

APPENDIX 4 LETTERS AND INFORMATION RECEIVED

Table 11 : Affinity Diagram**Description**

A way to assist identification of broad themes or "headings" by individuals repeatedly sorting a common set of cards on which they have written their ideas.

Use when you want to

Clarify the situation when the team is addressing many issues or ideas;
Allow breakthrough thinking; and
Produce order from chaos.

Steps

1. Each member list a standard number of issues to address (one per card);
2. Cards are placed in general view; and
3. In rotation, members (two at a time) group cards on similar issues.

Tips

- * Keep the team small;
- * Use "post it" notes to keep it simple;
- * Insist on silence when members are sorting;
- * Keep the process moving; and
- * Keep the number of headings small.

Source: Westmead Hospital Handout for Quality Project Teams.

Dr: Akram Almasri
P.O.Box 508
Lakemba 2195
N.S.W Australia

Date: 23/03/1995

Dr: Brian Redmayne
Director of Dental Services
Central Coast Area Health Service
P.O.Box 361
Gosford 2250

Dear Dr Redmayne,

My name is Akram Almasri, a MDSc candidate at the University of Sydney, and I am writing to seek your assistance with a research project entitled "Provision of Dental Services for Children with Down Syndrome in NSW. The aims of the study are:

1. Update existing data on dental services to children with Down Syndrome in NSW.
2. To determine the type of services provided to them.
3. To gather data for future planning of dental services.

It would be most appreciated, if you or your colleague(s) can provide me with:

1. How many children (age 0 to 14) with Down Syndrome had used the public dental service in your area for the last two years?
2. What type of treatment is offered to them?
3. If they need specialist services to where do you refer them?
A) Within your service?
B) External to your service.
4. Do you register or have a separate list of Down Syndrome patients ?

The return of this essential data by the end of April 1995, will enable an early analysis of the public dental services for children with Down Syndrome in Australia.

I look forward to hearing from you and thank you very much, in advance, for your kind co-operation.

With best regards.

Yours sincerely,

Akram Almasri

EASTERN SYDNEY AREA HEALTH SERVICE

DEPARTMENT OF HEALTH, NSW
DENTAL SERVICES



DACEYVILLE SCHOOL DENTAL
CLINIC, DACEYVILLE 2032.

Dr. Akram Almasri
P.O. Box: 436
Lakemba 2195.



Dear Dr. Almasri,

The children seen by the School Dental Service in our Area who are afflicted with Downes Syndrome are fairly rare. During the past year there would have been approximately seven or eight cases. Most of these are our regular patients and are those with mild to moderate symptoms. The more severely affected who require a General Anaesthetic are referred privately or to the Dental Hospital, as we do not have facilities to undertake these procedures.

We have three Clinics and two Mobile Vans in our Area and while all would be capable of treatment of the above, most of the work is done at the Daceyville Clinic.

Hope the above information will be of some help with your thesis.

Yours Sincerely.

Albert Cusick.
Area Dental Officer.

HUNTER REGION DEVELOPMENTAL DISABILITY SERVICE
Department of Community Services

STOCKTON CENTRE
Fullerton Street
STOCKTON 2295

TE NO.: (049) 28 0800

ADMINISTRATION
FAX NO.: (049) 28 3042

TO: DR. AKRAM ALMASRI		The confidentiality of information contained within this facsimile transmission may be protected by statute. Unauthorised disclosure or misuse of such confidential information obtained as a result of mistaken transmission may incur a liability for criminal penalty. Information contained within this facsimile transmission is intended only for use of the abovenamed recipient. Any other recipient is requested to immediately notify the Department by telephone so that arrangements can be made for return of the transmission to the Department.
REF NO.: 02 - 7508313		
FROM: PER HOLMBERG		
DATE: 19.8.94	NO. OF PAGES FOLLOWING: 1	

MESSAGE:

Attention DR. AKRAM Almasri
Re. Dental Data.



NSW DEPARTMENT OF
COMMUNITY SERVICES

HUNTER REGION
DEVELOPMENTAL DISABILITY SERVICE

DR AKRAM ALMASRI
PO BOX 463,
WAKEMBA
2195

Stockton CENTRE

Fullerton Road, ...

Stockton 2295
OUR REFERENCE:

YOUR REFERENCE:

TELEPHONE: ... (049) 280 912

FAX No. (049) 283 042

Dear Dr Almasri,

Regarding your request concerning treatment of patients with Down's Syndrome in the Hunter Area Health Service, Mr Wright asked me to give you some information.

There is no data how many patients with D.S are living in this area or how many having Dental treatment. However, everyone that is turning up at school and Community Dental Clinics are treated, if necessary under G.A.

The main institution for mentally disabled is Stockton Centre, where we have 54 Clients with D.S of a total number of 750. All are receiving comprehensive treatment.

Marrickville School Dental Clinic

Thompson ST
Marrickville 2204
P.H 560 0828

14/9/94

B

Dr: Akram Almasri
P.O.Box 436
Lakemba 2195
N.S.W

Date: 8/9/1994

Dr: Rathi Selvarajah
Team leader Dental Services
Central Sydney Area Health Service
Marrickville School Dental Clinic
Thompson Street
Marrickville 2204

Dear Dr Selvarajah

I am writing to you since my last letter on 01/08/94 requesting some information about the dental services in your area. I am a post graduate student doing Diploma in Public Health Dentistry at University of Sydney.

What is the nature of my thesis and how will this information be used.

The thesis is a partial requirement for the Diploma in Public Health Dentistry which I am doing and the information will be used only for this purpose.

What type of data I am requesting.

The type of data I am requesting like Sex, Number of visits, Referred by whom, Are they under dental cover, What type of dental service they had.

What age range is covered by the term 'children'

The age range requested from (0 to 14).

What period of time is this data to cover.

The period of time is this data to cover from (1990 to 1994).

I would appreciate your assistance.

21/9/94

Yours Sincerely

Akram Almasri

19/9/94

Dear Mr. Almasri, I did not receive your last letter dated 11/8/94. I could not phone you as you did not leave a telephone contact number. Please ring me on 11/9/94.

Dr Caroline Hong
Area Co-ordinator
Area Dental Services
Level 2, Vindin House
Royal North Shore Hospital
ST LEONARDS NSW 2065

Ref: Almasri

Tel: (02) 438 8217
Fax: (02) 906 6174

14th September, 1994

19/9/94

Dr. Akram Almasri
P.O. Box 436
LAKEMBA 2195

6

Dear Dr. Almasri,

I refer to your request for information relating to your Diploma in Public Health.

The Northern Sydney Area Health Service and most other Area Health Services have been collecting Dental Management Information System (DMIS) since 1991. The data is processed at the New South Wales Department of Health and reports are generated by the Dental Branch.

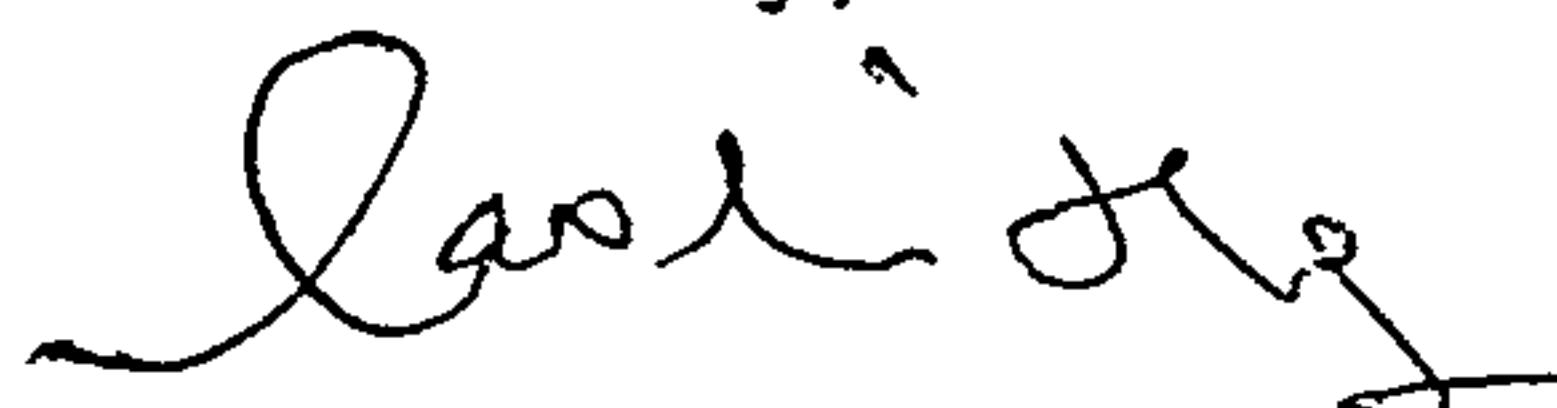
The data collected is voluminous. May I suggest that you contact:

Mr. Michael Jacobi, DMIS Manager
Dental Branch
NSW Department of Health
Level 5, 73, Miller Street
NORTH SYDNEY 2060

Tel: 391-9384 Fax: 391-9832

It would be useful if you make an appointment to see Michael as there are all kinds of data and reports available, which you may require permission to use in your studies.

Yours sincerely,



Dr. Caroline Hong,
Area Coordinator - Dental Services,
Northern Sydney Area Health Service.

F

INCORPORATING:

The Hospitals & Community Health Services of Gladesville-Macquarie, Hornsby Ku-ring-gai, Manly, Mona Vale, Royal North Shore and Ryde

ASSOCIATION WITH:

Centre for Bone & Joint Diseases, Homes of Peace Facilities - Greenwich & Neringah Hospitals & Graythwaite Nursing Home; Royal Rehabilitation Centre, Sydney and St Catherine's Villa

8/8/94

F

Royal north shore Hospital
and community health services
ST Leonards Sydney 2065

Return to →

Dr: Akram Almasri
P.O.Box: 436
Lakemba 2195
N.S.W Australia
Fax: (02) 750-8313

Date: 01/08/1994

6

Northern Metropolitan Sector
Chatswood Assessment Centre

Dear Sir/Madam

I am a postgraduate student doing Diploma in Public Health Dentistry at University of Sydney. As apart of my course is to do thesis. My thesis is A Provision of Dental Services for children with Down Syndrome.

To complete my thesis I need some information about this Syndrome How many children with Down Syndrome in N.S.W Has been registered through your department.

I thanking you in anticipation, since those information will be of great assistance in preparing my thesis.

Yours Sincerely

A. almasri

Akram Almasri

This information is protected by privacy laws
I suggest you contact the Down Syndrome Assoc



Service Director



8



ST. George Hospital
and community health
service
Kogarah 2217

The St. George Hospital

Our Reference:

Your Reference:

Writer's Direct Tel:

Writer's Fax No.:

24 August 1994

Gray Street
Kogarah NSW 2217
Australia
Telephone: (02) 350 1111

Dr Akram Almasri
PO Box 436
LAKEMBA NSW 2195

Dear Dr Akram

Re: Down's Syndrome

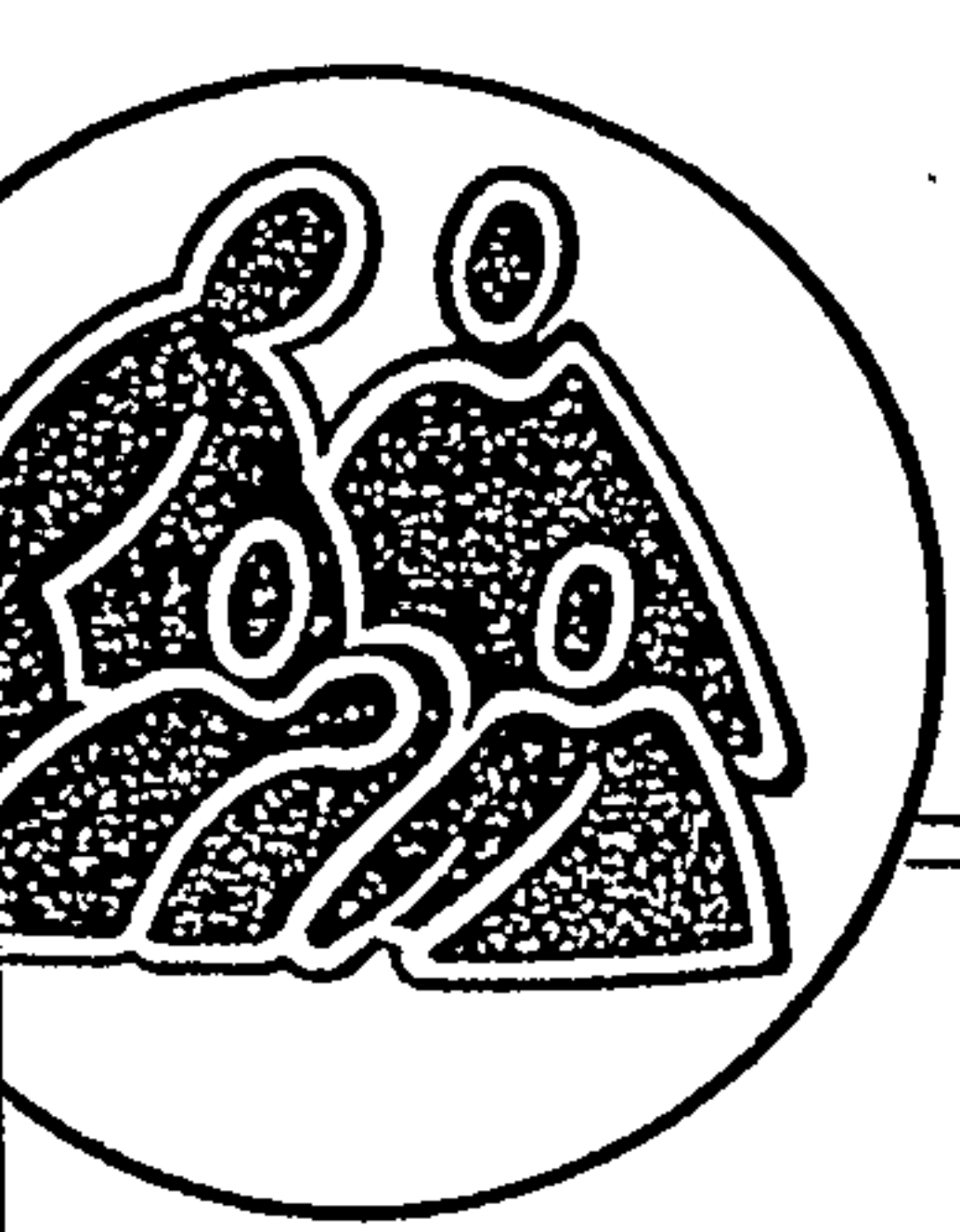
It is difficult to reply to your request for information on the number of children admitted to this Hospital with Down's Syndrome without you defining "children" and the time period for which you require the information.

The total number of Down's Syndrome patients admitted to St George Hospital in 1992 was 10 and in 1993 was 17.

If you require more precise information please contact Christine Senior, Deputy Director, Clinical Information Services on **350 2087**.

Yours sincerely,

JUDITH McDONALD
Director, Clinical Information Services



SOUTH WESTERN SYDNEY AREA HEALTH SERVICE



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Dr Akram Almassi

PC Box 436

Lakemba 2195

16th August 1994

Dear Dr Almassi.

It was with interest that I received your letter of request for information concerning dental services for children with Down's Syndrome.

Within South Western Sydney, children with Down's Syndrome access dental services in our public child clinics, or may access private dental services.

I am not in a position to comment on the service details of children who seek private dental treatment. In reference to public services we do not separately keep records for children with Down's. The treatment offered to them would be of the standard and expertise a Dental Therapist is capable of providing in conjunction with their supervisory Dental Officer. If specialist services were required a referral to Westmead Community Health or Westmead Paediatric Dental Department would be provided. All South Western Sydney Child Clinics (thirteen) do provide basic dental services to Down's Syndrome children.

As a general rule South Western Sydney Child Dental services treat the dental

SHAPING A HEALTHIER FUTURE

(2)

treatment needs of Down's Syndrome children in the same way as for all other children. Assessment and treatment is based on dental need; priority is based on clinical situation.

I hope this is of help to your thesis and I wish you well in your post graduate studies.

A handwritten signature in dark ink, appearing to be 'Helen Tscugranis', written in a cursive style.

Helen Tscugranis

Area Dental Co-ordinator

22/8/94

⑤

Date: 01/08/1994

Central West Child Guidance Clinic
Bathurst Community Health Centre

Dear Sir/Madam

I am a postgraduate student doing Diploma in Public Health Dentistry at University of Sydney. As apart of my course is to do thesis. My thesis is A Provision of Dental Services for children with Down Syndrome.

To complete my thesis I need some information about this Syndrome How many children with Down Syndrome in N.S.W Has been registered through your department.

I thanking you in anticipation, since those information will be of great assistance in preparing my thesis.

Yours Sincerely

A. Almasri

Akram Almasri

*This information (numbers only) should
be available from the Central
Office of the Dept. of Community
Services. Locked Bag 28
Ashfield. 2131.*

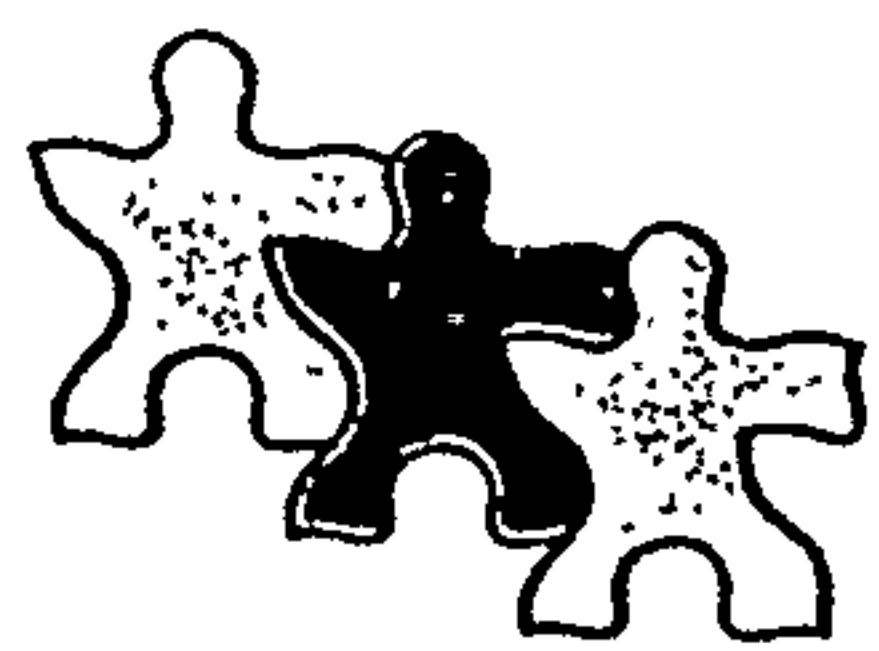
Phone. 02 7162757.

*M King, Manager
Bathurst D.C. Services*

Dr: Akram Almasri
P.O.Box: 436
Lakemba 2195
N.S.W Australia
Fax: (02) 750-8313

Department of community
services

Bathurst cluster
community services centre
p.o.Box 430
Bathurst. N.S.W 2795



NSW DEPARTMENT OF
COMMUNITY SERVICES

Linking families, individuals, communities:

164-174 LIVERPOOL ROAD
ASHFIELD 2131
LOCKED BAG 28
ASHFIELD 2131
OR DX 8528 BURWOOD

Dr Akram Almasri
P.O. Box 436
Lakemba
NSW 2195

Dear Dr Almasri

I am writing with regard to your recent letter requesting information on children with Downs Syndrome in NSW. In order to assist you with your request I will need additional information regarding the exact nature of the information you require.

The additional information needs to clearly identify:

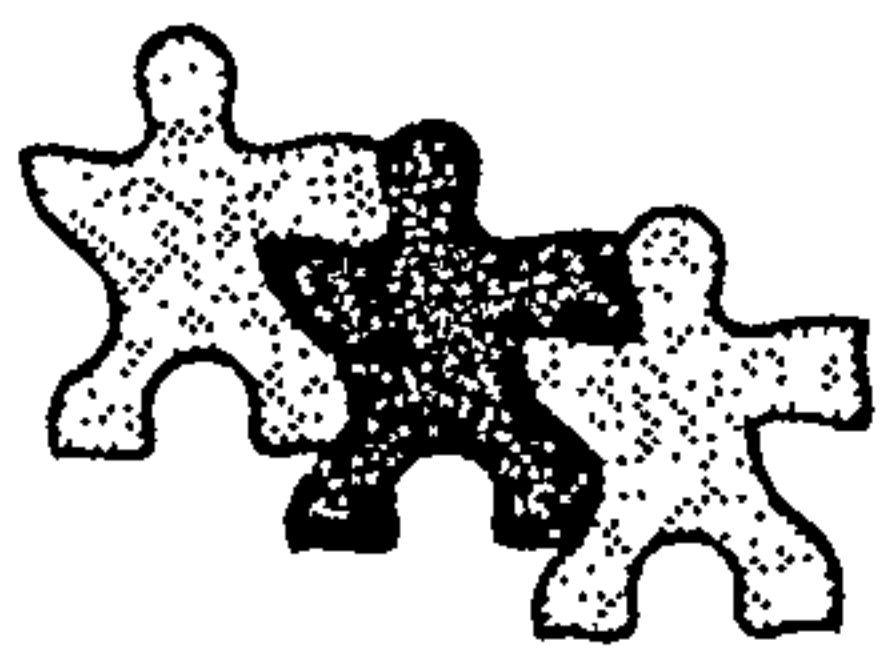
- * what is the nature of your thesis and how will this information be used.
- * what type of data are you requesting, e.g. is it non identifying numbers or is it individual data.
- * what age range is covered by the term 'children'.
- * what period of time is this data to cover.

Thank you for your enquiry, I will endeavour to assist you further when the nature of your request has been further clarified.

Yours Sincerely

Ethel McAlpine

Ethel McAlpine
Principal Policy Officer
Service Planning and Development Unit.
5/9 94



NSW DEPARTMENT OF
COMMUNITY SERVICES

10th August, 1994.

WOODSTOCK CENTRE
P.O. Box 294
Lavington, N.S.W. 2641
Reservoir Road
Lavington, N.S.W. 2641
Phone: (060) 49 0311
Fax: (060) 40 1051

Dr. Akram Almasri,
P.O. Box 436,
LAKEMBA NSW 2195

Dear Dr. Almasri,

I write in response to your letter of 1st August, 1994. In your letter you requested information concerning the number of children with Down Syndrome in N.S.W. registered through this Department.

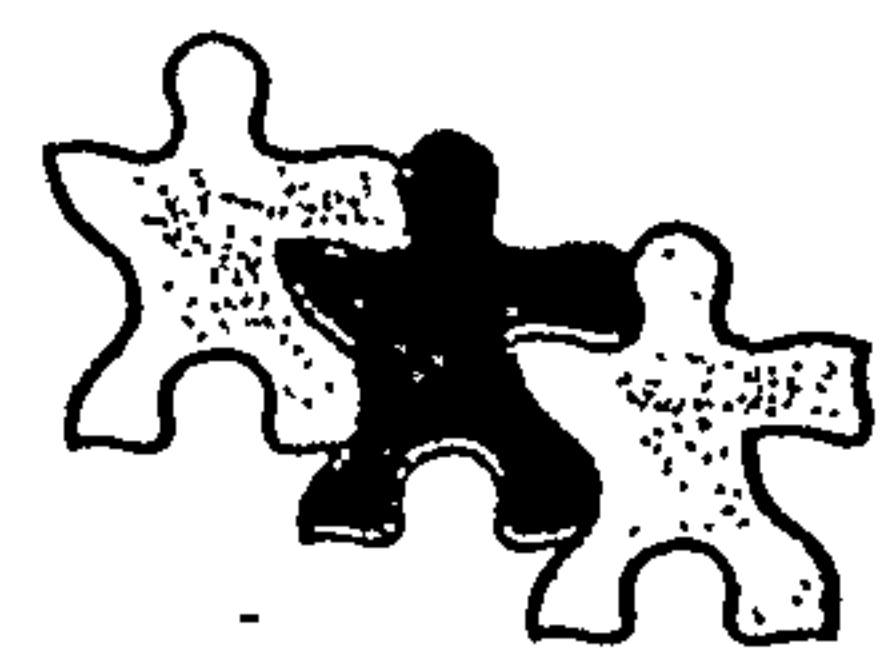
Woodstock Community Resource Team covers the Murray area of N.S.W. only. We would therefore only be able to provide information for this area. I suggest you contact our Computer Services Branch for this information. They can be contacted at:

Locked Bag 28,
ASHFIELD NSW 2131
Fax (02) 716-2723

I have forwarded your request to them but suggest you follow this up on your behalf.

Yours sincerely,

GLEND A BROWN
ASSISTANT MANAGER
COMMUNITY SERVICES



NSW DEPARTMENT OF
COMMUNITY SERVICES

Linking families, individuals, communities.

Dr Akram Almasri
P.O. Box 436
Lakemba
NSW 2195

164-174 LIVERPOOL ROAD
ASHFIELD 2131
LOCKED BAG 28
ASHFIELD 2131
OR DX 8528 BURWOOD

Dear Dr Almasri

Thank you for your letter of 8 September that provided additional details on your request for information in relation to your thesis. Unfortunately the type of information that you require is not collected through our data system. Therefore we are unable to assist you further with your request for information.

