD evokes strong reactions in those who come across it, and physicians are not immune to these reactions. Familiarity through exposure to the experience of the families living with diseases offers health specialists the possibility of coming to terms with their own emotional responses.

While much of the stigma and shame faced by HD families has diminished, it has certainly not disappeared. This history of the disease has shown how dramatically attitudes can change

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<sup>2</sup> Michael Bérubé, *Life as We Know It : A Father, a Family, and an Exceptional Child*, 1st ed. (New York: Pantheon Books, 1996).

over short periods of time. The philosopher Martha Nussbaum suggested in an interview that we view the human condition more as a plant than a jewel, “something rather fragile, but whose very particular beauty is inseparable from its fragility.”<sup>3</sup> Huntington’s disease reminds us in a deep way of the fragility of life. Although as human beings, we strive to control our environment, some things, like death and disease, are ultimately beyond our control. Some diseases are particularly prone to reminding us this fact, especially those which involve the changing of our identity and the loss of independence. But we can choose how to respond to these reminders.

In this dissertation, different ways of responding to reminders of our own mortality, and to the inevitable fragility of life, have been described. In the nineteenth century, in several families living with HD, the struggles of earlier pioneer life overshadowed the presence of a hereditary disease. In the twentieth century, eugenic thinking encouraged us to reject the reminder and to recoil from and vilify the messengers. Disability activists, including medical professionals and those early HD pioneers, have reminded us of the importance of focussing on the humanity of the people with diseases. Facing these reminders of our fragility head on, and trying to alleviate suffering, rather than adding to it, has meant a huge improvement for families living with this still tragic and challenging disease. HD families remind us that many kinds of lives are worth living, and that when we devalue difference, dividing the world into “us” vs “them”, we can add immeasurably to people’s suffering. Yet, we also have the ability to reduce suffering and mental anguish by affirming that all individuals belong within our circle of humanity. One of the moral lessons which can be taken from this history is the importance of empathy and compassion to a civilised life. Not all diseases can be cured, but

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<sup>3</sup> <https://understandingsocialtrust.wordpress.com/2014/03/27/martha-nussbaum-on-cosmopolitan-trust>. Accessed 31 Jan 2015.

life can be made more liveable when we accept disability and fragility as a central part of the human condition.



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# *Family Detectives Wanted*



## *HD in Australia: a Social History*

I am a neuropsychologist doing research into the social history of Huntington's Disease (HD) in Australia as part of a postgraduate thesis through the Unit for the History and Philosophy of Science at the University of Sydney, under the supervision of Dr Hans Pols.

In addition to looking at the history of HD from the perspective of the doctors and researchers who have written about it, we want to find more about how families thought about and managed HD prior to the formation of the state HD Associations in the 1970s. What difficulties did families face? What kind of discrimination did they experience? What support was available? How did the wider community react to families affected by HD?

The project will explore the way HD was described in the medical literature, but we also want to learn more about the experiences of people with HD. One method is to look through medical records of those who were admitted to mental health facilities. The earliest arrival we know of is 1842, but perhaps there were others earlier.

We can do some of the research from currently published sources, but in order to more fully explore the past experiences of HD families, we need to find out who the people were. If you have looked into your family history, or would be happy for me to help trace your family's HD background, we would greatly appreciate hearing from you.

Privacy concerns are extremely important in this project, and when this information is collated, no names or other identifying information will be published. We will not be collecting information on any living person without their written permission.

**If you would like to help out with this research, or would like to find out more, please contact Therese Alting by:**

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After you contact me, I will send out an Information Sheet and Consent form if you wish to be involved. Thanks for your interest.

*Therese Alting*