Yours Sincerely

Ethel McAlpine

Ethel McAlpine
Principal Policy Officer
Service Planning and Development Unit
15/9/94

21/9/94

THE NEW ENGLAND HEALTH SERVICE

Clair House
Rusden & Butler Streets
ARMIDALE NSW 2350
Tel: (067) 73 4788
Fax: (067) 72 1206

Dr Dan Naidoo
Principal Dental Officer
New England and North West Health Districts

Correspondence to:
Locked Mail Bag No. 8
ARMIDALE NSW 2350

16 August 1994

22/8/94

12

Dr Akram Almasri
PO Box 436
LAKEMBA NSW 2195

Dear Dr Akram,

DENTAL SERVICES AVAILABLE FOR CHILDREN WITH DOWN SYNDROME

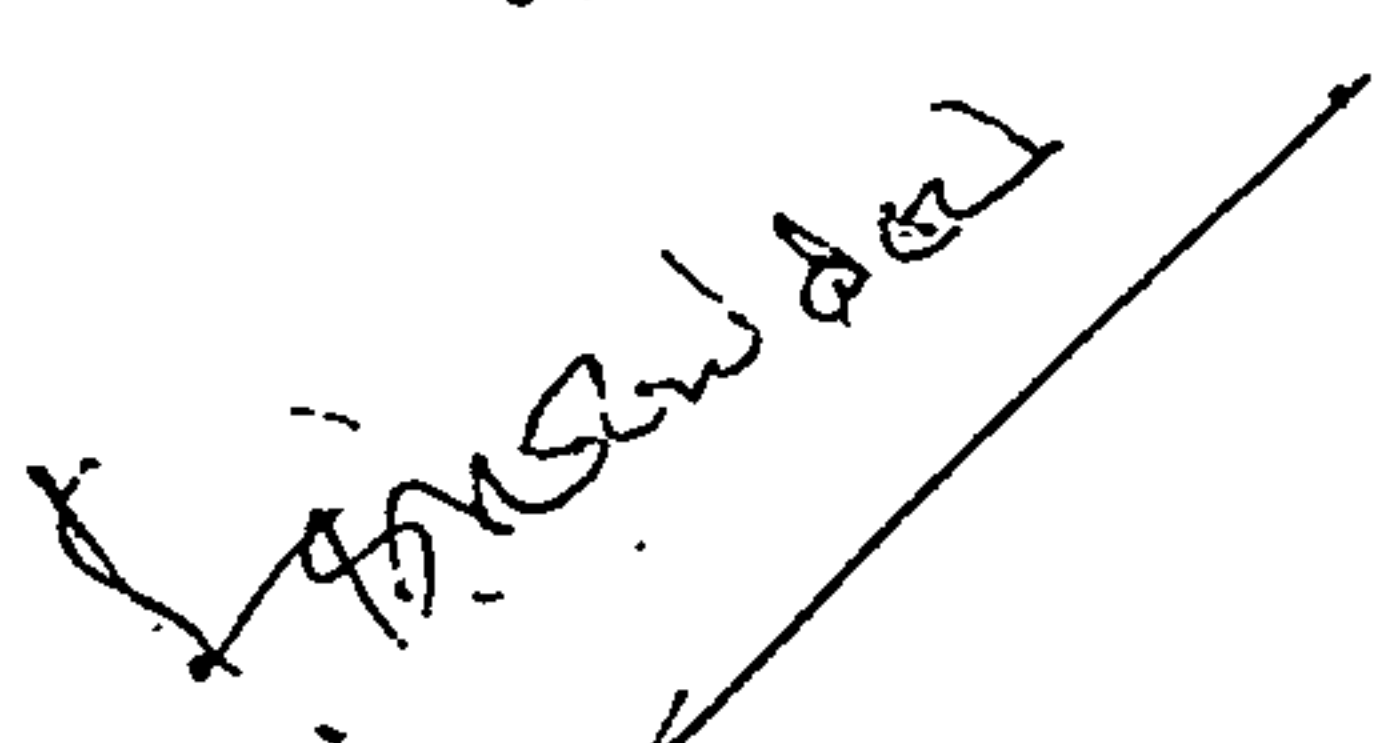
Thank you for your letter dated 1st August 1994.

Two Down Syndrome patients were treated in Moree last year and two in Taree.

Taree patients attend regularly. One is easily treated under local anesthetic, the other has to be treated under a General Anesthetic.

The two Moree patients are under eight years of age and with the cooperation of their parents respond well to oral hygiene instructions etc.

Yours sincerely,


Dr Dan Naidoo
PRINCIPAL DENTAL OFFICER



13

Dental Services
Direct Indial: (066) 20.2142
Ref: PRH

CHMOND EALTH ERVICE

Dr Akram Almasri
P O Box 436
LAKEMBA 2195

10/8/94

Office Box 419
more NSW 2480
(066) 218 000
(066) 217 088

Dear Dr Almasri

Receipt is acknowledged of your letter of 1 August 1994 regarding your thesis on Public Health Dentistry.

I have referred your letter to each of the Dental Clinics in the area with a request for them to reply directly to you with the information you seek.

Yours faithfully

P R HILL
Principal Dental Officer

na District Hospital
Box 523
a NSW 2478
(66) 862 111

lbo Hospital
ville Road
bo NSW 2470
(66) 651 203

n District
ital
ox 118
Bay NSW 2481
(66) 856 200

Campbell Hospital
ox 93
i NSW 2471
(66) 832 019

o & District
orial Hospital
ox 268
p NSW 2470
(66) 622 111

e Memorial
ital
ox 125
e NSW 2474
(6) 321 522

re Base
ital
ox 419
re NSW 2480
(6) 218 000

mbimby &
ct War Memorial
al
ox 240
mbimby NSW 2482
(6) 842 266

n District Hospital
Street
n NSW 2480
(6) 891 400

ville &
ct Hospital
aury Street
ville NSW 2475
(6) 341 319



13

Dental Services
Direct Indial: (066) 20.2142
Ref: MS

RICHMOND HEALTH SERVICE

11 August 1994

Dr Akram Almasri
P O Box 436
LAKEMBA 2195

Post Office Box 419
Lismore NSW 2480
(066) 218 000
(066) 217 088

Dear Dr Almasri

In reference to your letter of 1 August 1994, I'm afraid we don't have a breakdown of figures for the number of Down's Syndrome patients treated.

However, they are treated as normal patients and are offered a full range of conservative and prosthetic treatment. As you are aware a great many of them are "ideal" patients and are most co-operative. These are treated in the chair by either Dental Officers or Dental Therapists, dependent on their age.

If unco-operative, they are treated under general anaesthetic in the Day Surgical Unit where we have mobile dental equipment.

The three Dental Clinics in our District, i.e. Ballina, Lismore and Casino all offer these services.

Yours faithfully

M Syme
A/Principal Dental Officer.

Ballina District Hospital
Box 523
Ballina NSW 2478
(066) 862 111

Ballina Hospital
Municipal Road
Ballina NSW 2470
(066) 651 203

Ballina District
Hospital
Box 118
Ballina Bay NSW 2481
(066) 856 200

Campbell Hospital
Box 93
Casino NSW 2471
(066) 832 019

Casino & District
Memorial Hospital
Box 268
Casino NSW 2470
(066) 622 111

Casino Memorial
Hospital
Box 125
Casino NSW 2474
(066) 321 522

Lismore Base
Hospital
Box 419
Lismore NSW 2480
(066) 218 000

Lumbimby &
Vict War Memorial
Hospital
Box 240
Lumbimby NSW 2482
(066) 842 266

Lismore District Hospital
Municipal Street
Lismore NSW 2480
(066) 891 400

Lumbimby &
Vict Hospital
Municipal Street
Lumbimby NSW 2475
(066) 341 319



COFFS HARBOUR BASE HOSPITAL

FACSIMILE

Primary Health Care Services Dental Clinic

38 Gordon Street Coffs Harbour NSW 2450

Telephone: 066 - 522000

Facsimile: 066 - 512474

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To: DR AKRAM ALMASRI

From: DR GEOFF WEBSTER

Urgent: Yes ☒ No Confidential: Yes ☒ No

Date/Time: 18 AUGUST 1994 No. of pages (incl. cover) 1

MESSAGE

RE: DOWN SYNDROME CHILDREN

DR PETER HILL (PRINCIPAL DENTAL OFFICER

NORTH COAST REGION) FAXED YOUR REQUEST TO EACH

DISTRICT IN HIS REGION.

UNFORTUNATELY, THE MID NORTH COAST DISTRICT HAS NO

RECORDS OF DOWN SYNDROME CHILDREN TREATED

DURING THE LAST YEAR TO HELP WITH YOUR THESIS

ALBANY

GEOFF WEBSTER (DISTRICT DENTAL OFFICER)

Press all correspondence and Refer enquiries to:

COMMUNITY DENTAL SERVICE
180 PEEL STREET, TAMWORTH NSW 2340



Telephone: (067) 66 3341

Fax: (067) 66 3967

NWHS
North West Health Service

11/8/94

9th August, 1994

Dr Akram Almasri
P.O Box 436
LAKEMBA NSW 2195



Dear Dr Almasri,

In answer to your letter concerning how many "Down Syndrome" patients our clinic has registered, we are unable to give you a definite number.

WE do not register or separate "Down Syndrome" patients from our clientele, so without going through our thousands of patients cards individually we can only guess.

However, we can remember about six Down Syndrome children whom we treat and about 12 adults.

We are known to both the Home and Community Care Service and the special school in Tamworth who refer patients to us as required.

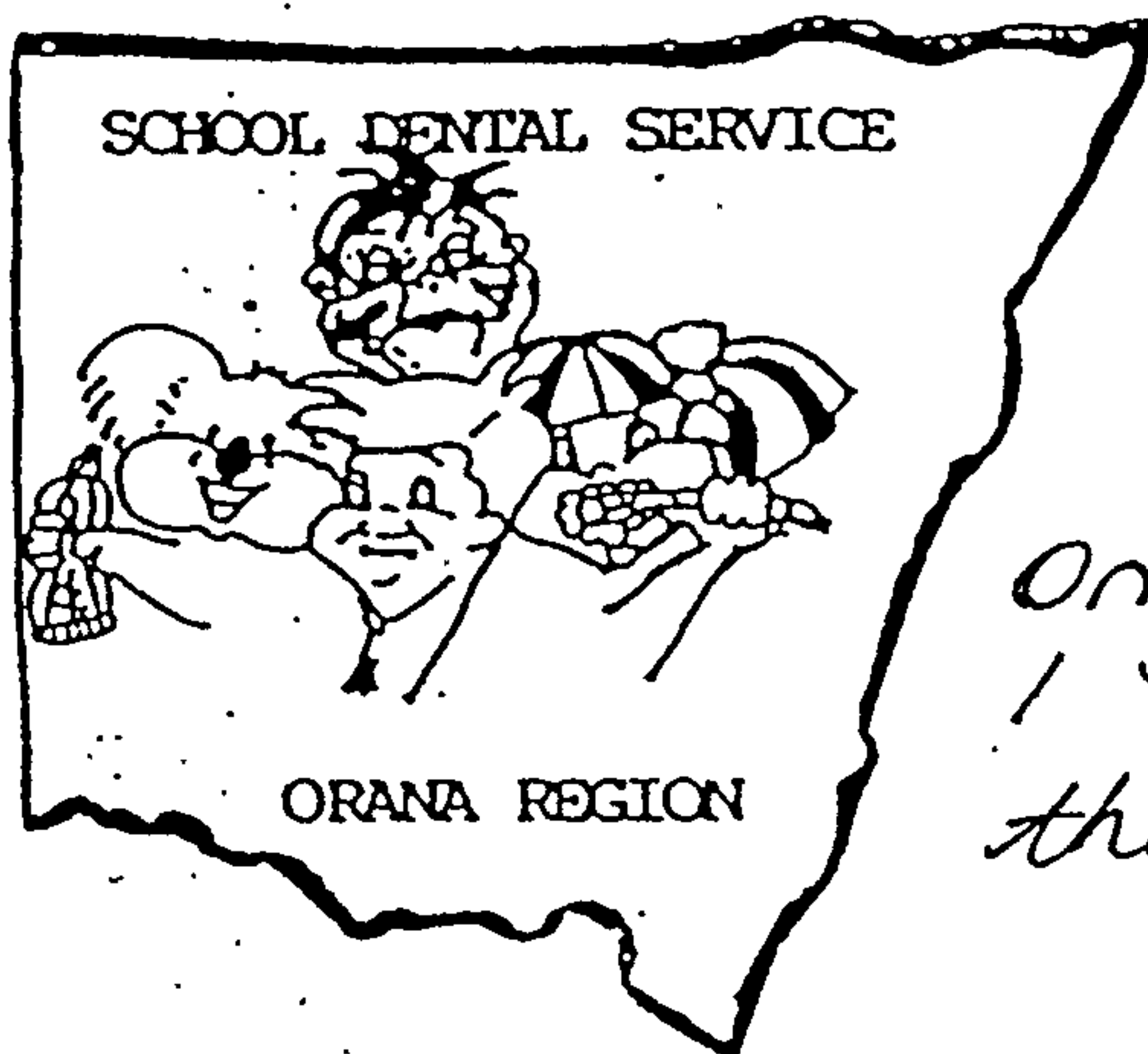
Hoping this information is of use.

Yours sincerely,

Lyn Haack
Senior Dental Therapist

**Tamworth
Base Hospital**

PO Box 83
Tamworth NSW 2340
Tel 067 66 1722
Fax 067 66 6638



WITH COMPLIMENTS
SOUTH DUBBO DENTAL CLINIC

These are records for the only Down Syndrome patients I am aware of who attend this clinic. (2 patients)
Hope this is of help.

RONALD STREET, DUBBO.

PHONE 826928.

DUBO.  Koyal.
Senior Dental
Therapist

1. 45. $\frac{12}{12}$ to review on the

✓ ✓ ✓ wait List to see P.D.O.

TC J Toynton

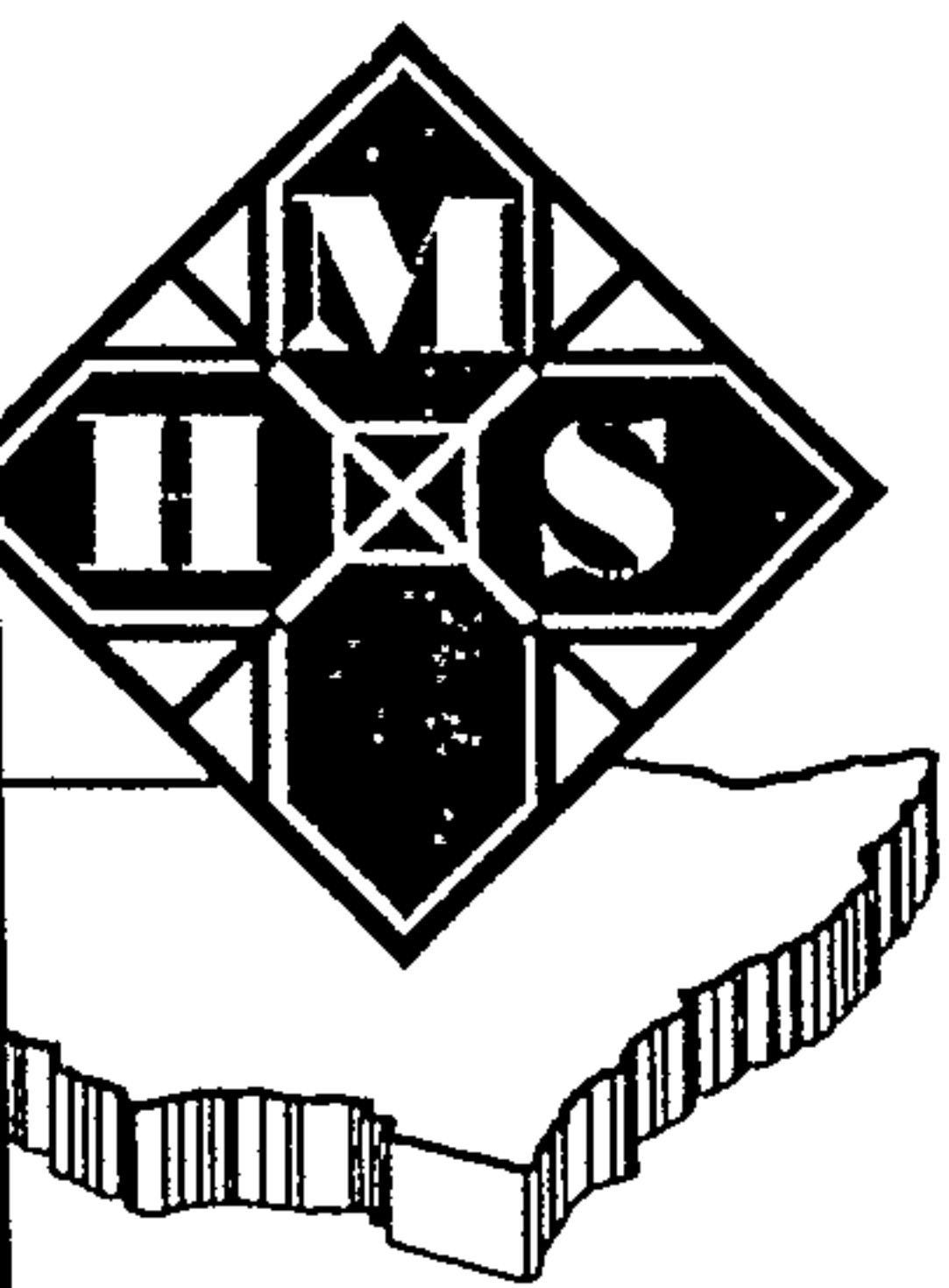
NAME Sherrie Tucker

DATE _____

LOWER ANT CROWDING 3 21, 11 IN CROSSBITE
ADVISED NO. REMOVE 73, 83, 63, 53 TO RELIEVE
CROWDING - TAKE 2 P.A.'S OF 22, 12 N.V.
ADVISED NO TO SEEK ANTIBIOTIC COVER
FOR GINGIV. N.V.

What kind of school

Unit 11 is opening class



MACQUARIE HEALTH SERVICE

Dubbo Community
Health Centre
2 Palmer Street
DUBBO, 2830
Telephone: (068) 85 8999
Facsimile: (068) 85 8901

Incorporating the hospitals and health services of Cobar, Coonamble, Dubbo,
Gilgandra, Gulargambone, Narromine, Nyngan, Trangie, Warren and Wellington.

9 September 1994

14

Dr. Akram Almasri
P. O Box 436
Lakemba 2195

Dear Dr. Almasri

Received your letter regarding research material on 'Down Syndrome' clients. At the Dubbo Community Health Centre, especially within the scope of our Child Adolescent and Family health Service, we do not maintain specific case details relating to this particular clinical condition.

Our paediatric clinicians whom I consulted on this matter have advised me to direct you to the Department of Community Services and Early Intervention Programme which gather specific details relating to their clientele suffering from Down Syndrome.

The address of these two agencies in Dubbo are given below for your information.

Department of Community Services
Divisional Office - Western Division
130 Brisbane Street
Dubbo 2830

Ms Genell Burke
Early Intervention Service
Baird Drive

West Dubbo

NSW 2830

068 - 820599

→ holiday
→ 10 October

068 845895

I am sorry that we could not provide you with more information regarding this matter. May I wish you every success in completing your post graduate studies.

068 845877 District Centre

Regards

Srimal Abeysekera
Information Systems Manager



UNITED DENTAL HOSPITAL OF SYDNEY

2 Chalmers Street, Surry Hills, N.S.W. 2010 (at Central Railway)

Address reply to the
General Manager

Your Ref:

Our Ref:

Phone: 282.0270

23 August 1994

(12)

Dear Dr Alnasri,

I am replying to your letter sent to Dr Wilkinson. I had pleasure in meeting you when you visited the UDH. I will endeavour to answer your questions as best I can.

It is impossible to give accurate statistics on Downs Syndrome patients as we don't distinguish between handicapped patients but rather treat them as a group within the community Dental Health department.

You asked about the type of treatment offered to Downs Syndrome patients. They, depending on the severity of their handicap, would receive the treatment as is needed but perhaps using a General Anaesthesia or relative anaesthesia rather than local anaesthesia, depending on their behavioural problems. I have found most Downs Syndrome patients to be acceptable to dental treatment under just local anaesthesia.

There are several clinics offering treatment to Downs Syndrome patients beside the UDH. The dental clinics in the Childrens' Hospital at Camperdown and Prince of Wales Hospital are the most notable.

I hope this helps with your thesis.

Yours sincerely,

David Murphy
Acting Department Head
Community Dental Health

HU▲E HEALTH SERVICE

Telephone: (060) 23 83 50
Facsimile: (060) 23 77 01

16

NH:15

Dear Dr Almasri

My apologies for the delay in responding to your letter.

In the South West Region no specific records are kept on dental services provided for children with Downs Syndrome.

Downs Syndrome children have full access to our school service clinics and our adult dental services later on if they are covered by a Health Care Card or Pension Card. Where possible treatment is carried out in a normal dental surgery setting but in some cases treatment is completed under general anaesthetic by a Dental Officer.

The treatment offered is mainly of a routine conservative nature with a big emphasis on oral hygiene.

Sorry I can't offer any specific patient numbers but if I can be of further assistance please re contact me.

Yours faithfully

Neville Heer
Acting Principle Dental Officer

Working Together to Make Hume Australia's Healthiest District

1. NAME	2. ADDRESS	3. CITY	4. STATE	5. ZIP	6. PHONE	7. FAX	8. E-MAIL	9. COMMENTS
10. NAME	11. ADDRESS	12. CITY	13. STATE	14. ZIP	15. PHONE	16. FAX	17. E-MAIL	18. COMMENTS
19. NAME	20. ADDRESS	21. CITY	22. STATE	23. ZIP	24. PHONE	25. FAX	26. E-MAIL	27. COMMENTS
28. NAME	29. ADDRESS	30. CITY	31. STATE	32. ZIP	33. PHONE	34. FAX	35. E-MAIL	36. COMMENTS
37. NAME	38. ADDRESS	39. CITY	40. STATE	41. ZIP	42. PHONE	43. FAX	44. E-MAIL	45. COMMENTS
46. NAME	47. ADDRESS	48. CITY	49. STATE	50. ZIP	51. PHONE	52. FAX	53. E-MAIL	54. COMMENTS
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307. NAME	308. ADDRESS	309. CITY	310. STATE	311. ZIP	312. PHONE	313. FAX	314. E-MAIL	315. COMMENTS
316. NAME	317. ADDRESS	318. CITY	319. STATE	320. ZIP	321. PHONE	322. FAX	323. E-MAIL	324. COMMENTS
325. NAME	326. ADDRESS	327. CITY	328. STATE	329. ZIP	330. PHONE	331. FAX	332. E-MAIL	333. COMMENTS
334. NAME	335. ADDRESS	336. CITY	337. STATE	338. ZIP	339. PHONE	340. FAX	341. E-MAIL	342. COMMENTS
343. NAME	344. ADDRESS	345. CITY	346. STATE	347. ZIP	348. PHONE	349. FAX	350. E-MAIL	



MACLEAN DISTRICT HOSPITAL

and Community Health Services

Please address all
Communications to the
CHIEF EXECUTIVE OFFICER

Telephone: (066) 45 2066
Fax: (066) 45 2862

P.O. Box 93,
Maclean. N.S.W. 2463.

September 29, 1994

Akram Almasri
PO Box 436
LAKEMBA NSW 2195

Dear Mr Almasri,

I refer to your request for information re:

Treatment of Downes Syndrome patients at this clinic.

This clinic has no record of treatment of Downes Syndrome patients.

Yours sincerely,

W O SCHWARZ
Dental Officer

MACLEAN, THE
SCOTTISH TOWN
IN AUSTRALIA



Reference: 9400928
Contact: James Young
Telephone: (06) 244 7505

Dr Akram Almasri
PO Box 436
LAKEMBA NSW 2195

Dear Dr Almasri

CHILD DISABILITY ALLOWANCE - CHILDREN WITH DOWN'S SYNDROME

I refer to your letter of 1 August 1994 in which you requested information on Department of Social Security recipients in New South Wales whose children have Down's Syndrome.

Children with Down's Syndrome qualify for the Child Disability Allowance. Whilst I am unable to provide you with information on Child Disability Allowance recipients by medical condition, I can provide you with information (as at 10 December 1993) on the number of children in receipt of Child Disability Allowance by sex and age for New South Wales. The cost of providing this information is \$50. If you would like to receive this information could you please send a facsimile message to (06) 244 7936.]

In October 1993 the Social Policy Division of this Department produced a policy discussion paper on Child Disability Allowance (Child Disability Allowance, Policy Discussion Paper Number 2, October 1993, ISBN 0 644 32713 8). This publication may be of use to you in your studies. If you would like to purchase this publication they are available, at a cost of \$7.50 per copy, from any Australian Government Publishing Service Bookshop. 2996737

Should you have any further enquires please contact James Young on (06) 244 7505.] 7

Yours sincerely

Glen Halloran

Glen Halloran
Director
Statistical Information Section
13 September 1994

06 244 6371
06 244 7788
Kent well
06 244 7714

Reference: 9400928
Contact: James Young
Telephone: (06) 244 7505

Dr Akram Almasri
PO Box 436
LAKEMBA NSW 2195

Dear Dr Almasri

CHILD DISABILITY ALLOWANCE - CHILDREN WITH DOWN'S SYNDROME

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Should you have any further enquires please contact James Young on **(06) 244 7505.** ↴

Yours sincerely

Glen Halloran

Glen Halloran

for Director

Statistical Information Section

13 September 1994

06 244 6371

06 244 7788

Kent well

06 244 7714



NEW ENGLAND EDUCATIONAL DIAGNOSTIC CENTRE

AN ASSESSMENT, COUNSELLING, REMEDIATION, TRAINING
RESOURCE AND RESEARCH CENTRE FOR SPECIAL EDUCATION

Cnr Mossman and Dangar Streets, ARMIDALE, N.S.W.

N.E.E.D. Centre,
P.O. Box 429,
ARMIDALE.
Australia. 2350
Phone: (067) 72 1711
Fax: (067) 72 9313

31st August, 1994.

12

Dr. Akram Almasri,
P.O. Box 436,
LAKEMBA. 2195

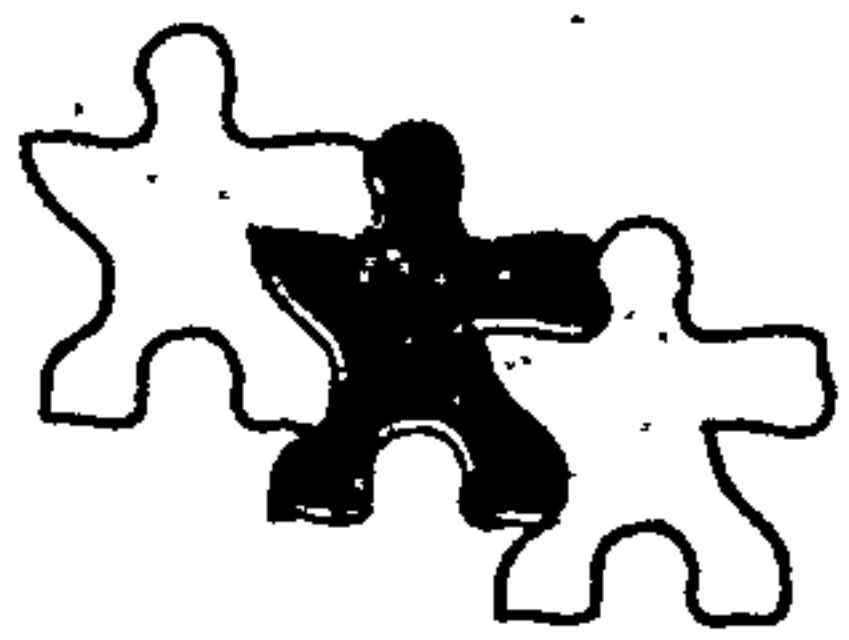
Dear Dr. Almasri,

Thank you for your enquiry about children having Down Syndrome.

The function of this Centre is to provide services to children having Learning Difficulties. Those children with Developmental Disabilities are assisted through other agencies. In this regard, I would suggest that you contact the Department of Health in Sydney. Another alternative would be Developmental Disabilities Staff Training Unit, telephone 02 692 7111.

Yours sincerely,

Vanessa Redmond.
Co-ordinator.



NSW DEPARTMENT OF
COMMUNITY SERVICES

CHILDREN'S COMMUNITY TEAM
(Disability Services)

2nd August, 1994

9/8/94

21 MOUNT OUSLEY ROAD
FAIRY MEADOW 2519
TELEPHONE (042) 29 3444
FACSIMILE (042) 26 4236

⑤

Dr Akram Almasri
P.O. Box 436
LAKEMBA NSW 2195

Dear Dr Almasri,

In reply to your letter dated 1.8.94 re: children with Down Syndrome living in the Illawarra area. While it is difficult to say how many children we have had registered through our service since its conception, I can tell you that we currently have 58 active clients with Down Syndrome. That is, children who are currently receiving some form of therapy or medical service from our team. We receive up to 8-10 new referrals of children with Down Syndrome each year. The Children's Community Team see children from 0-16 years. The Adult Team in the Illawarra Area can be contacted on (042) 26 3522.

I also suggest you contact the Down Syndrome Association of NSW (if you haven't already done so). Their address is 31 O'Connell Street, Parramatta 2151. Tel: **683 4333**.

Yours sincerely,

Lisa Polonis,
Secretary.

Dental Health Branch
NSW Health Department
LMB 961
North Sydney 2059

September 21st 1994

Dr Akram Almasri
PO Box 436
Lakemba 2195

6

Dear Dr Almasri

Dr Caroline Hong forwarded a letter you wrote to her asking for information for your Diploma in Public Health Dentistry.

We are not exactly sure what information you want. Some information follows. If you would like further information, please contact Michael Jacobi, Dental Health Branch (telephone 391 9384). He will help you if he can.

In NSW, all children from 0-14 years inclusive are eligible for free dental services in the School Dental Service (SDS). They are not necessarily referred by anyone, and do not necessarily have any dental cover. Also, any children/dependants (still at school) of health card holders are eligible for dental services in the SDS. They may be older than 14 years.

We have only limited data available for children using the School Dental Service in the Northern Sydney Area (NSA) for 1992 and 1993. Please see the table on the next page. Please note that the figures in the table refer to the Child Dental Health Survey (CDHS). They therefore represent a sample of the children seen/examinations done. (They are not the total number of examinations done.) We estimate that in 1992 in NSA, 3.7% of examinations done were reported in the CDHS. In 1993, approximately 4.3% of examinations were reported to the CDHS.

F

Table: Children aged 0-14 years, seen in the School Dental Service, and reported to the CDHS, Northern Sydney Area Health Service 1992 and 1993

	1992 Northern Sydney Area		1993 Northern Sydney Area	
	males	females	males	females
number new patients	158	166	211	191
number seen for first time in year	152	146	171	188
number recall exams (seen >1) within the year	37	31	58	64

We also know that the total number of examinations done in the SDS in NSA in 1992 was 19181. In 1993, 20622 exams were done. These numbers are for all ages, and may include children outside the 0-14 years range. We have no demographic data to go with this count of examinations.

We do not have types of service provision related to each child. If you wish, Michael Jacobi can get some information on the overall types of service provided in Northern Sydney School Dental Service in 1993.

I hope this helps you with your thesis. Please contact us again if we can help you further.

Yours sincerely

Jane Bell

Jane Bell

19 October 1994

Dr Akram Almasri
P.O. Box 436
LAKEMBA 2195

Dear Dr Almasri

**RE : INFORMATION FOR DOWN SYNDROME CUSTOMERS
MONARO HEALTH SERVICES**

As discussed over the telephone, Down Syndrome children with complications are referred to DR PETER WONG, Paedodontist in Canberra, ACT.

Child Dental Clinics	-	2
Adult Dental Clinic	-	1

Children attending 4 known cases

Children are only referred if treatment cannot be undertaken in clinics.

Yours sincerely



for ANGELA COPP
Senior Dental Therapist

COMMUNITY DENTAL HEALTH

1. DOWN SYNDROME:

Adults:	228
Children:	86

TOTAL:	314
--------	-----

2. ALL COMMUNITY DENTAL HEALTH PATIENTS

TOTAL:	11381
--------	-------

3. PAEDIATRIC DENTISTRY

Code 1:	Medically compromised
	Handicapped
	Syndromes
	Dental Anomaly

TOTAL:	504
--------	-----

Dental Health Branch
Administration Building Gladesville Hospital
Victoria Road, Gladesville, 2111
Phone: (02) 816 0304
Fax: (02) 816 0302

Dr A Almasri
PO Box 508
LAKEMBA NSW 2195

Dear Dr Almasri

I refer to your request for assistance with a research project, "Provision of Dental Services for Children with Down Syndrome in NSW".

Dental Health Branch is unable to assist with your request, as no statistics are held centrally on children with Down Syndrome.

I have forwarded your request to Ms Rowena Palogan, dental therapist at the Sunshine Home at Gore Hill in Sydney. Ms Palogan will be happy to answer, to the best of her ability, any questions you have. You can contact Ms Palogan on 439 2011.

You might also contact Dr Susan Buchanan, Deputy Director of Dental Services at the United Dental Hospital on 282 0240 and Dr Peter King, Director of Community Dental Health at Westmead Dental Clinical School on 633-7814.

Yours sincerely,

I.M. Searle

I.M. Searle
CDHP Coordinator

29/3/95

North coast
region



Ballina Dental Clinic
10-4-9

Dear Dr. Almanzi.

I received your request via the
Principal Dental Officer, Dr Peter Hill,
for information on Down Syndrome
children at our clinic.

The clinic has one therapist & 1 $\frac{3}{5}$
dental officers.

1. Approx. 5 individual DS children
in the last 2y's.

2. The usual, and a G.A. if necessary.

3. Often severe ortho. & ortho cases
are referred to specialist in Lismore.

H. No.

Hope the above is satisfactory.

Regards.

Max Dumas.

Post Office Box 419
Lismore NSW 2480
Ph. (066) 218 000
Fax (066) 217 088

Ballina District Hospital
PO Box 523
Ballina NSW 2478
Ph.(066) 862 111

Bonalbo Hospital
Urbenville Road
Bonalbo NSW 2470
Ph.(066) 651 203

Byron District
Hospital
PO Box 118
Byron Bay NSW 2481
Ph.(066) 856 200

The Campbell Hospital
PO Box 93
Coraki NSW 2471
PH (066) 832 019

Casino & District
Memorial Hospital
PO Box 268
Casino NSW 2470
Ph.(066) 622 111

Kyogle Memorial
Hospital
PO Box 125
Kyogle NSW 2474
Ph(066) 321 522

Lismore Base
Hospital
PO Box 419
Lismore NSW 2480
Ph.(066) 218 000

Mullumbimby &
District War Memorial
Hospital
PO Box 240
Mullumbimby NSW 2482
Ph.(066) 842 266

Nimbin District Hospital
Cullen Street
Nimbin NSW 2480
Ph.(066) 891 400

Urbenville &
District Hospital
45 Beaury Street
Urbenville NSW 2475
Ph.(066) 341 319

**RICHMOND HEALTH SERVICE
CASINO PRIMARY HEALTH CARE
CASINO DENTAL CLINIC
P O BOX 268
CASINO 2470**

**PH: (066) 622111 EXT 295
FAX: (066) 623744**

Friday 31st March

Dr Akram Almasri
P O Box 508
Lakemba 2195
N.S.W Australia

Dear Dr Almasri

With reference to your letter dated 23.3.95 regarding the research on " Provision of Dental Services for Children with Down Syndrome in NSW ". The information which follows is from the Casino Dental Clinic over the period of the last two years.

We have only had 1 Down Syndrome patient under the age of fourteen. The treatment has been carried out by Dental Therapists and the Dentist in the clinic over the last six years. The treatment which has been offered and carried out is as follows -

- * Regular examinations
- * Prophylaxis and scaling of teeth
- * Orthodontic assessment
- * Extraction of over-retained deciduous teeth
- * Referral to Royal Children's Hospital in Brisbane after requested by mother. Suggested referral to Royal Far West but mother preferred to go to Brisbane for treatment and orthodontic services
- * Mother was happy with treatment at the clinic and decided have any treatment which may be required to be done at the clinic.

If any specialist treatment is required in the future the staff will made arrangements so that treatment can be carried out within the Richmond Health Service or will be reffered to either Royal Far West or the Royal Children's Hospital in Brisbane as suits the parent.

We do not keep a register of Down Syndrome patients as we do not have very many requiring treatment at the clinic.

Yours faithfully

A handwritten signature in cursive script, appearing to read 'N F Cause'.

Dr N F Cause BDS
Dentist in Charge
Casino Dental Clinic

Reccast
ion

MACLEAY HASTINGS HEALTH SERVICE

Address Correspondence to
Dental clinic, Community Health
P O Box 126
PORT MACQUARIE NSW 2444

Tel. (065) 83 1552
Fax. (065) 84 2459

12th April, 1995

Dr. Akram Almasri
P.O. Box 508
LAKEMBA NSW 2195

Dear Dr. Almasri,

Re: Children with Downs syndrome

We offer routine dental care to these patients
sometimes under G.A.

In the past we have referred orthodontic cases
to Newcastle but we now have a visiting
orthodontist in our district.

Any oral surgery would be referred to Newcastle
(John Hunter Hospital).

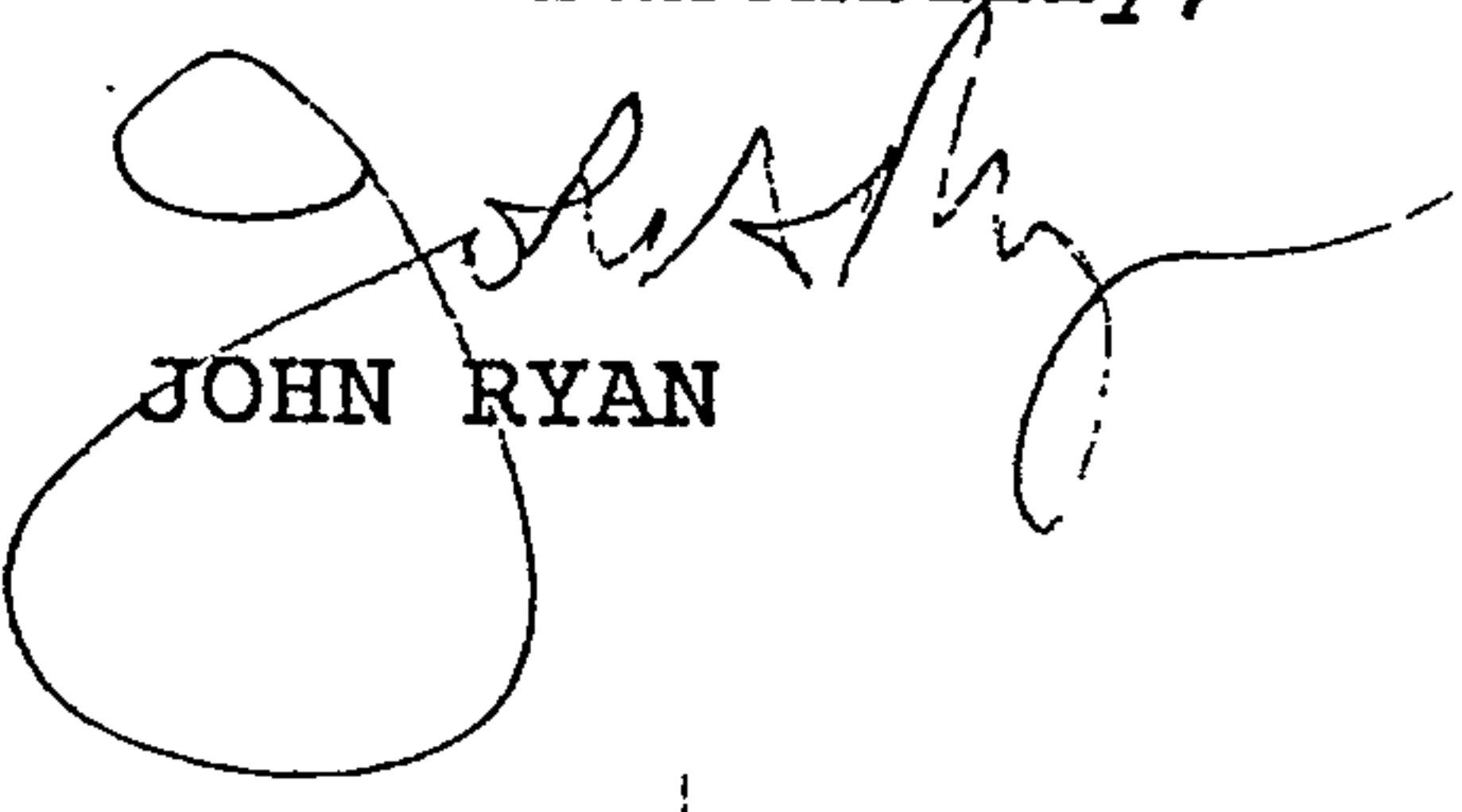
We do not keep a separate register of Downs
Syndrome patients.

As to the number of these patients who use our
public dental services my estimate would be.

KEMPSEY
School and Adult Clinic 6

PORT MACQUARIE
School and Adult Clinic 9

Yours faithfully,


JOHN RYAN

Recent
region

PRIMARY HEALTH CARE SERVICES DENTAL CLINIC

38 Gordon Street, COFFS HARBOUR 2450
Telephone: 066 -522000 Facsimile: 066 512474

7 April 1995

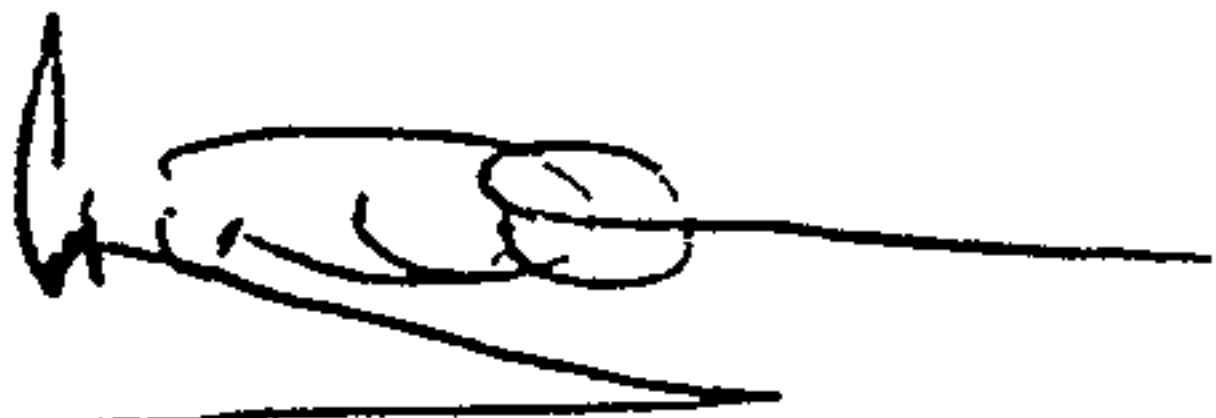
Dr Akram Almasri
PO Box 508
LAKEMBA 2195

Dear Dr Almasri

With respect to your correspondence of 23 March 1995, I can only provide the following:-

- 1) I estimate three Downs Syndrome children used the public Dental Service in the last two years.
- 2) Treatment ranged from conservative/preventative to general anaesthetic.
- 3) We have not had the need to refer, but would most likely refer externally.
- 4) We keep no register of Downs Syndrome children.

Yours sincerely



Geoffrey Webster
District Dental Officer
Mid North Coast Health Service

the coast
region

GRAFTON BASE HOSPITAL AND HEALTH SERVICE COMMUNITY HEALTH



P.O. BOX 368
GRAFTON. N.S.W. 2460

TELEPHONE: (066) 42 3933
FACSIMILE: (066) 42 4824

12 April, 1995

Dr Akram Almasri
PO BOX 508
LAKEMBA 2159 NSW

Dear Dr Almasri

The Grafton Base Hospital Dental Clinic received your letter "Provision of Dental Services for children with Down Syndrome in NSW".

Unfortunately we are unable to supply you with any information, as there are no down syndrome children accessing our service.

Of recent months I have been made aware of a couple of babies born in the Clarence Valley with down syndrome. Perhaps in the future they will utilise our service.

If you require any other information to assist your research we would be happy to assist.

Kind Regards

Elizabeth Power

Elizabeth Power
Dental Assistant

HUME HEALTH SERVICE

region

475 Townsend Street Albury
P.O. Box 503 Albury 2640

Telephone: (060) 23 0350
Facsimile: (060) 21 7701

Dr Akram Almasri
P.O. Box 508
LAKEMBA 2195

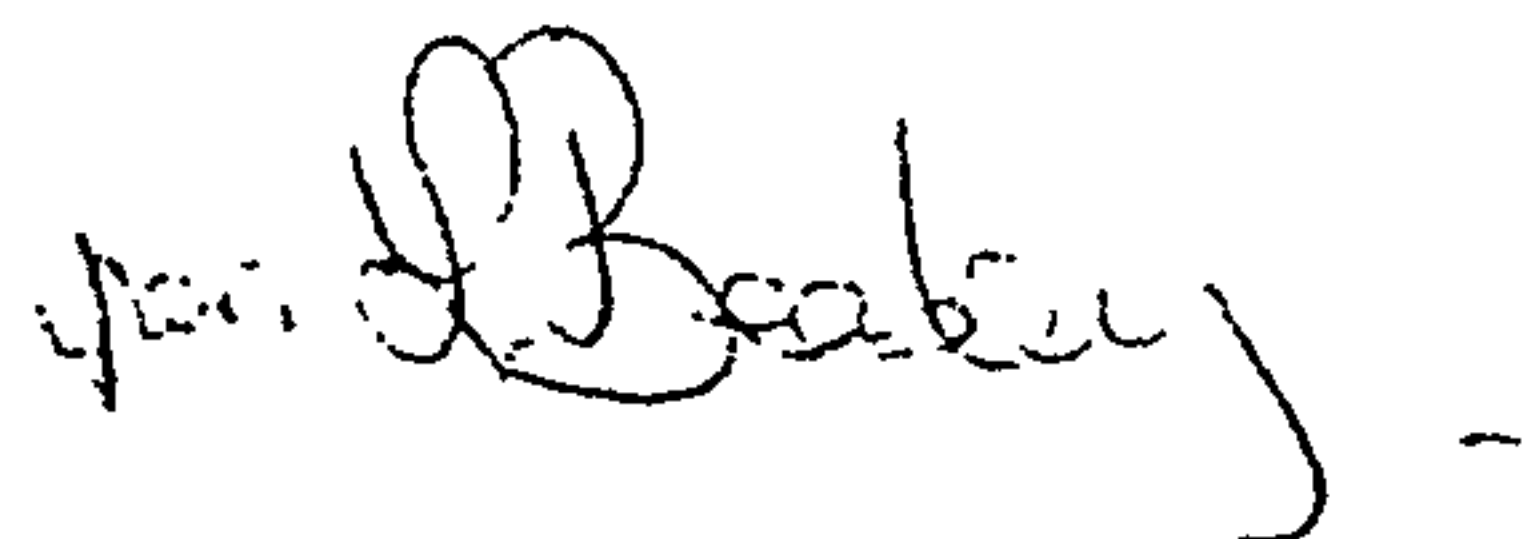
23rd May 1995

Dear Dr. Almasri

Please find enclosed your requested information on children with Down Syndrome from the Deniliquin Dental Clinic.

We apologise for this data being late, but thought that it had already been forwarded to you.

Yours sincerely



DR NEVILLE HEER
Acting Principal Dental Officer

Working Together to Make Hume Australia's Healthiest District

INCORPORATING

BURY BASE
H BROOK

BAYLOW
McCAUGHY MEMORIAL

COROWA
MERCY

CULCAIRN
TUMBARUMBA

BENTLEY
LUNN

HOSPITALS

The Deniliquin Hospital & Community Health Services

MEMO

Southwest
region

Edward Dental Clinic
1/2 Deniliquin Hospital
Deniliquin 2710

Mr Neville,

In reply to Akram Almasri's letter regarding,
"Provision of Dental Services for Children with Down Syndrome".

Question 1: Number of children age 0-14 with Down Syndrome,
who had used the public dental service in last 2 years

- 3 children. (Barham 1
Deniliquin 1
Berrigan 1)

2. What type of treatment is offered to them

- routine dental treatment

3. If they need a specialist, we would refer them
to the Albury Base Dental Clinic

4. We do not have a register of Down Syndrome
patients

Yours sincerely,

The Manager

Orana &
Far west
region

1

MACQUARIE & ASSOCIATED DISTRICTS
DENTAL HEALTH SERVICES

Windsor Court , 62 Windsor Parade ,
East Dubbo , NSW 2830
Tel (068)812222 Fax (068)812225

Dr. Akram Almasri
PO Box 508
Lakemba 2195
NSW

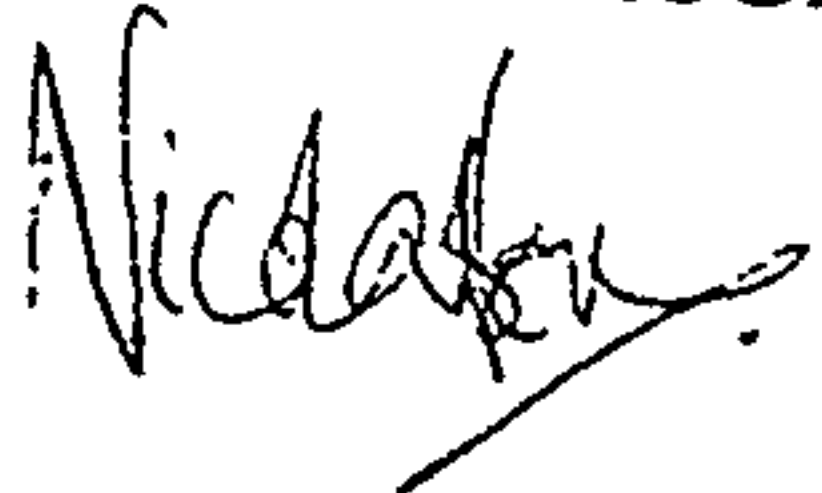
Dear Dr. Akram,

I am writing in response to your letter dated 23/3/95 regarding the provision of dental services for children with Down Syndrome in our area. The following is the information for the Macquarie area in response to the questions you asked;

1. 5 children with Down Syndrome have used the public dental service in this area in the last two years.
2. These children are offered access to all our general dental services. If appropriate they are treated by dental therapists in their locality or if this is not suitable they are referred to the Dental Officer who will provide all general dental treatment and where necessary treatment under R.A. or G.A.
- #. All treatment where possible is carried out within our service.
4. No, we do not register or have a separate list of Down Syndrome patients.

I hope this information will be of use to you. Sorry for the late response.

Yours Sincerely,



Nicola Bone
Dental Officer,
acting for Dr. Peter Roche, Principal Dental Officer,
Macquarie Health Service
11th May 1995

Dr: Akram Almasri
P.O.Box 508
Lakemba 2195
N.S.W Australia

Date: 23/03/1995

Dr: Peter Roche
Principal Dental Officer
Orana & Far West Region
P.O.Box M61
Dubbo 2830

Dear Dr Roche,

My name is Akram Almasri, a MDSc candidate at the University of Sydney, and I am writing to seek your assistance with a research project entitled "Provision of Dental Services for Children with Down Syndrome in NSW. The aims of the study are:

1. Update existing data on dental services to children with Down Syndrome in NSW.
2. To determine the type of services provided to them.
3. To gather data for future planning of dental services.

It would be most appreciated, if you or your colleague(s) can provide me with:

1. How many children (age 0 to 14) with Down Syndrome had used the public dental service in your area for the last two years? *5*
2. What type of treatment is offered to them? *mg. d.c. 6 11 12*
3. If they need specialist services to where do you refer them? *(if < 18 mg. d.c. 6 11 12)*
 - A) Within your service?
 - B) External to your service. *X*
4. Do you register or have a separate list of Down Syndrome patients? *NO*

The return of this essential data by the end of April 1995, will enable an early analysis of the public dental services for children with Down Syndrome in Australia.

I look forward to hearing from you and thank you very much, in advance, for your kind co-operation.

With best regards.

Yours sincerely,

Akram Almasri

Nicola
consult with Doreen
on this. She organises the screening
of Devel. Disabled children at
Fairview Hts. We do not make
any distinction between their conditions
Perhaps you can reply to him
on my behalf. A

Dr. Akram Almasri
P.O.Box 508
Lakemba 2195
N.S.W Australia

Date: 23/03/1995

Dr. E Piekarz
Director of Dental Services
Illawarra Area Health Service
Shellharbour School of Dental Therapy
Warilla 2528

Dear Dr Piekarz,

My name is Akram Almasri, a MDSc candidate at the University of Sydney, and I am writing to seek your assistance with a research project entitled "Provision of Dental Services for Children with Down Syndrome in NSW. The aims of the study are:

1. Update existing data on dental services to children with Down Syndrome in NSW.
2. To determine the type of services provided to them.
3. To gather data for future planning of dental services.

It would be most appreciated, if you or your colleague(s) can provide me with:

1. How many children (age 0 to 14) with Down Syndrome had used the public dental service in your area for the last two years?
2. What type of treatment is offered to them?
3. If they need specialist services to where do you refer them?
A) Within your service?
B) External to your service.
4. Do you register or have a separate list of Down Syndrome patients ?

The return of this essential data by the end of April 1995, will enable an early analysis of the public dental services for children with Down Syndrome in Australia.

I look forward to hearing from you and thank you very much in advance for co-operation.

With best regards.

Yours sincerely,

Akram Almasri

Gordon
I would appreciate
it you could provide
the response.
Regards
Gene.
28/3/95

North coast
region



RICHMOND HEALTH SERVICE

Post Office Box 419
Brisbane NSW 2480
Tel. (066) 218 000
Fax (066) 217 088

Ballina District Hospital
PO Box 523
Ballina NSW 2478
Tel. (066) 862 111

Bonvalbo Hospital
Bennett Road
Bonvalbo NSW 2470
Tel. (066) 651 203

Byron District
Hospital
PO Box 118
Byron Bay NSW 2481
Tel. (066) 856 200

Campbell Hospital
PO Box 93
Coraki NSW 2471
Tel. (066) 832 019

Casino & District
Memorial Hospital
PO Box 268
Casino NSW 2470
Tel. (066) 622 111

Coyote Memorial
Hospital
PO Box 125
Coyote NSW 2474
Tel. (066) 321 522

Esmore Base
Hospital
PO Box 419
Esmore NSW 2480
Tel. (066) 218 000

Gullumbimby &
District War Memorial
Hospital
PO Box 240
Gullumbimby NSW 2482
Tel. (066) 842 266

Hamblin District Hospital
Allen Street
Hamblin NSW 2480
Tel. (066) 891 400

Herbenville &
District Hospital
Beaury Street
Herbenville NSW 2475
Tel. (066) 341 319

Dental Services
Direct Indial: (066) 20.2142
Ref: RHS 503 PRH

Dr Akram Almasri
P O Box 508
LAKEMBA 2195

Dear Dr Almasri

Receipt is acknowledged of your letter dated 23 March 1995
regarding your research project on children with Down Syndrome.

A copy of your letter has been sent to all North Coast dental
clinics with a request that they reply directly to you with any information
they may have to assist you.

Yours sincerely

P R Hill
Principal Dental Officer



Hunter Area Health Service

COMMUNITY, AGED AND MENTAL HEALTH SERVICES

Dental Service Administrative Unit
Adamstown Dental Clinic
Cnr Kyle and Gosford Streets
ADAMSTOWN NSW 2289
Ph: (049) 57-4816, (049) 52-3033
Fax: (049) 52-9932

Dr Akram Almasri
PO Box 508
LAKEMBA 2195

Your Ref:

Our Ref:

28 March, 1995

Dear Dr Almasri,

The Hunter Area Dental Health Service would like to have been of some assistance to your research project entitled "Provision of Dental Services for children with Down Syndrome in NSW". However, we do not have a separate register or list of Down Syndrome patients at the moment and therefore it is almost impossible to provide you with information you have requested. In order to try and gather requested information one will have to go through all the patient record files in each of our 17 clinics and frankly we do not have the resources or the funding for such an exercise.

It is with great regret that we inform you of our inability to help with your research project. If you would like to discuss the matter any further please contact me on (049) 52 3033.

We hope you have better success with other areas and wish you all the best with your project.

Yours sincerely,

Sophia Lee
Clinical Team Leader
HUNTER AREA DENTAL HEALTH SERVICES

Dr. Akram Almasri
P.O.Box 508
Lakemba 2195
N.S.W Australia

Date: 23/03/1995

Dr. D Naidoo
Principal Dental Officer
Locked Bag No 4
Armidale 2350

Dear Dr Naidoo,

My name is Akram Almasri, a MDSc candidate at the University of Sydney, and I am writing to seek your assistance with a research project entitled "Provision of Dental Services for Children with Down Syndrome in NSW. The aims of the study are:

1. Update existing data on dental services to children with Down Syndrome in NSW.
2. To determine the type of services provided to them.
3. To gather data for future planning of dental services.

It would be most appreciated, if you or your colleague(s) can provide me with:

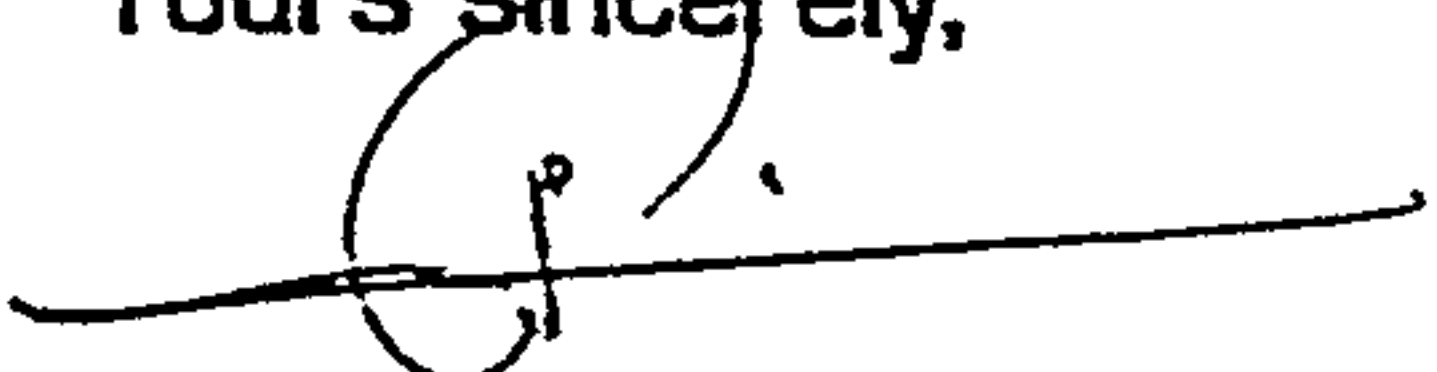
1. How many children (age 0 to 14) with Down Syndrome had used the public dental service in your area for the last two years? 1
2. What type of treatment is offered to them? *examinations.*
3. If they need specialist services to where do you refer them? *private dentists*
A) Within your service? *Dental officer.*
☒ B) External to your service.
4. Do you register or have a separate list of Down Syndrome patients? *NO.*

The return of this essential data by the end of April 1995, will enable an early analysis of the public dental services for children with Down Syndrome in Australia.

I look forward to hearing from you and thank you very much, in advance, for your kind co-operation.

With best regards.

Yours sincerely,


Akram Almasri

Dr. Rath, Selvarajah
Area School Dental Office,
Marrickville School Dental
Clinic,
Thompson Street,
Marrickville 2204,
12/4/95

Dr. Akram Almasri
P. O. Box 508
Lakemba 2195

Dear Dr. Almasri, I received your letter two weeks ago ... I am sorry that I will not be able to provide you with any of the information you require with regards to children with Down Syndrome in NSW because the School Dental Service has only treated very few children with Down's Syndrome over the years.

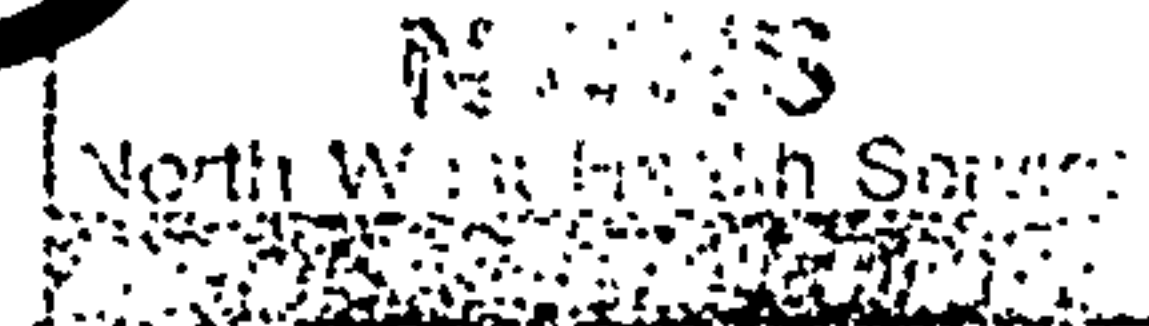
- 1) There is no register or a separate list of Down's Syndrome patients.
- 2) Treatment offered includes routine dentistry as carried out in the school dental clinics if patients are compliant. If not referral to the Dental Hospital Westmead.
- 3) For specialist services they are referred to the United Dental Hospital depending on eligibility criteria or privately.

Yours Sincerely,
RS Raju

England
region



North West Health Service
PO Box 83, Taree NSW 2340



Dr Akram Almasri,
P.O. Box 508.
LAKEMBA. N.S.W. 2195

Dear Dr Almasri,

I am in receipt of your letter dated 23.3.95 seeking assistance with your research titled "Provision of Dental Services for Children with Down Syndrome in NSW".

Below are the answers to your questions:

1. How many children (aged 0 - 14) with Down Syndrome had used the public dental service in your area for the last two years?

6 Down Syndrome children.

2. What type of treatment is offered to them?

All treatment is offered including general dental care, orthodontics and General anaesthetic etc.

3. If they need specialist services to where do you refer them?

As stated previously we provide most specialist services. If we are unable to help them we then refer to private dentists and specialists if needed.

4. Do you register or have a separate list of Down Syndrome patients?

No

I hope this is of some help to your Research Project.

Yours sincerely,

A handwritten signature in cursive script, appearing to read "Lyn Haack".

Lyn Haack
Senior Dental Therapist

SOUTH WESTERN SYDNEY AREA HEALTH SERVICE

Dr John Sanders
Area Dental Co-ordinator
Narellan Community Health
Queen Street
NARELLAN 2567

2nd May 1995

Dr Akram Almasri
P.O. Box 508
LAKEMBA 2195

Dear Dr Almasri

Thank you for your request for information regarding the provision of dental care to children with Down Syndrome in NSW.

Unfortunately, this information is not kept at the Area level and the only information available at this stage is in the larger institutions.

I am sorry that I cannot be of more assistance.

Yours sincerely

R. Howard

for: Dr John Sanders
Area Dental Co-ordinator

Dr. Caroline Hong
Area Co-Ordinator
Area Dental Services
Level 2, Vindin House
Royal North Shore Hospital
ST. LEONARDS NSW 2065

Tel: (02) 926 8217
Fax: (02) 436 3717 or
(02) 906 6174

Ref: E:\WP51\Downs

13th June, 1995

Mr. Akram Almafra
P.O. Box 508
LAKEMBA 2195

Dear Mr. Almafra,

Further to your recent request for information regarding children with Downs Syndrome, I advise that this Area Health Services does not collect specific information routinely on patients with Downs Syndrome.

To my knowledge, Dr. Antonia Scott undertook a short research project on Downs Syndrome patients not very long ago at Royal North Shore Hospital. I believe she is a staff member teaching at the Oral Surgery Department of the United Dental Hospital.

I am sorry I cannot help you with your Thesis as I do not have a copy of her report.

Yours sincerely,



Dr. Caroline Hong,
Area Coordinator - Dental Services,
Northern Sydney Area Health Service.

CORPORATING:

The Hospitals & Community Health Services of Gladesville-Macquarie, Hornsby Ku-ring-gai, Manly, Mona Vale, Royal North Shore and Ryde.

ASSOCIATION WITH:

Centre for Bone & Joint Diseases, Homes of Peace Facilities - Greenwich & Neringah Hospitals & Graythwaite Nursing Home; Royal Rehabilitation Centre, Sydney and St Catherine's Villa.

MURRUMBIDGEE HEALTH SERVICE

Griffith Base Hospital

PO BOX 1013
GRIFFITH NSW 2680
TELEPHONE (069) 62 1266
FACSIMILE (069) 62 7578
(069) 64 1587 (General Manager)

Communications to be addressed
to the General Manager



IN REPLY PLEASE QUOTE

REFERENCE JM.DD

PHONE EXTENSION 240

South
west region

27th April 1995

Dr. Akvam Almasn
PO Box 508
LAKEMBA NSW 2195

Dear Dr. Almasn

I am writing in reply to your request for data to aid you in your research project. I hope you find the information of some help.

1. How many children (age 0 - 14) with Down Syndrome had used the public dental service in your area for the last two years?

Having looked through all children registered with our clinic (2,106 children as at 10th October 1994), I could only find one child.

2. What type of treatment is offered to them?

People with Down Syndrome are offered the normal range of treatment that every other patient is offered.

3. If they need specialist services to where to you refer them?

Usually by the time they are seen by our service they have been assessed by others such as paediatricians.

- a. Within your service?

The only referral within our service is to the Dental Officer.

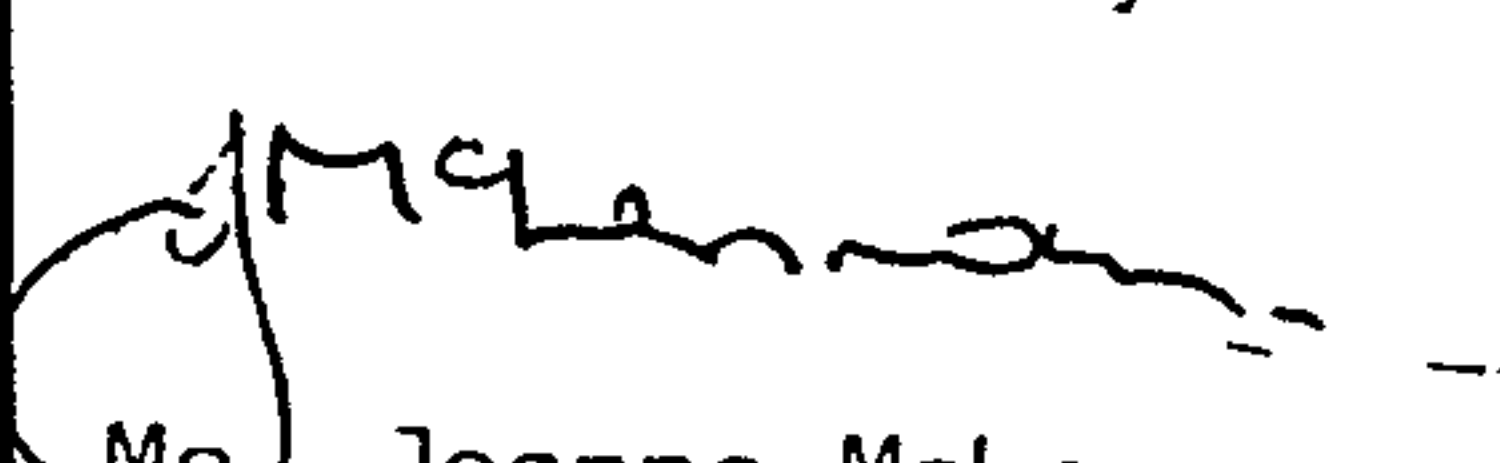
- b. External to your service?

The standard referrals to oral surgeons, orthodontists and speech pathologists are available if they are required by the patient.

4. Do you register or have a separate list of Down Syndrome patients?

Definitely no, as part of integrating people with disabilities into the general community there is no call for such a register. It would only serve as a form of discrimination to people with Down Syndrome. All our patients are offered and provided with the same dental care.

Yours faithfully


Ms Joanne McLennan
Senior Dental Therapist

STATE GOVERNMENT

NEW SOUTH WALES

Dr R.N.G. Weidenhofer
Director Dental Services
Department of Health
73 Miller Street
North Sydney NSW 2060
Postal: Locked Bag 961
North Sydney NSW 2059
Telephone: (02) 391 9425
Facsimile: (02) 391 9519

AUSTRALIAN CAPITAL TERRITORY

Dr M.J. Fleetwood
Principal Dental Officer
ACT Department of Health
Cnr Moore and Alinga Streets
Canberra City ACT 2601
GPO Box 825
Canberra ACT 2601
Telephone: (06) 245 4552
Facsimile: (06) 257 6907

NORTHERN TERRITORY

Dr A. Westwater
Director
Dental Services
Department of Health & Community Services
PO Box 40596
Casuarina NT 0811
Telephone: (089) 89 2786
(089) 89 5511

QUEENSLAND

Dr B.T. Homan
Director, Oral Health
Division of Public Health Services
Queensland Health
1st Floor
Queensland Health Building
147-163 Charlotte Street
Brisbane QLD 4000
GPO Box 48
Brisbane QLD 4001
Telephone: (07) 234 0640

SOUTH AUSTRALIA

Dr I.A. Stead
Chief Executive Officer
South Australian Dental Service
C/- Adelaide Dental Hospital
Frome Road
Adelaide SA 5000
Telephone: (08) 223 9211
Facsimile: (08) 223 1648

TASMANIA

Mr T. Sansom
Senior Policy Officer
Clinical Services Planning
Department of Health
PO Box 191B
Hobart TAS 7000
Telephone: (002) 33 3923
Facsimile: (002) 23 1163

VICTORIA

Mr H. Raysmith
Director
Statewide Operations
Health Department Victoria
555 Collins Street
Melbourne VIC 3000
Telephone: (03) 616 8153

Ms N. Savin
Manager
Policy and Programme Development
Dental Services
Statewide Operations
Health Department Victoria
555 Collins Street
Melbourne VIC 3000
Telephone: (03) 616 7491

Mr J. McLennan
Operations Manager
Dental Health Services
448 St Kilda Road
Melbourne VIC 3004
Telephone: (03) 268 7883

WESTERN AUSTRALIA

Mr D.C. Neesham
Director
Dental Services
Health Department of Western Australia
PO Box 50
Como WA 6152
Telephone: (09) 313 1622
Facsimile: (09) 313 1302

Dr J Rogers
Dep Health
Victoria
(03) 868 784

MACLEAY HASTINGS HEALTH SERVICE

Address Correspondence to
General Manager
PO Box 126
PORT MACQUARIE NSW 2444

Tel. (065) 83 1066
Fax: (065) 84 9531

TO: DR AKRAM ALMASRI
P.O. BOX 436
LAKEMBA 2195

FROM: JOHN RYAN (DENTAL OFFICER)
COMMUNITY HEALTH CENTRE
MORTON STREET
PORT MACQUARIE 2444

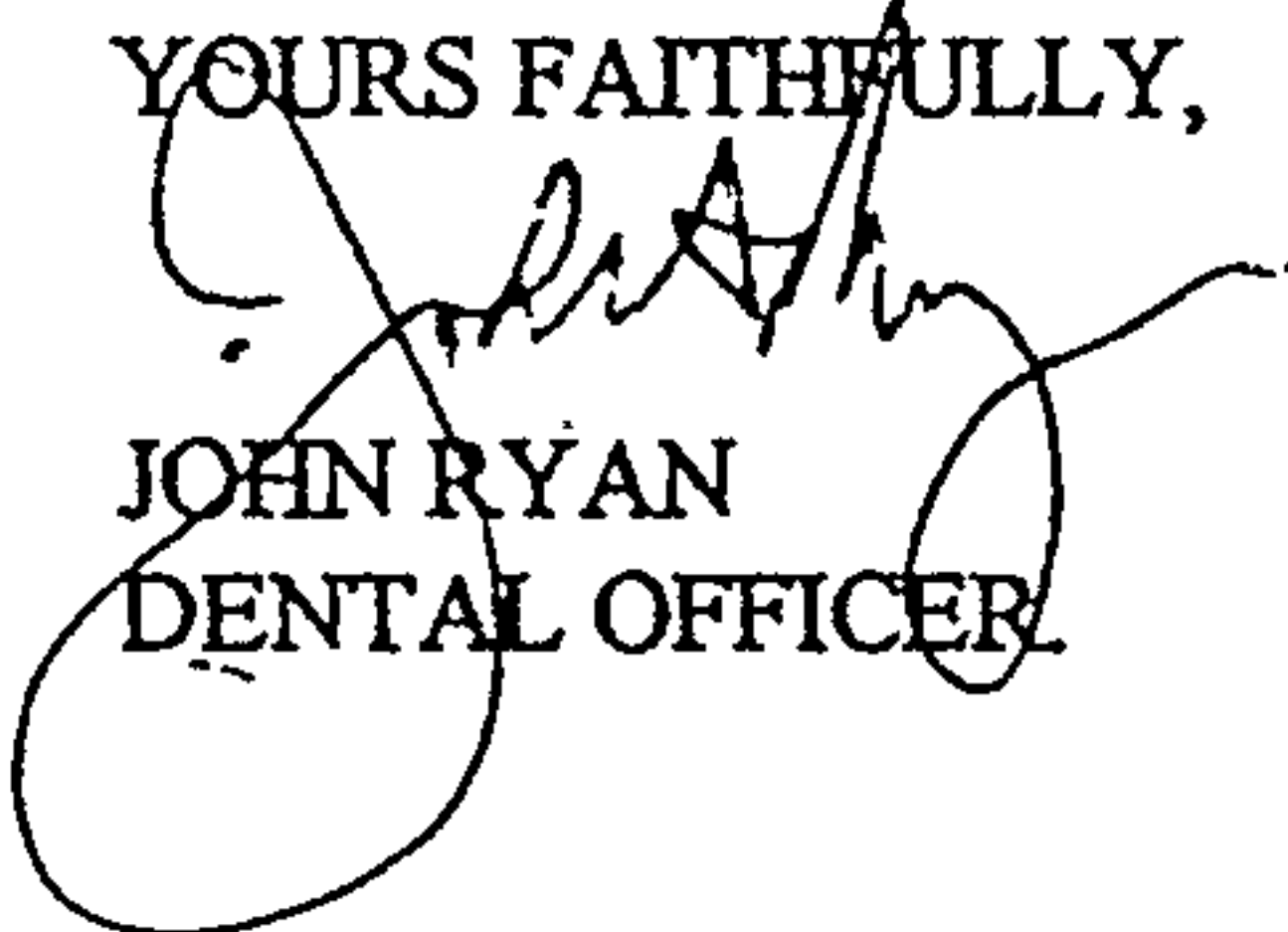
RE:- INFORMATION ON DOWN SYNDROME PATIENTS BEING TREATED.

APPROXIMATELY 8 TO 10 CASES WERE TREATED HERE LAST YEAR.

TREATMENT RANGES FROM ROUTINE TREATMENT FOLLOWING EXAMINATION ALL
CARRIED OUT IN THE DENTAL CHAIR TO G.A TREATMENT.

THIS IS OFFERED AT THIS CLINIC ONLY.

YOURS FAITHFULLY,


JOHN RYAN
DENTAL OFFICER

19 October 1994

Dr Akram Almasri
P.O. Box 436
LAKEMBA 2195

Dear Dr Almasri

**RE : INFORMATION FOR DOWN SYNDROME CUSTOMERS
MONARO HEALTH SERVICES**

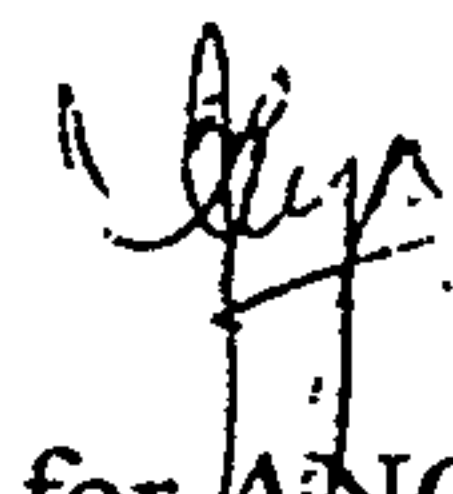
As discussed over the telephone, Down Syndrome children with complications are referred to DR PETER WONG, Paedodontist in Canberra, ACT.

Child Dental Clinics	-	2
Adult Dental Clinic	-	1

Children attending 4 known cases

Children are only referred if treatment cannot be undertaken in clinics.

Yours sincerely



for ANGELA COPP
Senior Dental Therapist



Illawarra Area Health Service

Shellharbour Hospital

Address all correspondence:

Executive Officer

PO BOX 52,

SHELLHARBOUR SQUARE 2529

Dr Akram Almasri,

P.O. Box 508,

Lakemba 2195.

Telephone (042) 952480

Ext 533.....

YOUR REF:

OUR REF:

Dear Dr Almasri,

Dr Piekarz has asked me to reply to your letter dated 23-3-95 concerning your project 'Provision of Dental Services for Children with Downs Syndrome in N.S.W.'

Question 1.

There are no statistics available in our region that specifically relates to the number of children aged 0-14 with Downs Syndrome that have used the service. However, developmentally disabled patients in general share the same facilities available to all other children in the region. Special services are available according to special needs and patients abilities to cooperate, but not specifically according to if they have a specific disability such as Downs Syndrome.

Question 2.

Treatment available is the same as other children which includes services for special needs. Enclosed is a hand out relating to specific protocol and guidelines used for the treatment of developmentally disabled patients.

Institutionalised developmentally disabled patients have a priority recall system. This allows them to be seen routinely on a regular basis. Reports are given to the patients case manager after each visit.

Question 3.

Patients requiring specialised services have a range of services available within the service including,

A\

- Special Dental Service at Shellharbour District Hospital where general dental treatment and minor oral surgery can be carried out under local anaesthetic, relative analgesia, sedation or general anaesthetic as necessary.

- Domiciliary Service.

- Orthodontic services at Port Kembla Dental clinic.

- Maxillo-facial Service at Port Kembla District Hospital.

B\

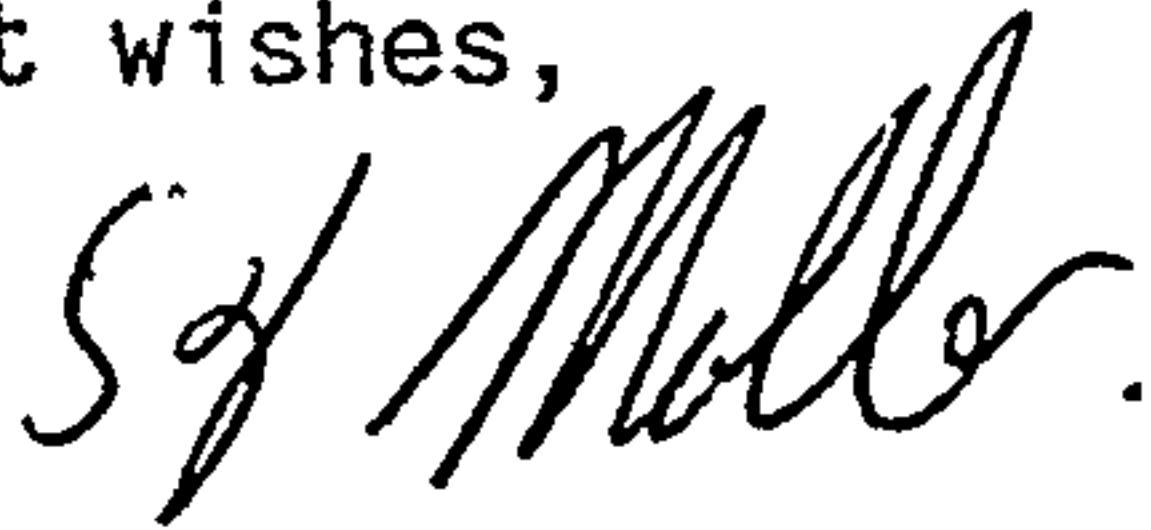
- Westmead Hospital Dental Department.

Question 4.

We do not have a separate register of Downs Syndrome patients.

I hope this information is helpful in your study. Please contact me if you require further details.

Best wishes,

A handwritten signature in cursive script, appearing to read 'G. Moller'.

Dr Gordon Moller.
Dental Officer in Charge,
Special Dental and Oral Surgery Service.
18th April 1995.

ILLAWARRA AREA HEALTH DENTAL SERVICE.

Dental Care For Developmentally Disabled Children and Adults

All patients, no matter how severe their physical condition, can be given dental treatment.

1) A programme of complete dental care for the disabled child should be started as early as two years of age. Some children may require treatment at an earlier time and fluoride should be taken from birth.

2) Patients on drug therapy, such as dilantin, may require more examinations and visits to the dentist.

3) The presence of dental disease in the disabled child is due to the same causes as in other children. However, because of the difficulties which sometimes present themselves in the dental treatment of the disabled, the teeth and gums may be in especially poor condition. If parents or health care workers are unable to clean the patient's teeth regularly, this will contribute to tooth decay and gum disease.

4) Home care is essential to the dental health of the patient. This consists of tooth brushing and a carefully chosen diet. Specially tailored oral hygiene measures and programmes may be required in order to initially gain optimal dental health for each patient and then to maintain it.

5) a) Ideally teeth should be brushed after meals, within ten minutes, and before going to bed. It may be necessary for parents or health care workers to help with this procedure.

b) A well balanced diet, avoiding sticky sweetened foods, and not eating frequently between meals will also reduce the incidence of tooth decay and gum disease.

c) Fluoride drops or tablets should be taken daily from birth up to ten years of age, if the water is not fluoridated. Topical fluorides at regular dental visits will also make the teeth more resistant to decay.

6) Anything which appears abnormal in the patients mouth if noticed by the parent or health care worker should be brought to the attention of the dentist. Often a dental problem in severely disabled patients may only be picked up by the patients carer by perhaps noticing a change in eating habits or other behaviour changes.

At The First Visit To The Dental Clinic:

An assessment will be made at the patients first dental visit to determine the child's or adult's dental health. A treatment programme will be made which will have the following aims:

- Assess the level of dental health, any factors contributing to any dental condition present, and the patients ability to undergo any dental treatment or preventive programme.

- Devise a comprehensive dental treatment programme tailored to each patients level of treatment needs and ability.

- Treat any dental disease present in a painless, relaxed atmosphere.

- Maintain dental health by individualised preventive programmes.

Every endeavor is made to get patients accustomed to having their treatment performed normally in the dental chair. The patient is also encouraged to maintain their own oral hygiene as best as they are able. This may require the use of special aids, such as an electric toothbrush, or may require oral hygiene to be maintained completely by the carer as necessary. The aim is to give the patient the opportunity to develop and achieve their maximum independence in both their receiving dental treatment and in their preventive dental programme. Multiple, short dental appointments may be required at the clinic to complete dental work for some patients.

Patients may be assessed as requiring their treatment to be performed under general anaesthetic. This is when it has proved impossible to perform the dental treatment otherwise, if the degree of operative treatment needed is better performed this way. Once the initial dental condition is under control, subsequent treatment may often be able to be carried out as normal in the dental surgery. The amount of treatment required at future dental visits will depend on the effectiveness of preventive dental measures carried out at the time.

Information needed at the initial visit are details of medical history including the patients degree of disability and their ability to understand and communicate. Details of past dental treatment, dental hygiene, and dietary habits can also be very relevant in planning treatment. It is very helpful if the patients parent(s), guardian or 'Person Responsible' can attend at least the initial visit so that details can be discussed and consent can be gained when needed.

Gordon Moller
August 1993.

At The First Visit To The Shellharbour Hospital Dental Clinic:

An assessment will be made at the patients first dental visit to determine the child's or adult's dental health. A treatment programme will be made which will have the following aims:

- Assess the level of dental health, any factors contributing to any dental condition present, and the patients ability to undergo any dental treatment or preventive programme.
- Devise a comprehensive dental treatment programme tailored to each patients level of treatment needs and ability.
- Treat any dental disease present in a painless, relaxed atmosphere.
- Maintain dental health by individualised preventive programmes.

Every endeavor is made to get patients accustomed to having their treatment performed normally in the dental chair. The patient is also encouraged to maintain their own oral hygiene as best as they are able. This may require the use of special aides, such as an electric toothbrush, or may require oral hygiene to be maintained completely by the carer as necessary. The aim is to give the patient the opportunity to develop and achieve their maximum independance in both their receiving dental treatment and in their preventive dental programme. Multiple, short dental appointments may be required at the clinic to complete dental work for some patients.

Patients may be assessed as requiring their treatment to be performed under general anaesthetic. This is when it has proved impossible to perform the dental treatment otherwise, or if the degree of operative treatment needed is better performed this way. Once the initial dental condition is under control, subsequent treatment may often be able to be carried out as normal in the dental surgery. The amount of treatment required at future dental visits will depend on the effectiveness of preventive dental measures carried out at home.

Information needed at the initial visit are details of medical history including the patients degree of disability and their ability to understand and communicate. Details of past dental treatment, dental hygiene, and dietary habits can also be very relevant in planning treatment. It is very helpful if the patients parent(s), guardian or 'Person Responsible' can attend at least the initial visit so that details can be discussed and consent can be gained when needed.

SHELLHARBOUR DISTRICT HOSPITAL DENTAL CLINIC. (G.J.M.'93.)

Dental Care of Developmentally Disabled Children and Adults

All patients, no matter how severe their physical condition, can be given dental treatment.

1) A programme of complete dental care for the disabled child should be started as early as two years of age. Some children may require treatment at an earlier time and fluoride should be taken from birth.

2) Patients on drug therapy, such as dilantin, may require more examinations and visits to the dentist.

3) The presence of dental disease in the disabled child is due to the same causes as in other children. However, because of the difficulties which sometimes present themselves in the dental treatment of the disabled, the teeth and gums may be in especially poor condition. If parents or health care workers are unable to clean the patient's teeth regularly, this will contribute to tooth decay and gum disease.

4) Home care is essential to the dental health of the patient. This consists of tooth brushing and a carefully chosen diet. Specially tailored oral hygiene measures and programmes may be required in order to initially gain optimal dental health for each patient and then to maintain it.

5) a) Ideally teeth should be brushed after meals, within ten minutes, and before going to bed. It may be necessary for parents or health care workers to help with this procedure.

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c) Fluoride drops or tablets should be taken daily from birth up to ten years of age, if the water is not fluoridated. Topical fluorides at regular dental visits will also make the teeth more resistant to decay.

6) Anything which appears abnormal in the patients mouth if noticed by the parent or health care worker should be brought to the attention of the dentist. Often a dental problem in severely disabled patients may only be picked up by the patients carer by perhaps noticing a change in eating habits or other behaviour changes.

Addresses

Head of Dental Services
Dental Administration,

PO Box 117
WARILLA 2528
Tel: (042) 971.044

ADULT SERVICES:

CLINIC/HOSP/C.H.C.

Port Kembla District Hospital
Cowper Street,
WARRAWONG. 2502.
Tel: (042) 755.968

Bulli District Hospital
Hospital Road,
BULLI. 2516.
Tel: (042) 830.659

Warilla Dental Clinic,
Belfast Avenue,
WARILLA. 2528.
Tel: (042) 97 1055

Shoalhaven District Memorial
Hospital,
Shoalhaven Street,
NOWRA. 2541.
Tel: (044) 213.111

Ulladulla Dental Clinic,

ULLADULLA. 2539. *

Domiciliary Dental Service,
Port Kembla Dental Clinic,
WARRAWONG. 2502
Tel: (042) 755.968

Shoalhaven District Hospital
Mulligan Boulevard
Shoalhaven 2522
Referrals only. Enquiries no.
044 213 111

Commonwealth Dental Program.

The Commonwealth Dental Program only applies to persons over 18 years who are either dependants of Card Holders or Holders of Health Cards.

The relevant cards are:

- Pensioner Concession Card
- Health Care Card.
- Health Benefits Card.
- Commonwealth Seniors Health Card

Eligible patients may obtain a maximum of 2 Emergency vouchers or 1 General voucher in any 12 month period. These vouchers can be taken to any participating practitioner. Patients unable to select a practitioner can be shown lists of practitioners known to participate in the scheme. Dental Services are not permitted to release these lists.

Emergency vouchers are for a limited range of services and have a maximum value of \$100 at the approved fee schedule.

General Vouchers cover a wider range of services but have a maximum value of \$400. The value of any treatment carried out on Emergency vouchers is deducted from this maximum value. After a General voucher is issued no other voucher can be issued for 12 months.

Any treatment carried out in excess of the maximum figure is a private contact between the patient and the practitioner. There is no provision for reimbursement of fees.

Vouchers are only issued at the adult clinics and patients must normally attend in person. Patients unable to attend personally may be required to present a medical certificate from a Medical Practitioner or a Community Nurse stating the medical reason for the patients non attendance. The relevant entitlement card must be sighted by the issuing officer.

General vouchers are available to patient already on the waiting lists but exceptions are made for medical reasons in individual cases. Most developmental disability patients would be considered for a General Voucher.

ULLAWARRA AREA HEALTH DENTAL SERVICE.

DENTAL CARE FOR THE DEVELOPMENTALLY DISABLED.

School Dental Clinics.

Preschool and school children up to the age of 15 can have appointments made at the nearest school dental clinic. (See directory attached.) Developmentally disabled children will normally be given an appointment to initially see the visiting dental officer, who will assess the patient and organise a treatment programme as necessary. Subsequent treatment may be carried out by a Dental Therapist as assessed by the Dental officer.

Hospital and Community Health Dental Clinics.

Adults above the age of 15, who have an appropriate Commonwealth Government benefits card, can be given appointments to see the dentist at the nearest adult dental clinic. Patients over 18 years of age may also be eligible for treatment under the Commonwealth Dental Programme as outlined on page 6/.

All adult dental clinics, with the exception of the Ulladulla mobile, have wheelchair access.

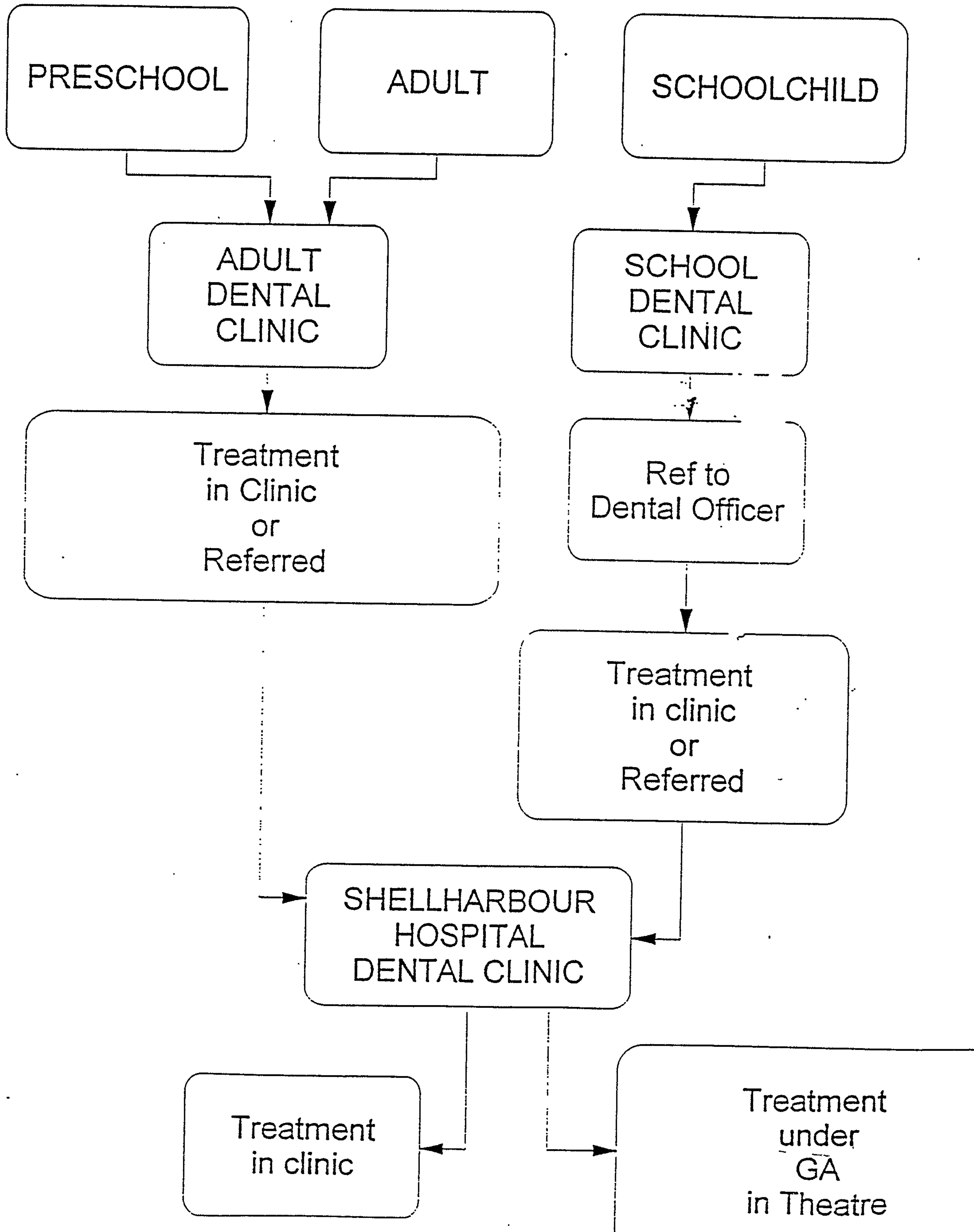
Homely Care Service.

Homely care visits can be arranged by phoning the Port Kembla Dental Clinic. Patients are seen when the patient is not immediately able to be transported to a dental clinic. Follow-up dental treatment is usually necessary to be carried out at dental clinic. Periodical home assessments to determine patients dental needs can be arranged.

Shellharbour Dental Clinic.

Patients are referred as necessary by the dental officer from above clinics to the Shellharbour Dental Clinic. This includes patients that may require treatment to be carried out under general anaesthetic. On completion of this treatment, patients will normally be able to continue their ongoing routine dental treatment at the referring dental clinic.

DD
Dental
Patients



ENQUIRIES BT Homan
PHONE 234 0637 **Fax:** 234 1223
OUR REF 0800-0181-001
YOUR REF

Dr Akram Almasri
PO Box 508
LAKEMBA NSW 2195

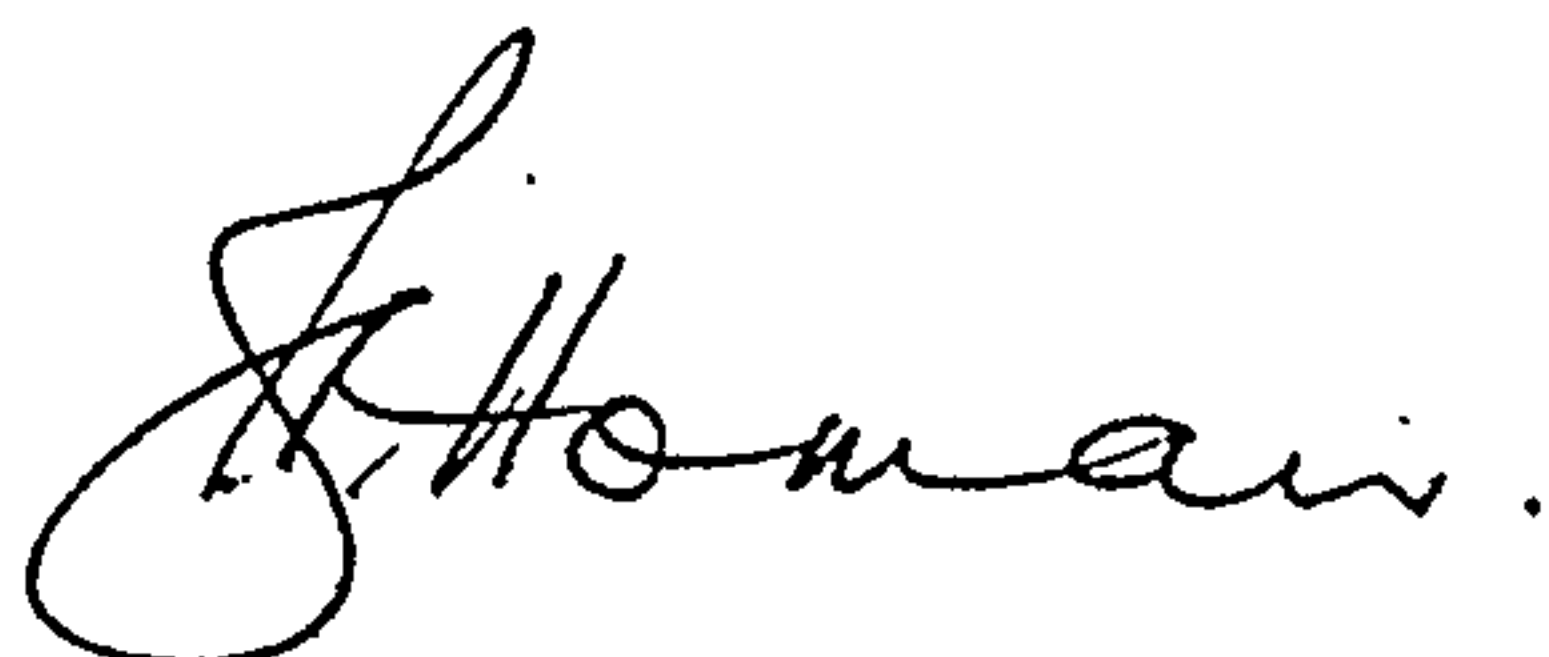
Dear Dr Almasri

Thank you for your letter of 23 March 1995 requesting information for your research project "Provision of Dental Services for Children with Down Syndrome in Australia".

I regret that we are unable to provide the information you require at this time, as this type of information is not currently collected in the management information system. A complete data system is under development in conjunction with the Commonwealth Dental Health Program, which will provide this capacity in the future.

I wish you the best in your study.

Yours sincerely



BT HOMAN
DIRECTOR, ORAL HEALTH

28 April 1995



File: 94/2862

11 April 1995

Dr Akram Almasri
PO Box 508
LAKEMBA NSW 2195

Dear Dr Almasri

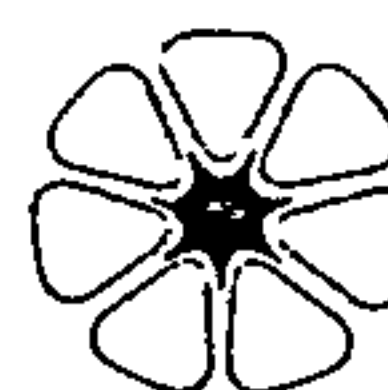
Thank you for your letter dated 23 March 1995 enquiring about dental services to Downs Syndrome patients.

We do not specifically identify these patients therefore we cannot provide numbers or numbers of services to them. We have no special lists. They are just treated as a part of our service to handicapped patients and where possible treated in the surgery but otherwise treated under general anaesthetic.

I am sorry I can provide no further information.

Yours sincerely

Agnes Westwater
Program Director, Dental



SADSA 09/
AC:sk

27 April 1995

Dr Akram Almasri
PO Box 508
LAKEMHA 2195
NSW

Dear Dr Almasri

With regard to your request for information to assist you with your research project entitled "Provision of Dental Services for Children with Down Syndrome in Australia" I am, unfortunately, able to supply you with very little specific information in response to your four questions.

- 1) **"How many children (age 0 to 14) with Down Syndrome had used the public dental service in your area for the last two years"**

The School Dental Service(SDS), a division of the SA Dental Service, does not maintain any register of client details, at a clinic or state level, which could provide any information 'classified' by medical condition.

- 2) **"What type of treatment is offered to them?"**

The full range of dental services for all children eligible for care by the SDS are available for children with Down Syndrome. These children are eligible for SDS care at any of the 85 fixed clinics and also at the mobile clinics which are used in some country areas. There is no discrimination nor restriction on the type and quality of dental treatment these children may receive. This care includes treatment provided by teams of dentists and dental therapists and, based on the needs of the individual, includes routine examination, preventative and restorative care. The SDS does not provide specialist orthodontic care, but where clients are eligible for orthodontic care at the Adelaide Dental Hospital this service is available for those requiring care.

- 3) **If they need specialist services to where do you refer them?**

- a) **Within your service.**

- i) Specialist Paedodontic services are available within the SDS - up until 1994 Dr John Burrow provided care at one of the metropolitan SDS clinics, the Adelaide Dental Hospital pedo clinic and at the Adelaide Children's Hospital (now Women's and Children's Hospital).

On the retirement of Dr Burrow, care is provided by Dr Andrew Bills at that clinic (Dr Bills also provides a general anaesthetic dental service at some community hospitals in the southern suburbs of Adelaide for SDS patients requiring GA's), and Dr Sue Springbett who is studying for her Masters Degree in Paedodontics and who works as a SDS District Dentist.

Eligible (Cardholders and Dependants) Down Syndrome children are also eligible for Specialist Dental Services at the Adelaide Dental Hospital (a division of SADS) and may be cared for in any number of specialised clinics including Oral and Maxillofacial Surgery, Periodontics, Complex Restorative and Prosthetic and at the Tooth Wear or High Caries Risk Clinics.

b) External to your service

- ii) Specialist dental services are also able to be provided by the Dental Clinic at the Adelaide Women's and Children's Hospital, Kermode St, North Adelaide 5006 where Dr Vita Luks is the dentist in charge. This clinic also offers a comprehensive range of dental services either by staff or specialists or by referral if a speciality is not available on staff.

Services available at the Women's and Children's Hospital include orthodontic care and may also include craniofacial surgery. You may wish to contact Dr Luks directly for further details about dental services provided by the Women's and Children's Hospital - she has indicated she would be happy to assist you, as she has an interest in this area also.

Specialist dental services are also provided, at the clients expense, by private dental specialists on referral. The SDS dentist would discuss the need for any such referral with the parents/guardian of the patient and if they were not eligible for care at the Adelaide Dental Hospital, the patient may elect to seek private care. All Down Syndrome children are however eligible for treatment at the Women's and Children's Hospital.

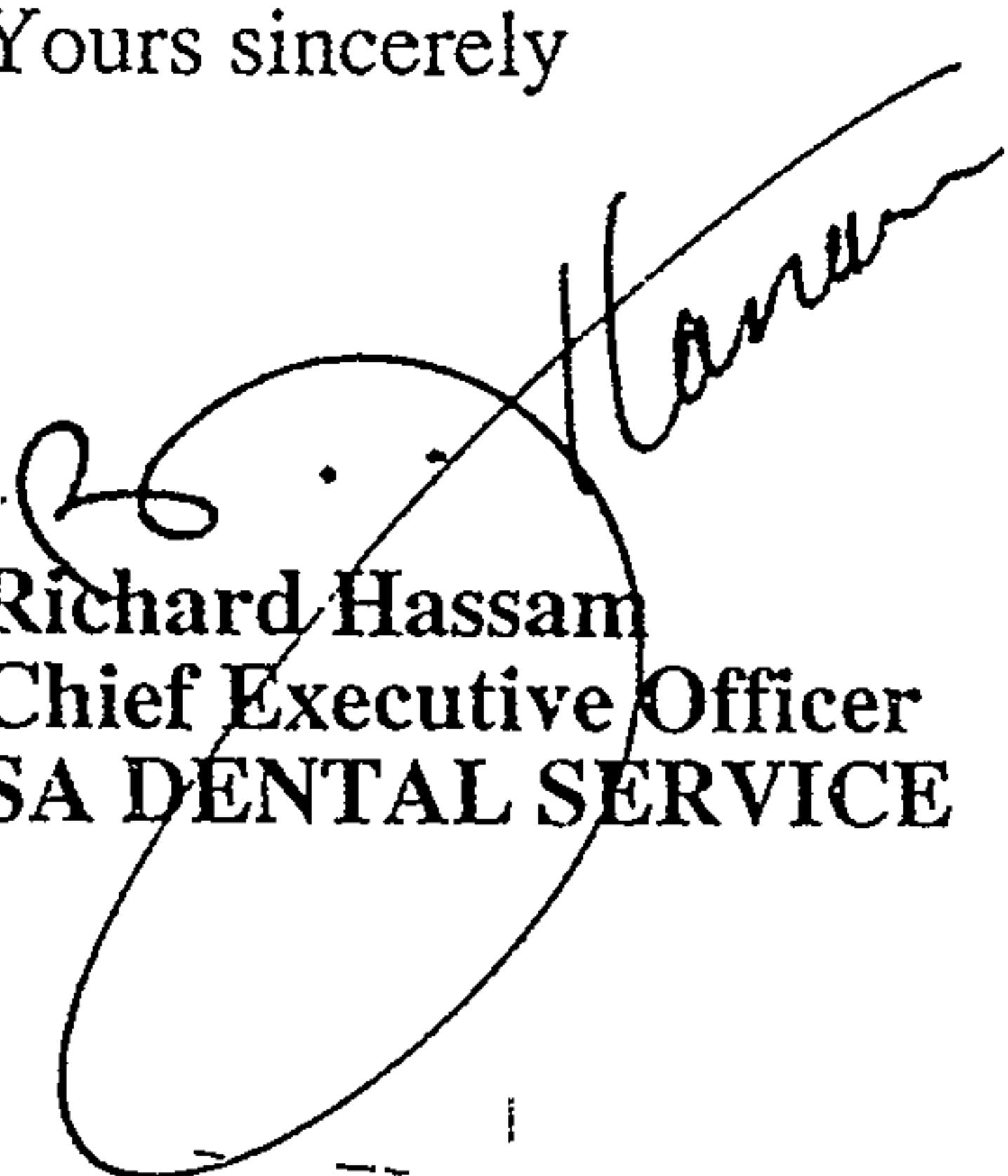
4 **Do you register or have a separate list of Down Syndrome patients?**

No, the SDS does not maintain a separate register of Down Syndrome patients. I am aware that the Women's and Children's Hospital may have data on the numbers of children they have seen but they also do not currently maintain a register of Down Syndrome patients.

There is a Birth Defects Register in SA - maintained by Dr Eric Haan of the Genetics Department of the Women's and Children's Hospital - but this is not a list of patients seeking dental services.

I wish you well in your research project and if I am able to be of assistance in the future please feel free to contact me.

Yours sincerely



Richard Hassam
Chief Executive Officer
SA DENTAL SERVICE

Your ref

Our ref

Enquiries

Mr P McAuliffe

Dr Akram Almasri
PO Box 508
LAKEMBA NSW 2195

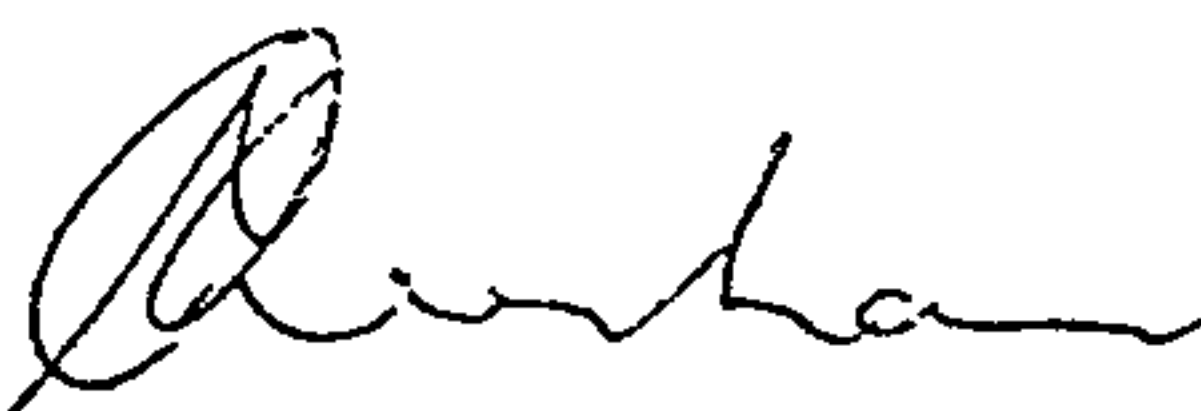
Dear Dr Almasri

Thank you for your letter of 23 March 1995 seeking information for your research project on dental services for children with Down Syndrome. Information requested is as follows:-

1. Statistics are not kept on the numbers of children with Down Syndrome treated in School Dental Service or other public dental clinic. It is likely most are treated in School Dental Service clinics with those requiring specialist care being referred to either Perth Dental Hospital if they meet eligibility criteria, or private practice.
2. All children from preschool to the end of Year 11 are eligible for dental care under the School Dental program. This program provides non specialist care. Children requiring specialist services if eligible are referred to Government clinics where they receive a full range of specialist care. Non eligible children requiring specialist care are referred to private practice. (Care under general anaesthesia is considered a specialist treatment).
3. Patients requiring specialist services are referred within the Service if they meet eligibility criteria for subsidised care, or if not, referred to private specialists.
4. No.

I trust this information is of assistance to you.

Yours sincerely



D C NEESHAM
DIRECTOR
DENTAL SERVICES

11 May 1995
PMcA:CB/almasri

13 Mt Henry Road Como WA 6152 Tel 09 313 1522 Fax 313 1302

Letters PO Box 50 Como WA 6152



Australian Capital
Territory

Department of Health

GPO Box 825
Canberra ACT 2601

☎ (06) 205 0979

Fax (06) 205 0984

File No.

Dr. Akram Almasri,
P.O. Box 508,
Lakemba,
NSW
2195.

Dear Dr Almasri,

Thank you for your letter dated 23 March 1995.

The ACT Dental Service does not specifically record services provided to children with Downs Syndrome. I have however spoken with Dr. Mohan Bhullar who treats the majority of the disabled children that present to the service. The figures quoted are estimations based of clinical experience.

1. Approximately 20.
2. Usually whatever is required, except that for any client the service offers only limited orthodontics, and no crown and bridge work. Restoration and extractions are regularly provided, under G.A. if necessary.
3. Some Orthodontic and oral surgical assistance is available within the service, and clients can also be referred outside the service, particularly in particular to a paedodontist.
4. No.

I hope this information is of assistance to you. Good luck with your research project.

Yours sincerely,

Michael J. Fleetwood BDS MSc DDPH.
Principal Dental Officer.

Our reference
Your reference



**Dental Health
Services**

448 St Kilda Road
Melbourne Vic 3004
Tel: (03) 868 7888
Fax: (03) 867 1380

5th May, 1995.

Dr Akram Almasri,
Dentist,
P.O. Box 508,
LAKEMBA 2195.

Dear Akram,

I am the dentist who provides most of the dental treatment for children with disabilities for Dental Health Services in Victoria. Your letter addressed to the Operations Manager was therefore forwarded to me, and I apologise for the delay in replying to it.

Unfortunately, I am unable to provide you with a great deal of specific information. My answers to your questions are:

1. No figure available.
2. Full basic dental service commensurate with degree of co-operation. The service I provide is addressed to children attending in "segregated" settings - "Special Developmental" and "Special" schools, and aims to achieve a maximum recall period of 12 months. Children can be seen regularly throughout the year as a single surgery van visits the school for frequent short periods. Other children in some "Special" schools and those integrated into main-stream schools may have basic recall periods of 24 months unless categorised to be recalled in 12 months. In the "segregated" settings the children are seen by dentists. In the integrated settings they are seen by therapists and dentists if requested. It is difficult to estimate, but it is likely that a majority of young children with Down Syndrome are now integrated into primary schools for most of the school day. A greater proportion of the post-primary aged children are in "segregated" settings.
3. A] Nil
B] Public Sector: Royal Children's Hospital, Department of Dentistry;
Royal Dental Hospital of Melbourne.
Private specialists - at parents'/caregivers' expense.
4. No.

I contacted the Secretary of the Down Syndrome Society of Victoria regarding statistics. She is not aware that children born with Down Syndrome are specifically recorded in Victoria so that the number in the age group 0 to 14 would only be an estimate based on the accepted incidence rate (? 1:680) in the population of this age group (I guess with other allowances made for a different infant mortality rate, etc.). All such children attending schools would be eligible for treatment within our service. Consent rates vary at different schools, and we have no information to indicate whether children with Down Syndrome are a normal part of this variation.

For children in both integrated and "segregated" settings, Dental Health Services does not classify or register children according to disability.

I trust that this information - or its lack - is of use to you. Please contact me if you wish to check something further.

With best wishes for your project,

A handwritten signature in black ink, appearing to read 'Nick Baker', with a stylized flourish at the end.

Nick Baker (Dentist).
Tel (03) 646 3938/5361.



P.O. BOX 4142
AUCKLAND 1

12 August 1994

22 August 1994

Dr A. Almasri
P.O. Box 436
Lakemba 2195
NSW
Australia.

Dear sir,

Thank you for your letter of 1st August 1994.

We would suggest you contact the Down Syndrome Association of New south Wales and in particular request the papers written by Antonia Scott. The Association would also be able to provide you with information from 'Down Syndrome - Advances in Medical Care' Ira T. Lott, Ernest McCoy Editors. As we are only a relatively small organisation we don't produce many papers or finance research - our primary aim is the support of parents.

I enclose a brief description of our Association's aims and objectives and also a recommended reading list which may be of assistance.

Yours faithfully,

D. Shaw
Secretary

The Down's Association

Affiliated with IHC



P.O. Box 4142
AUCKLAND 1

*Do you have a child with Down's Syndrome?
Do you know a family caring for someone with Down's Syndrome?*

Then you need:—

THE DOWN'S ASSOCIATION

- Up-to-date information about Down's Syndrome
- Meetings with Professional Speakers
- Family Outings
- Monthly Newsletter
- A Support Network — someone to talk to
- Help for appropriate education for your child

*YES — I HAD BETTER JOIN!!!
— How Much?*

\$20 Membership Fee (Donations are tax deductible)

For this I will receive . . .

- A monthly newsletter — up-to-date information
- Support and contact
- Meetings

I WILL JOIN NOW!!!



Detach and Post

The Secretary,
Down's Association
P.O. Box 4142,
AUCKLAND

Name:

Address:

Phone:

Receipt Required: Yes: No:



P.O. BOX 4142
AUCKLAND 1

The Down's Association

The Down's Association is a non-professional, parent-driven organisation affiliated to IHC and has branches throughout New Zealand.

It's aims are;

- (a) To support parents
- (b) To develop the potential of the person with Down syndrome to it's fullest extent
- (c) to promote public awareness about Down Syndrome

To meet these objectives the Association provides a wide range of services:

- Parents who have undergone training are available to visit new parents. It can be immensely reassuring to talk with parents who have experienced and understand the issues and emotions and worries which arise upon the birth of an infant with Down Syndrome.
- Hospital kits containing introductory information are provided by the Association and available at maternity hospitals and also upon request to members of the public interested in learning more about Down Syndrome.
- Support groups are organised and are held informally in the various centres
- Newsletters are produced and distributed on a national basis.
- Education forums are held from time to time on such issues as Wills and Trusts, siblings and the child with Down Syndrome etc
- Speakers are provided to groups, students and community organisations etc
- Recreational and social gatherings are organised from time to time.



P.O. BOX 4142
AUCKLAND 1

RECOMMENDED READING ON DOWN SYNDROME

Stray-Gundersen K ed, *Babies with Down's Syndrome - A New Parent's Guide*. Woodbine House, USA 1986.

Pueschel S, *A Parent's Guide to Down Syndrome/Towards a Brighter Future*. Paul Brooks Publishing Co. 1990.

Down Syndrome Advances in Medical Care. Edited Lott, McCoy. Publisher Wiley-Liss, New York. 1993.

Shepperdson, *Growing up with Down Syndrome*. Published by Hodder & Stoughton, June 1990. \$186.95. (Supplied by Penguin).

Lane D & Stratford B, *Current Approaches to Down Syndrome*. Published by Hodder & Stoughton, June 1990. \$124.95. (Supplied by Penguin).

Byrne, *Family & Child with Down Syndrome*. Published by Hodder & Stoughton, January 1989. Hardback \$135.00, Paperback \$57.95. (Supplied by Penguin).

Selkowitz, *Down Syndrome the Facts*. Published by Oxford. 1989. \$26.95. Supplied by Random Century.

Newton R, *Down Syndrome*. Published by Optima. 1992. \$15.95.

Cunningham C, *Down Syndrome : An Introduction for Parents*. Souvenir Press, 1988.

Cairo, Shelley et al, *Our Brother has Down's Syndrome - An Introduction for Children*. Annick Press. 1985.

DOWN'S SYNDROME ASSOCIATION OF IRELAND

5 FITZWILLIAM PLACE DUBLIN 2 TEL: 6769255/59/63 FAX: 6769242

TO: Dr Akram Almasri

FROM: Joseph Greevy Chief Executive D.S.A.I.

DATE: 10th August 1994

PAGES (incl. cover note) 1

MESSAGE:

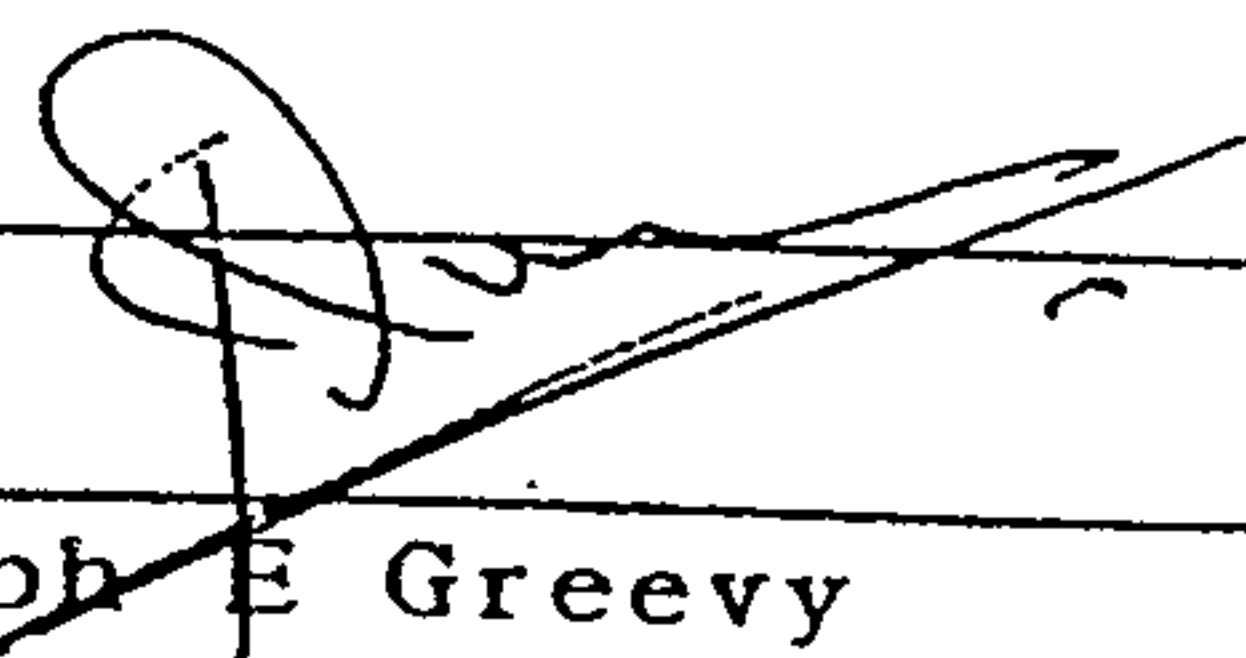
Your letter of 1st August refers. There are Down Syndrome Associations in Australia at the following addresses:-

(1) Down Syndrome Association of New South Wales Inc,
31 O'Connell Street, Parramatta NSW 2150, P.O. Box 2356,
North Parramatta, Australia.

(2) Down Syndrome Association of Queensland, P.O. Box 1293,
Milton, Queensland 4064, Australia.

I suggest you contact one of these groups to get the information you seek. I also suggest you acquire a copy of "Down Syndrome - The Facts" by Mark Selikowitz, who is a Consultant Paediatrician at the Prince of Wales Children's Hospital, Sydney, Australia.

Yours sincerely,



Joseph E Greevy

CHIEF EXECUTIVE

IF YOU DO NOT RECEIVE ALL THE PAGES PLEASE TELEPHONE IMMEDIATELY



DOWN SYNDROME ASSOCIATION OF THE NORTHERN TERRITORY INC

P.O. BOX 41545,
CASUARINA, N.T. 0811
AUSTRALIA.
PHONE: (089) 27 2211
FAX: (089) 27 2399

22/9/94.

Dear Sir,

Thank-you for your enquiry
about information re Provision of Dental
Service for children with Down Syndrome.
We would advise you that there
is an Association in N.S.W. and
you can contact them on the
following number - 6834333 (telephone
Fax - 4282302 or P.O. Box 2356, Al. Panameter
I am sure they will be able to help
you more personally

Regards

Joan Halverson

information from mencap

LEARNING DISABILITY (MENTAL HANDICAP)

WHAT IS LEARNING DISABILITY?

Learning Disability is the current term for what is still often known as mental handicap. It implies a level of intelligence significantly below the normal range with associated poor social skills. In most cases, the condition is present from birth, though it is not always immediately recognised. In some cases, it results from illness and or injuries suffered during childhood.

There are over 1 million people with some degree of learning disability, and perhaps 160,000 adults and children in England with severe disability. Learning disability will not be identified by IQ tests alone; but those with an Intelligence Quotient of less than 65 will commonly be considered to have a learning disability. Further broad distinctions are drawn between those with mild, moderate, severe and profound learning disability. The more severe the learning disability, the greater the likelihood of additional physical disabilities.

WHAT ARE THE CAUSES OF LEARNING DISABILITY?

By no means all the causes of learning disability are known; but some hundreds are. They range from defects in the cells, some inherited and some not; through infections or health problems affecting the Mother during pregnancy; to accidents around the time of birth; to infections and accidents after birth.

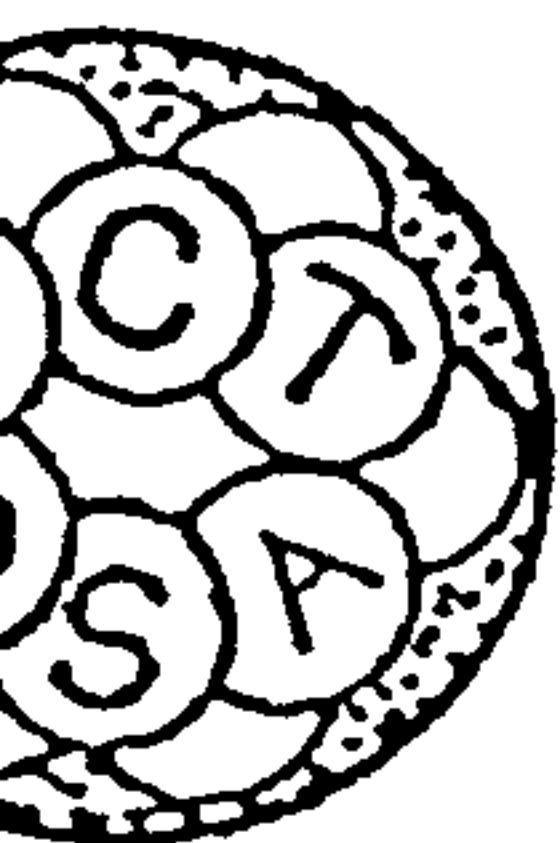
WHAT CAN I DO TO REDUCE THE CHANCES OF HAVING A CHILD WITH LEARNING DISABILITY?

Taking the normal steps to ensure a healthy pregnancy and good postnatal care. If there is a family history of learning disability, seek genetic counselling.

HOW IS LEARNING DISABILITY IDENTIFIED? WHAT HELP IS AVAILABLE?

With some, but not all children the signs are immediately apparent. Good care for Mother and baby, in hospital and at home, from birth through the early pre-schools years, should enable any problems to be recognised. It is not always easy for parents to recognise something is not quite right, especially if this is a first child; but the Mother is often the first person to identify the need for further investigation. Sometimes, development milestones are not reached at around the usual age because of problems with sight or hearing, and it is important to have all the possibilities checked out.

Under the Education Acts, parents can ask for a full assessment even before the age of 2., when there are problems which suggest that special help before school starts and at school might be needed.



Australian Capital Territory A.C.T Down Syndrome Association Incorporated

P.O. Box 717, MAWSON A.C.T. 2607

SHOUT Office, Pearce Community Centre, Collett Place, Pearce A.C.T. 2607. Phone 290 1984

Wednesday 10 August 1994

Dr Akram Almasri
PO Box 436
Lakemba NSW 2195

Dear Dr Almasri

I am sending you the information you requested in your letter dated 1.8.94 and hope it will be useful to you.

You would be very welcome as a member of our association although it might be better for you to make contact with the NSW Down Syndrome Association as they are much closer to you. Their address is 31 O'Connell Street, Parramatta, and the phone number is (02) 683 4333, they are open between 9.15am and 3.15pm. They also have a very extensive library.

Please don't hesitate to contact again if we can be of any assistance.

Yours sincerely

Karen Connaughton
President.

ACT Down Syndrome Association Inc.

SHOUT OFFICE: P.O. Box 717, Mawson, ACT 2607.
Pearce Community Centre,
Collett Place, Pearce. ACT. 2607.

PHONE: 290 1984

The ACT Down Syndrome Association Incorporated is a self help organisation which was formed in 1987 by a group of interested parents.

Aims

The aims of the Association are to provide support and information to families with a member who has Down Syndrome, to promote improvements in the quality of life of persons with Down Syndrome and to stimulate within the wider community an awareness of the very real abilities, as well as the needs of, people with Down Syndrome.

Family contact.

One of the Association's greatest concerns is that of the family with a new baby with Down Syndrome. Through our parent support activities we provide support, information and encouragement to help these families.

We encourage the parents of new babies to meet with the parents of an older child, not only because of the particular information that can be passed on, but also because there can be a special kind of rapport between people who have experienced the same trauma. Our parent support contact is available to visit the parents of a new baby either in hospital or in the home whenever parents feel that they would like to meet another parent.

Information services

The Association has a resource library which contains information on different aspects of Down Syndrome. These books and videos are available from the SHOUT office. In addition the Association operates a Computer Resources Centre for parents to borrow and trial educational software to see if it meets their child's needs.

The Association publishes a quarterly newsletter and provides speakers to any group wishing to know more about Down Syndrome.

The Association is a member of the Australian Down Syndrome Association and therefore has access to a wide range of information and resources.

improving life styles of people with learning disabilities

bild

Information Package

BRITISH INSTITUTE OF LEARNING DISABILITIES

improving life styles of people with learning disabilities.

bild

INFORMATION AND RESOURCES

INFORMATION AND RESOURCES

If you have found this publication useful you may be interested in some of the other services on offer through Information and Resources at BILD:

- *Reading Lists*

We have a number of ready made selected reading lists on topics ranging from Advocacy to Staff Training.

- *Literature Searches*

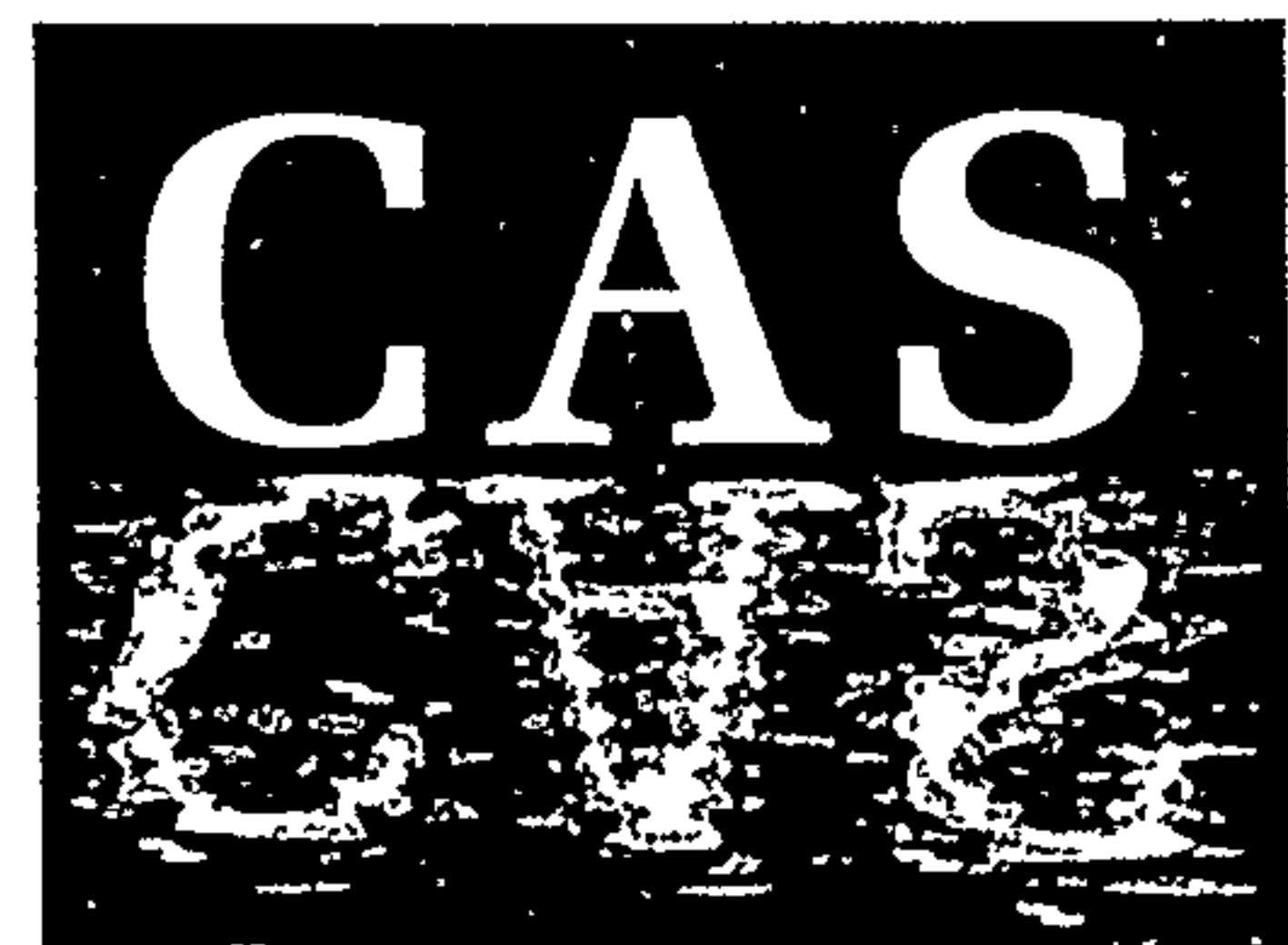
Our database holds references to books and journals from 1985. Searches can be made using key words or topic headings.

- *Library / Information Centre*

An extensive collection of resources is available for reference at BILD. This includes books, reports, training packages, audio visual materials and journals. Visitors are welcome by appointment. BILD members are able to use the library as a loan facility.

For further details of these services
please contact:

Information and Resources
BILD
Wolverhampton Road
Kidderminster
Worcs DY10 3PP



PLEASE DO NOT REMOVE THIS FORM . PHOTOCOPY IT FOR EACH EVENT YOU WISH TO BOOK PLACES ON
Complete in BLOCK CAPITALS and return to: BILD, Wolverhampton Road, Kidderminster, Worcs. DY10 3PP Telephone: 0562 850251

EVENT TITLE		EVENT CODE	BOOKING DETAILS	
			NUMBERS	COST
			BILD Members	
			Non-Members	
			TOTAL	

PARTICIPANT DETAILS

FULL NAME (indicate male / female)	JOB TITLE	ADDRESS inc. POSTCODE & TELEPHONE	SPECIAL REQUIREMENTS Dietary / Loop / Wheelchair
1.			
2.			
3.			

(please continue on another sheet if necessary)

Payment enclosed OR please invoice (name of organisation)
ORGANISATION DETAILS
Please give address, inc. postcode and telephone number for:

INVOICE	CORRESPONDENCE (if different)
Confirmation and further details will be forwarded approximately 10 days prior to the event NB: The following cancellation charges should be noted. Three months or more prior to the event: £10.00 Less than 3 months prior to the event: Half fee One month or less prior to the event: Full fee	

VAT Number: 487 8535 82
Authorised signature:
Order / purchase ref (if applicable)

What is Down's Syndrome?

Down's syndrome is a genetic condition caused by the presence of an extra chromosome. People with Down's syndrome have forty-seven chromosomes instead of the usual forty-six. About one baby in every thousand has Down's syndrome. It is the most common form of learning disability (mental handicap).

An increasing number of children with Down's syndrome are now attending mainstream schools and going on to gain employment and lead semi-independent lives as full members of the community.

The Down's Syndrome Association is the only national charity working exclusively for people with Down's syndrome and their families. We have a network of volunteer parent-led branches and groups throughout England, Wales and Northern Ireland.



Membership of the Association

The Association exists to support parents and carers of people with Down's syndrome and improve the lives of people with the condition. We are a membership Association and without members we would not exist. The more members we have the more we can help each other.

Who can join?

Anyone is welcome to join us.

Just fill in the form and send it to the Down's Syndrome Association, FREEPOST, 155 Mitcham Road, London, SW17 9BR or ring us on: 081 682 4001.

Full membership which confers voting rights, is open to parents, adults with Down's syndrome and their carers. Associate membership is open to all others, be they grandparents or people with a professional or personal interest in the condition.

All members of the Association receive our regular Newsletter and information about events and conferences organised throughout the year.

YES, I would like to join the Down's Syndrome Association

Mr/Mrs/Miss/Ms _____

Address _____

Postcode _____

Telephone _____

• Are you a **PARENT**

CARER

GRANDPARENT

ADULT WITH

DOWN'S SYNDROME

PROFESSIONAL

OTHER (PLEASE SPECIFY) _____

• I enclose my subscription of

£4

£15

£25

£50

other £ _____

There is no fixed subscription. The suggested subscription is £15, and the minimum is £4. Please give as generously as you can.

NOTE: Membership is free for the first year for parents of children with Down's syndrome.

• Please tick box for free membership.

• I enclose a cheque/postal order

Signature _____

Date _____

DOWN SYNDROME DOWN UNDER

WINTER 1994
EDITION

NEWSLETTER FOR AUSTRALIAN DOWN SYNDROME ASSOCIATION INC.
PATRONS: THE HON. JUSTICE MICHAEL KIRBY, A.C., C.M.G.,
MARGARET YOUNG, R.N., and WAYNE GRADY

WORLD MOURNS DEATH OF NOTED RESEARCHER

OBITUARY

by

Jan Robertson, National President of Australian Down Syndrome Association.

People involved with intellectual disability worldwide are mourning the sad and untimely death of Professor Jerome Lejeune, formerly noted researcher and Professor of Fundamental Genetics at the Institut de Progenese, Paris.

Most people will know Jerome Lejeune from textbooks as the geneticist who discovered the cause of Down syndrome - namely Trisomy 21 - or the third chromosome, No. 21.

I knew him as the most energetic scientist, friend and advocate for people with Down syndrome. He was a biochemist of unmatched determination in his search for the cure to the chemical imbalance caused by that third chromosome.

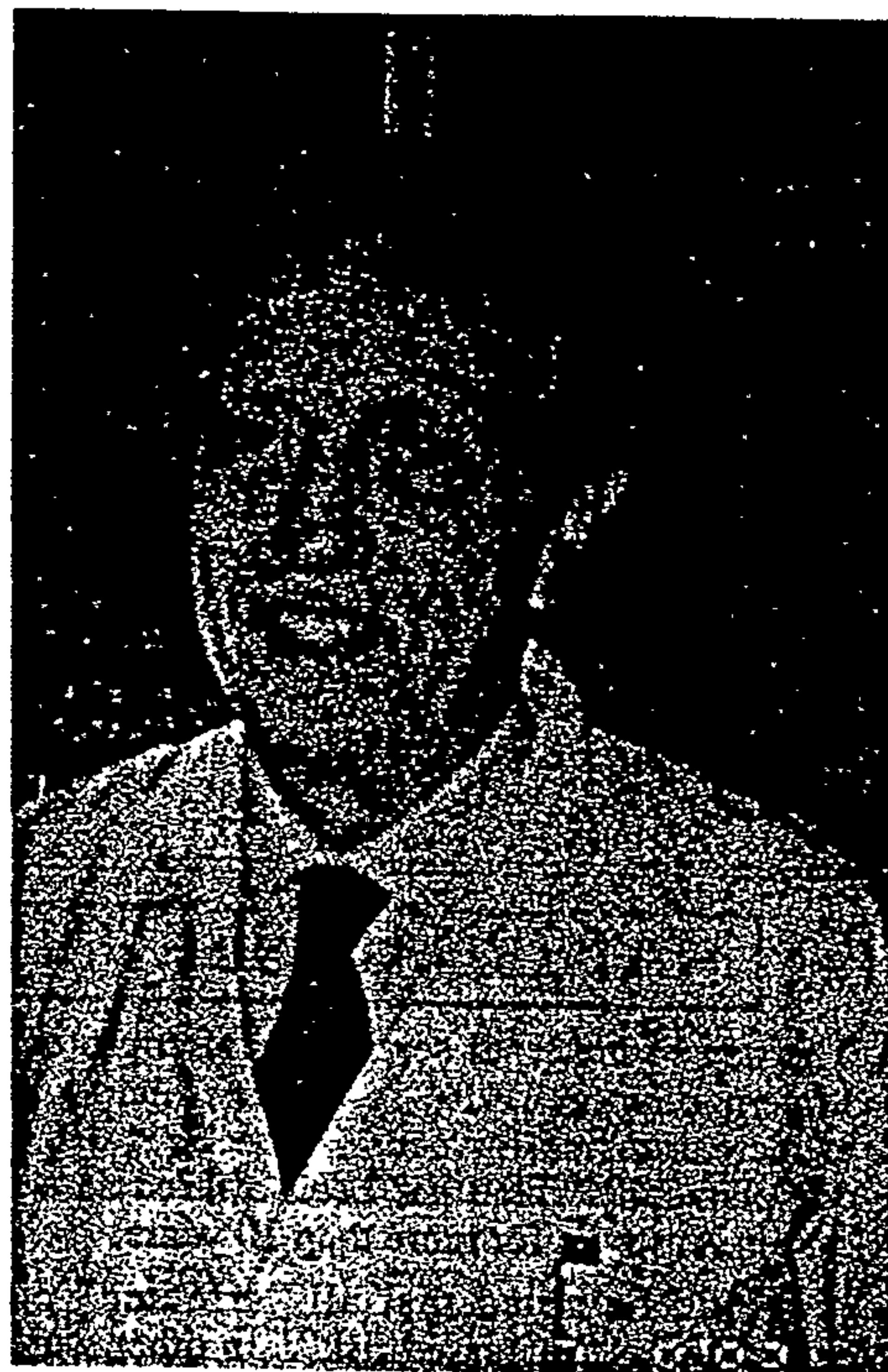
I knew he had lung cancer when I met with him again last August in Paris, but he did not tell me. He spoke of his love of Australia, and he looked forward to his proposed lecture tour of this year which as our association was planning. I left our meeting spurred on by his energy and enthusiasm and belief in the marvellous characteristics enhanced in people with Down syndrome as a result of Trisomy 21. I now understand the urgency of his research.

As a genetic researcher and he had discovered 10 chromosomal disorders including Fragile X syndrome and Cri du Chat. He was the "expert witness" called upon in the frozen embryo Court case in the United States last year.

He was a strong pro-life member, and he summed up his beliefs in this profound statement: "I do not understand that medicos can abort the patient because they have not yet found the cure."

I knew that a cure will be found, but unfortunately death claimed him before he could give this to the world.

An address given by Professor Jerome Lejeune is printed later in this newsletter for the information of readers.



Professor Jerome Lejeune



Margaret Young, Patron of ADSA, promoting her book 'WE ARE TOO,' at the Beta Sigma Phi 14th National Convention, Ramada Hotel, Glenelg, S.A. This event celebrated the "Centenary of Women's Suffrage and 100 Years of Votes for Women in South Australia, 1894-1994".

CONTENTS OF THIS ISSUE

- Current Down Syndrome research - Prof. Lejeune.
- Maternal Serum Testing.
- Language Development in children with D.S.
- Social Values.
- Employment Initiatives for people with disabilities.
- Research into children's literacy learning.
- Child Disability Allowance Review.
- Obesity Study Report.
- Reversible Dementia in young adults with D.S.
- Research into Abuse of Intellectually Disabled.
- ADSA assists Philippines establish Toy Library.
- Restless Dancers progress step by step.
- High Court verdict on sterilisation.
- Marathon runner breaks world records.
- Back to Back Theatre.
- A Circle of Friends.
- Review of video, "Eddie the Unbelievable".
- New Book Reviews.

WINNEBAGO



MOTOR
HOMES

This is a publication of:
AUSTRALIAN DOWN SYNDROME ASSOCIATION INC.
91 Hutt Street, Adelaide, South Australia, 5000
Telephone (08) 232-0688. FAX (08) 223-7368

D.S.A.V. VIDEO LIST (AUGUST 1993)

The following videos are available for hire from the Down Syndrome Association of Victoria's office - 55 Victoria Pde, Collingwood 3066 (phone 419 1653 or fax 416 0297).

Hire fee of \$5.00 per video, for a one week loan period.

(Videos can be collected during office hours 9.30 -3.00 weekdays, or posted out)

* * * * *

New Parents & General Information About Down Syndrome

The First Day's Hardest - NSW Association

Our Baby Has Down Syndrome - SA Association

Helen's Story - UK Association

Wendy : Potrait of a Down Syndrome Child - USA Association

Right Now -CSV

Late News - Late diagnosis of Disability - CSV

Tongue Reduction & Communication Camps

The Silent Minority

Augmented Communication

The case for and against

Early Intervention

Preview - Early Intervention - CSV

Approaches in Early Intervention - CSV

The Early Intervention Resource Unit - CSV

Time to Learn - Child with Multiple Disabilities - CSV

Showing the Way - EPIC's 10th anniversary

Small-Steps - Macquarie Univesity Program-NSW

Side by Side - Resource Unit for Children with Special Needs - WA

Pre-School

Adrian - CSV

Self-Help Skills

Open Wide - Eating Skills - CSV

General

Gavin Carter - A Victorian Painter

St Helen's Special Needs Dance Company - UK

David - Canadian Teenager + Special Olympics - USA

Kids Like These, starring Tyne Daly & Richard Crenna - USA Movie

National Down Syndrome Week, 9-16 June, 1991 - Rahlene Llewelyn



Down Syndrome Association of Victoria Inc.

Patrons: Mrs. Hazel Hawke
Mr Paul Jennings
Mr John Platten

55 Victoria Parade
Collingwood 3066
Tel: 419 1653
Fax: 416 0297

16.8.94

Dr A. Almasri
PO Box 436
Lakemba 2195

Dear Akram,

Thank you for your recent contact with our association regarding information on Down syndrome and dentistry. We enclose all that we have on file on this topic. You may also like to contact the Down Syndrome Association of N.S.W., as one of their members is a dentist and has written several articles for them as well as done presentations at their conferences. Phone (02) 683 433 for more details.

Dr Nicholas Baker is a Victorian Dentist whom we often refer to for information as an association. You may also like to contact him on (03) 646 3938.

Our Association also has a Parent Information Folder, which was compiled by parents to assist in answering many of the questions asked by parents of a new baby with Down syndrome. This folder is supplied free to new parents, but there is a \$10.00 charge for service providers. If you would like to purchase a copy, or if you require additional information, please contact us again.

With a new parent, our association is able to send one of our parents to chat to the new family, in the hospital, at home, or over the phone. They bring the Parent Information Folder with them. If the new family is not ready to meet with another parent, we are more than happy to post them the folder. The policy of our association is to make contact only when we have been asked by the family.

As part of Down Syndrome Awareness Week this year, we have produced an information folder for health professionals. This kit was compiled by doctors and parents to inform the health professional of the whole of life medical needs of people with Down syndrome and how to see past the label to the person. There is a \$10.00 charge for this kit.

The association can supply a speaker for staff, or parents and staff, or students. However, we would ask you to meet the travelling expenses, as our speaker is a parent doing this task on a voluntary basis. Our association is a parent-based family support group and our funds are always at a premium.

Although it is our association's policy to supply information to who so ever requests it, we are nevertheless a Parent-based Family Support Group and funds are always at a premium. We ask that if you could support us by forwarding a \$5.00 donation to cover the cost of supplying the enclosed material. This donation is tax deductible.

We trust that this has answered your queries.

Yours sincerely,

Judy M. Egan
Fae Egan,
Office Co-ordinator.

DSAV CONFERENCE NOVEMBER 19-20TH, 1994
"CHANGES and CHOICES"
Contact the Office for registration

Office Hours: Monday to Friday 9.30am to 3pm.

Some books which could be helpful to new parents

- Down Syndrome: An Introduction for Parents. Cliff Cunningham. Human Horizon Series. Revised 1989.
- Your Down Syndrome Child—Everything Today's Parents need to know about raising their special children. Eunice McLurg. Doubleday & Co. Inc., Garden City, New York. 1986.
- Babies with Down Syndrome—A New Parent's Guide. Edited by Karen Stray-Gunderson. Woodbine House Inc. 1986.
- Down Syndrome—Past Present and Future. An understanding and positive guide for families, friends and professionals. Brian Stratford. Penguin Group, 27 Wrights Lane, London. 1989.
- Activities for Babies and Toddlers with Down Syndrome: A Physiotherapy Approach. Rose Anne Kelso and Sue Price. Fred & Eleanor Schonell Special Educational Research Centre, Uni. of Qld, St. Lucia, 4067.
- Down Syndrome Growing and Learning. Siegfried M. Pueschell, Editor. Human Potentials for Children Series.
- Your Down Syndrome Child. Division of Health Education, Health Commission of New South Wales.
- Down's Syndrome. Early Education of Children with Special Needs. Joy Goodfellow. Sydney Kindergarten Teachers College.
- Small Steps—An Early Intervention Program for Children with Developmental Delays. Moira Pieterse and Robin Treloar with others. A series of 8 books. Titles include *Personal and social skills*, *Developmental skills inventory*. Macquarie Uni. Press. 1989.
- Facing the Crowd—Managing other people's insensitivities to your disabled child. Deborah Fullwood and Peter Cronin. Burwood Education Series No. 7. Royal Victorian Institute for the Blind.
- Your Child is Different. Edited by David Mitchell. A handbook for parents of young children with special needs. 1982.
- The Baby Exercise Book. Dr. Janine Levy. Pantheon Books (a division of Random House).
- Hope for the Families. New Directions for Parents of Persons with Retardation or other Disabilities. Robert Perske. Abingdon Press.
- Come and Join the Dance—A creative approach to movement for children with special needs. Jan Guthrie and Jan Roydhouse. Hyland House Publishing Pty Ltd.
- Teaching Your Down's Syndrome Infant—A Guide for Parents. Mard Hansen. University Park Press, Baltimore.

INTRODUCING
THE D.S.A.V.



Down Syndrome Association
of Victoria Inc.

Patrons: Mrs Hazel Hawke
Mr Paul Jennings
Mr John Platten

Updated: May 1993

Application for Membership

Name

Address Postcode

Phone No.

Child's Name

Child's Date of Birth

Centre/School Attended

Interest if other than Parent

I enclose herewith \$ being membership for 199 ..

Signature

Send to: The Secretary, Down Syndrome Association of Victoria Inc.
55 Victoria Parade, Collingwood, 3066.

MEMBERSHIP FEES:

FAMILY	\$20.00
CONCESSION (Pensioner/Student)	\$12.00
SERVICE PROVIDERS	\$30.00

Donations of \$2 and over
are tax deductible.

What is Down Syndrome?

Down Syndrome — an accident of nature for which no-one is to blame — was in 1959 the first disorder found to be linked to a chromosomal error, although Dr. Langdon Down first described the characteristics of the Syndrome in 1886.

In most cases it is due to a biological error in the distribution of chromosomes in the fertilised egg. This error consists of having three chromosomes 21 instead of the usual pair. Each chromosome controls thousands of genes, and although the genes on chromosome 21 are normal, because there are three instead of two, the gene balance is upset and thrown out of harmony. So it is not surprising to find that as the body grows there are minor deviations from normal found in every cell and tissue of the body. Many features are noticeable at birth, but the one which concerns parents most for the future is mental retardation.

It is important to realise:

- * that the range of achievements of the Down Syndrome person varies with each individual (as with normal people)
- * that they are individual personalities with the same physical and emotional needs as other people
- * they need to be loved and cared for
- * they need to recognise their own worth, and have that worth recognised by others
- * they need to develop their own self-confidence and self-esteem

We need to forge attitudes in society so that persons with Down Syndrome will be accepted for what they are, and that they will be offered a status which observes their rights and privileges as citizens and preserves their human dignity.

Given these conditions the person with Down Syndrome can blossom and thrive, can contribute as a valuable member of the family and can provide society with a most valuable influence.

The Down Syndrome Association of Victoria Inc. was formed in 1978 by interested parents in order to:

- * promote in every way possible improvements in the quality of life of persons with Down Syndrome;
- * provide understanding support, information and encouragement to persons with Down Syndrome and their families;
- * ensure that the Down Syndrome member of the family has every assistance to enable him/her to reach the potential of which he/she is capable;
- * stimulate the interest and awareness of the community and the medical profession as to the needs and attributes of persons with Down Syndrome;
- * provide a State-wide association to bring people who have like needs together.

The Down Syndrome Association of Victoria Inc. is an entirely voluntary association almost totally staffed by volunteers and is dependent on subscriptions and donations to continue its services.

How can you help?

- * Become a member.
- * Make a donation — (Donations of \$2 or more are tax deductible).
- * Tell others about the D.S.A.V.
- * Become a voluntary helper.

Contact:

The Secretary
D.S.A.V. Inc.
55 Victoria Parade
Collingwood 3066

Phone: 419 1653
Fax: 416 0297

The Association

- * has established a trained parent support group;
- * provides personal support for parents — especially when a new baby has been born;
- * has printed brochures and articles for parents;
- * has printed articles for students;
- * provides up-to-date accurate information on Down Syndrome and the needs of persons with Down Syndrome for:
 - Parents
 - Professionals
 - Students
 - Other interested people
- * prints regular newsletters and journals to report items of interest and bring information relating to Down Syndrome;
- * provides library facilities for lending and reference;
- * arranges regular open meetings covering a wide range of topics;
- * provides speakers to groups wishing to know more about Down Syndrome;
- * runs Communication Camps in conjunction with LaTrobe University.
- * keeps up-to-date with current research, both medical and educational;
- * provides information for teachers in a regular school situation who have a Down Syndrome child in the classroom;
- * represents the needs of people with Down Syndrome to Government and community areas;
- * has established regional contacts;
- * is a general resource and information centre.

Feel the need to talk?

The initial period following the birth of a child with Down Syndrome is usually one of frustration and bewilderment. The mother, confined to a hospital bed, may feel helpless and unable to cope. Advice, well meant, will come from many quarters, but very often from persons with no direct experience of children with Down Syndrome. Should you feel the need to talk with someone who has that experience, don't hesitate to phone.

Aims of the Association

The Down Syndrome Association of Victoria was formed in 1978 by interested parents to:

Provide support and advice to parents of persons with Down Syndrome.

Encourage early intervention and other developmental programs.

Increase public awareness of the roles that persons with Down Syndrome can play in the community.

Promote in any other way possible improvements in the quality of life for people with Down Syndrome.

If you would like to know more about the Association's activities, or want any further information, please write to:

The Secretary
Down Syndrome Association of Victoria
55 Victoria Parade
Collingwood 3066
Phone: 419 1653
Fax: 416 0297

Be sure to include your name, address and postcode so that we can contact you.

Some books which could be helpful to new parents

Down Syndrome: An Introduction for Parents. Cliff Cunningham. Human Horizon Series. Revised 1989.

Your Down Syndrome Child—Everything Today's Parents need to know about raising their special children. Eunice McLurg. Doubleday & Co. Inc., Garden City, New York, 1986.

Babies with Down Syndrome—A New Parent's Guide. Edited by Karen Stray-Gunderson. Woodbine House Inc. 1986.

Down Syndrome—Past Present and Future. An understanding and positive guide for families, friends and professionals. Brian Stratford. Penguin Group, 27 Wrights Lane, London. 1989.

Activities for Babies and Toddlers with Down Syndrome: A Physiotherapy Approach. Rose Anne Kelso and Sue Price. Fred & Eleanor Schonell Special Educational Research Centre, Uni. of Qld, St. Lucia, 4067.

Down Syndrome Growing and Learning. Siegfried M. Pueschell, Editor. Human Potentials for Children Series.

Your Down Syndrome Child. Division of Health Education, Health Commission of New South Wales.

Down's Syndrome. Early Education of Children with Special Needs. Joy Goodfellow (Sydney Kindergarten Teachers College).

Small Steps—An Early Intervention Program for Children with Developmental Delays. Moira Pieterse and Robin Treloar with others. A series of 8 books. Titles include *Personal and social skills*, *Developmental skills inventory*. Macquarie Uni. Press. 1989.

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Your Child is Different. Edited by David Mitchell. A handbook for parents of young children with special needs. 1982.

The Baby Exercise Book. Dr. Janine Levy. Pantheon Books (a division of Random House).

Hope for the Families. New Directions for Parents of Persons with Retardation or other Disabilities. Robert Perske. Abingdon Press.

Come and Join the Dance—A creative approach to movement for children with special needs. Jan Guthrie and Jan Roydhouse. Hyland House Publishing Pty Ltd.

Teaching Your Down's Syndrome Infant - A Guide for Parents. Marci Hansen. University Park Press, Baltimore.

OUR CHILDREN WITH DOWN SYNDROME



Down Syndrome Association
of Victoria Inc.

Patron: Mrs Hazel Hawke

Updated: August 1990

What is Down Syndrome?

Down Syndrome occurs more frequently than any other specific kind of intellectual handicap, numbering one in 700 births.

The pattern of features in a Down Syndrome baby allows doctors to make a very confident diagnosis, which can be confirmed by a blood test.

In 1866, when Dr. Langdon Down described the Syndrome, he remarked on the resemblance of the facial features to those of Mongolian races, hence the unfortunate use of the word "mongolism".

There are other features noticeable at birth, the most common of which is poor muscle tone.

Certain abnormalities in the heart or in the intestines may also be present. These can all be detected by doctors in the early days of life, and do not develop subsequently.

The feature which concerns parents most for the future is mental retardation and all would like to be given a precise statement of the child's ultimate abilities at the moment of birth.

It is no more possible to give this advice than it is to give a precise statement about the potential of a normal baby.

The important difference is that the parents of a baby with Down Syndrome want to ask this question, whereas parents of a normal baby usually do not feel the same concern. In both instances it is possible to describe the range of abilities within which most babies will fall.

It is most important never to lose sight of the fact that the genetic endowment of the baby with Down Syndrome does set a limit to his or her ultimate achievement, which is lower than that for most normal children.

An accident of cell development

How does the Syndrome occur?

Each cell of the human body contains 23 pairs of chromosomes and each chromosome controls several thousand genes, which govern growth and development. In Down Syndrome, generally, the smallest chromosome is present in triplicate, rather than as a pair.

This means that one or two thousand genes are present in triple dose instead of in duplicate. As the body grows, it is not surprising that minor deviation from normal can be found in every cell and tissue in the body, including brain cells.

But how does this mistake happen?

Formation of egg cells and sperm cells involves the natural selection of one chromosome out of every pair. This means that one member of each pair of chromosomes comes from the mother and the other from the father. At conception, the union of egg and sperm normally restores pairs of chromosomes. If the egg or the sperm contained both of one pair, instead of only one, then conception would produce a baby with this chromosome present three times.

This is usually a genuine mistake without specific cause. It may occur in either partner, although it does happen more often in women. The mistake becomes more frequent as women grow older, especially beyond the age of about 35 years. But a mother's physical or emotional condition during her pregnancy could certainly not result in the birth of a baby with Down Syndrome.

In only about one per cent of families who have babies with Down Syndrome is there a truly hereditary cause. Most couples who have produced a baby with Down Syndrome have little risk of producing a second baby with the condition. However, these couples are naturally very anxious and an amniocentesis or chorion villus test early in a subsequent pregnancy can be used to reassure them.

Parents and child need help

At home, the baby with Down Syndrome might appear to progress normally for the first few months. Nevertheless, delay must be expected in passing milestones such as sitting, crawling, walking, talking and self-feeding.

Babies with Down Syndrome need more help and encouragement than normal children if they are to reach their milestones as rapidly and effectively as possible. Parents have a vital role to play here as they must provide a stimulating learning environment.

Parents will often feel at a loss about where to start. "How can we teach him to sit up?" they may ask. "How do we help to overcome his poor muscle tone? How do we encourage him to talk?" Questions of this sort, which may never arise with a normal child, have to be faced. And, if the child with Down Syndrome is to progress, parents too will need support and guidance. This vital support and guidance is needed from birth. The Down Syndrome Association of Victoria (D.S.A.V.) was formed to provide this help.

Early intervention

Whether in the home or within the training group, the principle of early intervention is to aid the development and maximise the future potential of children with Down Syndrome.

Genetic make-up sets an upper limit to the abilities of any child, and education and training determine how near the child will come to achieving his or her individual limit. The efforts of educationalists involved in developing new approaches to the training of children with Down Syndrome are all aimed to this end.

Additionally, there are now several groups operating in both the city and the country. Some provide toy and play facilities, others provide more formal programmes of early intervention and care, but all create a common ground and support for parents of children with Down Syndrome. The D.S.A.V. will help to put parents in touch with all relevant groups.

Down Syndrome Association of Victoria Inc.

APPLICATION FOR/RENEWAL OF MEMBERSHIP

Family Name Given Names

Address

Phone No. Postcode

Child's Name

Child's Date of Birth

Centre/School Attended

Interest if other than parent

I enclose herewith \$ being membership for 199 .
(Pensioner/Student concessions available)

Signature Date

Send to: The Treasurer
D.S.A.V. Inc
55 Victoria Parade
Collingwood 3066

MEMBERSHIP FEES:	
FAMILY	
CONCESSION	\$20
(Pensioner/Student)	\$12
SERVICE	
PROVIDERS	\$30

Donations of \$2.00 and over are tax deductible.

Please Note: Membership fees fall due in January each year.
New Members who join on or after 1st October remain financial until the end of the following year.



Down Syndrome Association of Victoria Inc.

55 Victoria Parade

Collingwood 3066

Phone: 419 1653 Fax: 416 0297

12/6 -

Down Syndrome

"A Family Experience"

1994 is the Year of the Family. Families these days can consist of any number of variations, such as those with a single parent, extended family members, "blended families", and those including children with special needs.



The Tuddenham family
Esther loves school and playing
with her friends

Some of these families, such as those including a child with Down syndrome, may require extra assistance, but with support they are just one of the crowd.

Down syndrome is the most common intellectual disability in our community.

The syndrome results from a faulty chromosome combination at conception, where the cell receives an extra chromosome. This combination of extra genetic material generally results in a degree of intellectual disability. But people with Down syndrome, like everybody else, have varying physical and intellectual abilities.

People with Down syndrome work hard to use their abilities to overcome their disabilities. They don't need sympathy, but would enjoy having your understanding and support.

The Down Syndrome Association of Victoria Inc. is a non-profit self-help group formed by parents to offer assistance and information on all aspects of Down syndrome.

For further information, ring our office on 419 1653, fax 416 0297



National Down Syndrome Week March 20-27th, 1994

Down Syndrome-A life experience, NOT a life sentence.

Down Syndrome Awareness Week

19th to 26th March 1995

Graham has achieved the dream of every athlete - he's won in his sport at international level. Graham, who has Down syndrome, won a Gold Medal for gymnastics at the 1991 Special Olympics. He's also been honoured by the Victorian Governor and by his local community for the example he sets for all sportspeople. Graham has already shown that he can use his abilities to overcome disability. He doesn't need sympathy but he'd enjoy having your understanding and support.

WHAT IS DOWN SYNDROME?

Down Syndrome is a biological error that occurs at conception. About one in every 600 to 700 babies is born with Down syndrome. In the human body, each cell should contain 23 pairs of chromosomes. People with Down syndrome have three of chromosome 21, instead of the usual pair. Because every chromosome controls thousands of genes, the gene balance in people with Down syndrome is upset. A syndrome simply means a set of characteristic symptoms. Not everyone with Down syndrome has the same set of characteristics, but some degree of intellectual disability is usual.

PEOPLE WITH DOWN SYNDROME AREN'T ALL THE SAME.

Like everybody else, people with Down syndrome have varying physical and intellectual abilities.

Like everybody else, they are individuals with individual physical and emotional needs.

Like everybody else, they need to be loved and cared for and to be recognised for their individual worth.

Like everybody else, they need to develop their own self-confidence and self-esteem.

WE NEED TO FORGE ATTITUDES IN SOCIETY WHICH ACCEPT PEOPLE WITH DOWN SYNDROME FOR WHO THEY ARE AND WHICH OFFER THEM THE SAME RIGHTS, PRIVILEGES AND DIGNITY AS ALL CITIZENS,

In these conditions, people with Down syndrome do contribute as valuable members of their families and their communities.



Graham's *up* where he belongs.

When you think *Down*, think *up*.



For further information, contact: Down Syndrome Association of Victoria Inc.
55 Victoria Pde Collingwood, 3066 Ph 419 1653 Fax 416 0297



Fundraising for Mencap

Without the help of Mencap's supporters our work would grind to a halt.

There are many ways in which you can help. Besides making a donation you can also take part in our National Lottery or one of our many competitions, attend one of our exciting social events, apply for a Leeds Visa Card (it's like any other card except that Mencap gets a donation every time you use it), have fun taking part in a sponsored event or shake a can during a day.

Remember every pound you raise will give us the power to work harder. For more information and a copy of our fundraising pack contact:

The Appeals Department
Mencap National Centre
123 Golden Lane London EC1N 0RT
Telephone 071 696 5557



A campaigning force

The Mencap message is simple. People with a learning disability should have the same basic rights as everyone else. To be part of a community, to develop their abilities to the full and to be accepted as individuals with their own unique talents and needs.

Mencap is campaigning for the aspirations of people with a learning disability to be taken seriously. We act on issues which effect the welfare of people with a learning disability, their families and carers. Mencap's campaigning voice is backed up by a range of practical services offering vital support to people with a learning disability. To find out more about any of the services mentioned in this leaflet or for more detailed information about Mencap's work locally or nationally and how you can get involved, contact:

Information Department
Mencap National Centre
123 Golden Lane London EC1N 0RT
Telephone 071 696 5595 (between 2pm-5pm)
Civility Card number 22217



making the most of life



mencap

making the most of life



Supporting the family

At a local level, Mencap offers support and practical help to people with a learning disability and their families through its network of 500 societies. Every society is different, but all welcome new members, volunteers and supporters to help with fundraising, local projects and their ongoing campaign to get the best possible local services.

Learning for life

Mencap works with education policy makers to ensure that people with a learning disability get every chance to enjoy educational opportunities equal to those enjoyed by other children and young people and wherever possible, in ordinary schools and colleges. However, some people continue to have learning needs which are currently best met in specialist provision. Mencap's three residential Further Education Colleges, for example, provide young people with an opportunity to acquire the skills and independence needed to achieve a successful transition from school to adult life.

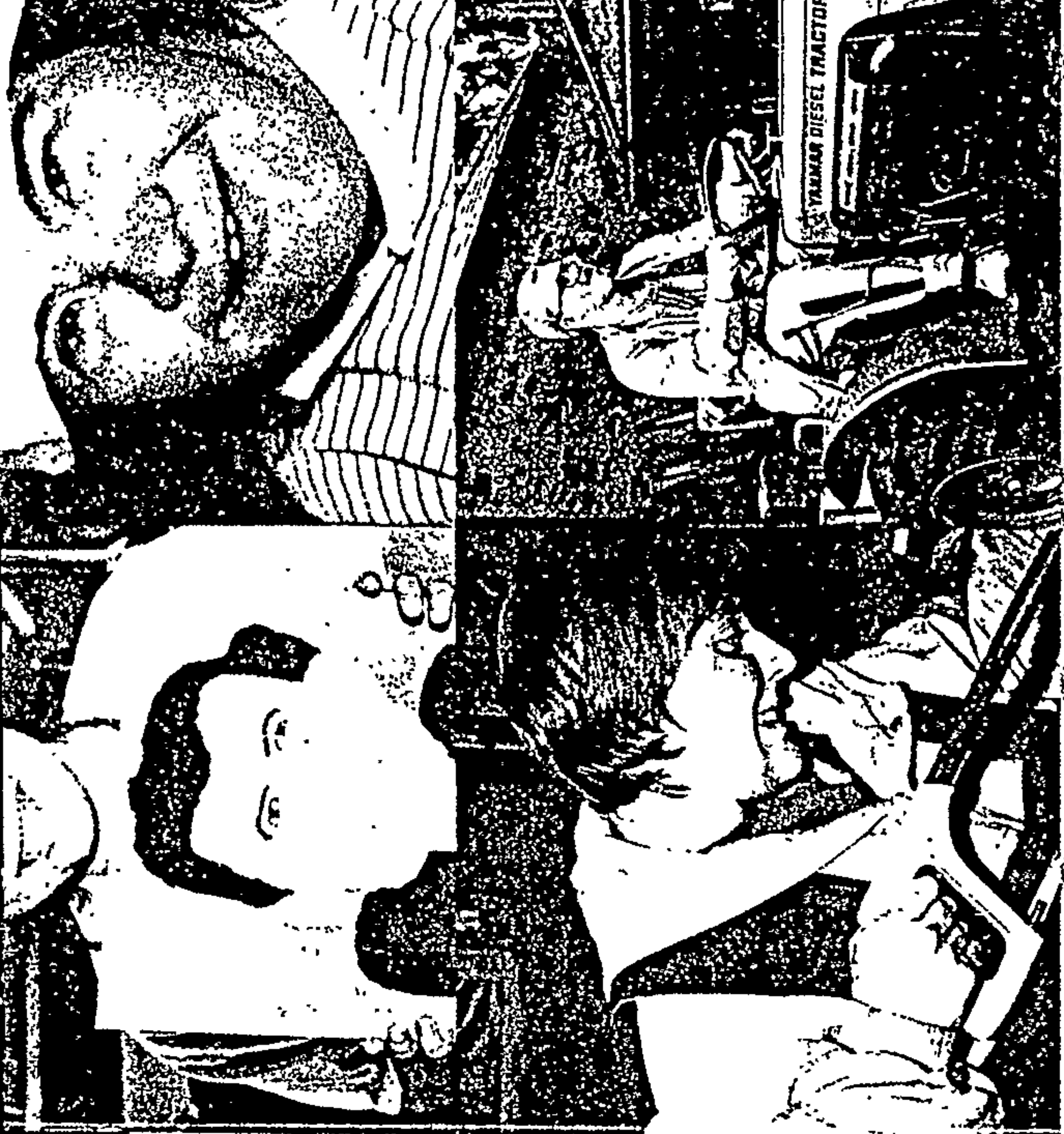


My own home

Many people with a learning disability continue living with their parents well into adult life, whether they want to or not. Others have spent a lifetime in bleak hospital wards. Mencap is the UK's largest provider of residential services for people with a learning disability, currently helping over 2,500 live more independent lives in ordinary houses across the country. Mencap will continue to campaign for appropriate accommodation for everyone with a learning disability.

Leisure should be a pleasure

Mencap's Gateway Services recognises that leisure time is particularly important for people with a learning disability. It provides opportunities for its members to develop new skills, new friends and new horizons. Gateway activities have traditionally been centred around the national network of over 700 clubs—highly valued by members. Increasingly, however, people with a learning disability want to share their leisure time with non-disabled people, and Gateway works to expand these opportunities too.



On holiday

This year, more than 400 people with a learning disability will go on holiday with Mencap, thanks to its programme of week-long breaks. People of all ages are offered the chance to make friends and try something new—like power boating or rock climbing—or just to relax and enjoy a change of scenery. For many, it will be their first time away from home and a chance to develop confidence and independence with the help of Mencap staff and trained volunteers.

Just the job

Mencap's Pathway Employment service is the UK's most successful scheme for finding permanent employment opportunities for people with a learning disability. Since its foundation in 1975, Pathway has made over 7,000 placements in a wide range of jobs, providing the ongoing support and advice needed to help the placements succeed. Right across the country, employers have found that people with a learning disability make first-class, committed employees.

mencap

People with a learning disability (mental handicap) are the largest group of disabled people in the UK. Over one million people have some form of learning disability.

Since its humble post-war origins as a parent support group, MENCAP has become the largest single organisation committed to learning disability issues.

With turnover in excess of £50 million, 2000 staff and 100,000 parent and user members, MENCAP is committed to providing high quality services, advice and support.

At the same time, MENCAP continues its tireless campaign to ensure this important group of people win the right to the fullest possible opportunities in every area of life.

All this takes money and MENCAP still needs your help and financial support.

work, you can contact us at:

MENCAP National Centre
123 Golden Lane
London EC1Y 0RT
Telephone 071 454 0454

MENCAP provides nationwide support through its seven Divisional Offices, 30 District Offices and an extensive network of some 500 local societies.

Divisional Office Addresses

Northern Division **London Division**
48 East Parade, Harrogate 115 Golden Lane
North Yorkshire HG1 5LE London EC1Y 0RT
Telephone 0423 563162 Telephone 071 454 0454

Eastern Division **MENCAP in Wales**
31 Scotgate, Stamford 169 City Road
Lincolnshire PE9 2MB Cardiff CF2 3JB
Telephone 0780 511199 WALES
Telephone 0222 191933

Western Division **MENCAP in Northern**
84 Aldridge Road Ireland
Perry Barr Segal House
Birmingham B42 2TP 4 Annadale Avenue
Telephone 021 356 7306 Belfast BT7 3JH

Southern Division **NORTHERN IRELAND**
115 Golden Lane Telephone 0232 691 351
London EC1Y 0RT
Telephone 071 454 0454

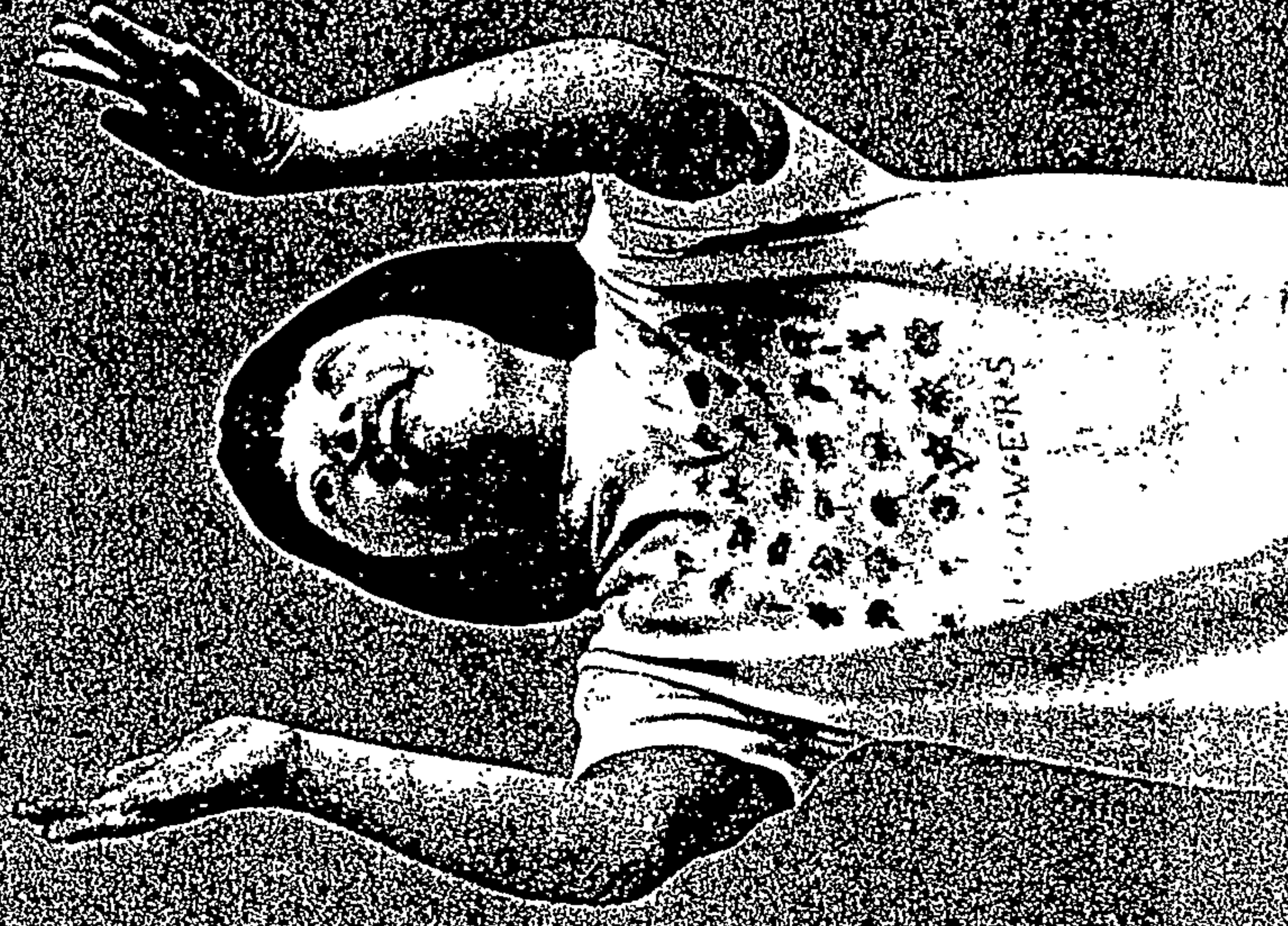
Royal Society for Mentally
Handicapped Children and Adults
MENCAP is a registered charity



mencap
making the impossible life



a campaigning force





citizenship

Many people with a learning disability are still denied ordinary civil rights. The chance to work; to choose your own friends; to find a partner, and to live in a place of your own, are rights MENCAP wants to see extended to all citizens regardless of their intellect or ability.

MENCAP is fighting for anti-discrimination legislation which offers the same rights and protection as those for gender and race.

MENCAP combines campaigning, legal, parliamentary and information services which aim to create a climate of opinion where it is unthinkable that people with a learning disability should be excluded from the normal decisions affecting their lives.



employment

Thousands of people with a learning disability feel that having a job is a badge of citizenship. Being paid shows in the clearest way that their contribution has value. Money opens other doors - to getting a home, enjoying leisure and having choice. Employment is the linchpin of modern life.

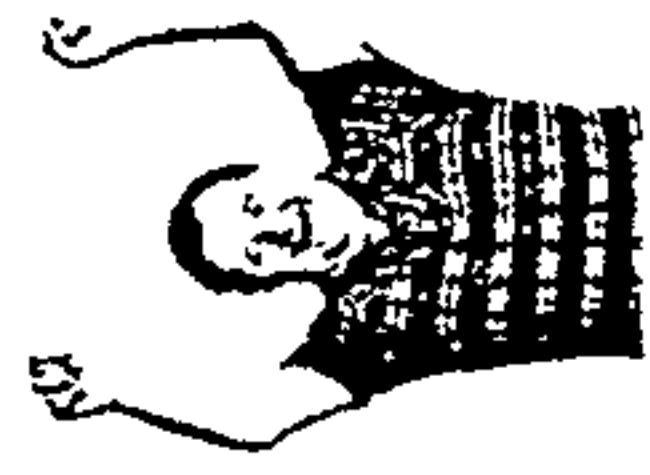
For 16 years, MENCAP's Pathway Employment Scheme has been proving that these ambitions are entirely realistic. Since 1976, Pathway has found jobs for over 2000 people. The previous obstacles of prejudice, ignorance and fear are slowly being overturned by positive experience as people with a learning disability demonstrate they are highly valued employees.



family life

For the families of people with a learning disability responsibility does not end once their child reaches the age of 19. Far from gaining freedom, many parents become more tied to the home. Throughout Britain, carers face many problems but receive little support or recognition for their efforts from the statutory services. Families cannot be left to "get on with it".

MENCAP aims to shift opinion to the point it is considered unacceptable for people with a learning disability and their families to have so little support. By working together with thousands of people with a learning disability and their families, MENCAP will fight to ensure their local authorities provide the necessary resources for this long neglected group.



leisure

Sport and recreation provides a route through which people with a learning disability can demonstrate and experience real achievement. However, many people are exposed to a narrow range of choices with access, transport difficulties, cost and prejudice all working against them.

MENCAP's national network of Gateway clubs act as a springboard and focal point for all sorts of achievement. We are committed to changing the attitudes of those who can facilitate (or deny) access for people with a learning disability to enjoy integrated sport and leisure - whoever they may be.



education

Education allows people to develop to their full potential. When MENCAP was founded in 1946, children with a learning disability were considered ineducable. MENCAP's campaigning has helped to secure education as a right from the age of two. Students with a learning disability now take their rightful place in the classroom, sometimes in mainstream schools.

Today MENCAP runs three residential colleges, which work with over 200 people with a learning disability each year, using some of the most advanced training techniques available. Students learn vital life skills which allow them to have more control over their lives and their future.



housing

Moving people from institutions into ordinary housing vastly improves their quality of life.

MENCAP's Homes Foundation provides over 400 homes throughout Britain where over 2000 people with a learning disability live, making their own decisions, supported by trained staff. In such settings, even people with the most profound learning disabilities can make real progress that will benefit them the rest of their lives.

There are still 25,000 people with a learning disability living in a hospital and 65,000 people living at home with elderly parents. MENCAP believes everyone with a learning disability should be able to live in a situation which is right for them.

ISSN 0952-9608

SUBSCRIPTION RATES FOR VOLUME 7 1994

QUARTERLY

Library/Institution

Individual/School

Student

£55.00 US\$109.00

£28.50 US\$ 56.00

£16.50 US\$33.00

Mental Handicap Research

Editors: John Corbett and John Harris

Published for the British Institute of Learning Disabilities under the Channel View imprint of Multilingual Matters Ltd, this quarterly publication is a research journal which has a significant part to play in the dissemination of research and in promoting debate about people with learning disabilities and the services we are able to provide for them.

With the ever increasing number of high quality papers being submitted to this Journal, the recent appointment of an international editorial board of professionals and academics will ensure the continuing high quality of the material published.

MENTAL HANDICAP RESEARCH Volume 6:3

- TURK, V. and BROWN, H.: The Sexual Abuse of Adults with Learning Disabilities. Results of a Two Year Incidence Survey.
- SZIVOS-BACH, S. E.: Social Comparisons, Stigma and Mainstreaming: The Self Esteem of Young Adults with a Learning Difficulty.
- HASTINGS, R. and REMINGTON, B.: On Terminology: A New Look at Labels for Mental Handicap and Challenging Behaviour.
- SHANLEY, A. and ROSE, J.: A Consumer Survey of Adults with Learning Difficulties Currently doing Work Experience.
- PETTIPHER, C. and MANSELL, J.: Engagement in Meaningful Activity in Day Centres: An Exploratory Study
- Letters and Book Reviews.

Other forthcoming papers include:

- ROSE, J.: Stress and Staff in Residential Setting: The Move from Hospital to the Community.
- BALLINGER, C.: Do Smaller Homes Result in Increased Integration.
- REED, J., CALLOW, H. and DAVIS, J.: Recognising the Facial Expressions of Adults with Mental Handicaps.
- DAGNAN, D. J. and STURMEY, P.: A Comparison of Joint Reviews and Life Plans in a Hospital Population of Older People with Learning Difficulties.
- ROSE, S. J.: Adventurous Outdoor Activities: An Exploratory Investigation into the Benefits to People with Severe Learning Difficulties.

The SLD Experience

Editor: Judith Coupe-O'Kane

This completely new publication takes the form of a plain-speaking, termly newsheet aimed at all who are involved with the education of children with severe learning difficulties.

As well as providing a wealth of information for professionals and for parents, The SLD Experience aims to become a positive medium for exchange.

Innovative Practice, Updates on Regional Curriculum Groups, Curriculum Matters, School Management and Legislation are just a few of the areas The SLD Experience will cover as regular features.

Multiple Copies. Schools/Libraries paying at the appropriate rate will be sent 10 copies of each issue for internal distribution.

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- Research Lines ● SLD and the Law ● Sexuality, Relationships & Abuse: Sexuality, learning difficulties and doing what's right; Don't Look! you might see something you don't like ● Television & Learning ● Parents' Voice
- International Perspective: A strategic plan for Wales; A joint European project - Lithuania, England & France working together ● In Response: Parents for Special Teachers (SLD); Language and Communication Assessment ● In Print: Books, Resources & Articles ● News of Regional Development Groups.

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Editorial Group: Nish Chaturvedi; Aileen Clarke; Simon Cohn; Maria Evandrou; Janet Flaherty; Paul Higgs; Nikki Joule; Jonathan Koffman; Sian Rees; Jill Russell; Rick Stern.

Critical Public Health is a journal of the politics of public health. Published quarterly, each issue focusses on a particular topic and includes original articles, book reviews and an information exchange and correspondence section. Topics are selected to appeal to a large group of people interested in health, health services and public health policy and practice and the approach is to explore these topics from a critical perspective.

Critical Public Health offers readers a critique of current thinking, an angle on issues that is distinctly different from other journals, as well as covering subjects that may not get an airing elsewhere. It emphasises political and economic issues affecting health; gives space to views from grassroots workers and service-users; and confronts sexism, racism and other forms of discrimination. Recent issues have included the following articles:

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- Rationing - Implicit, Explicit or Merely Complicit
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- Rationing and Health Gain
- Rationing and Older People
- Public Participation in Decisions about Health Care
- The Role of the Public in Health Care Rationing
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- Inequalities Research
- Unhealthy Surveillance
- Teenage Pregnancy
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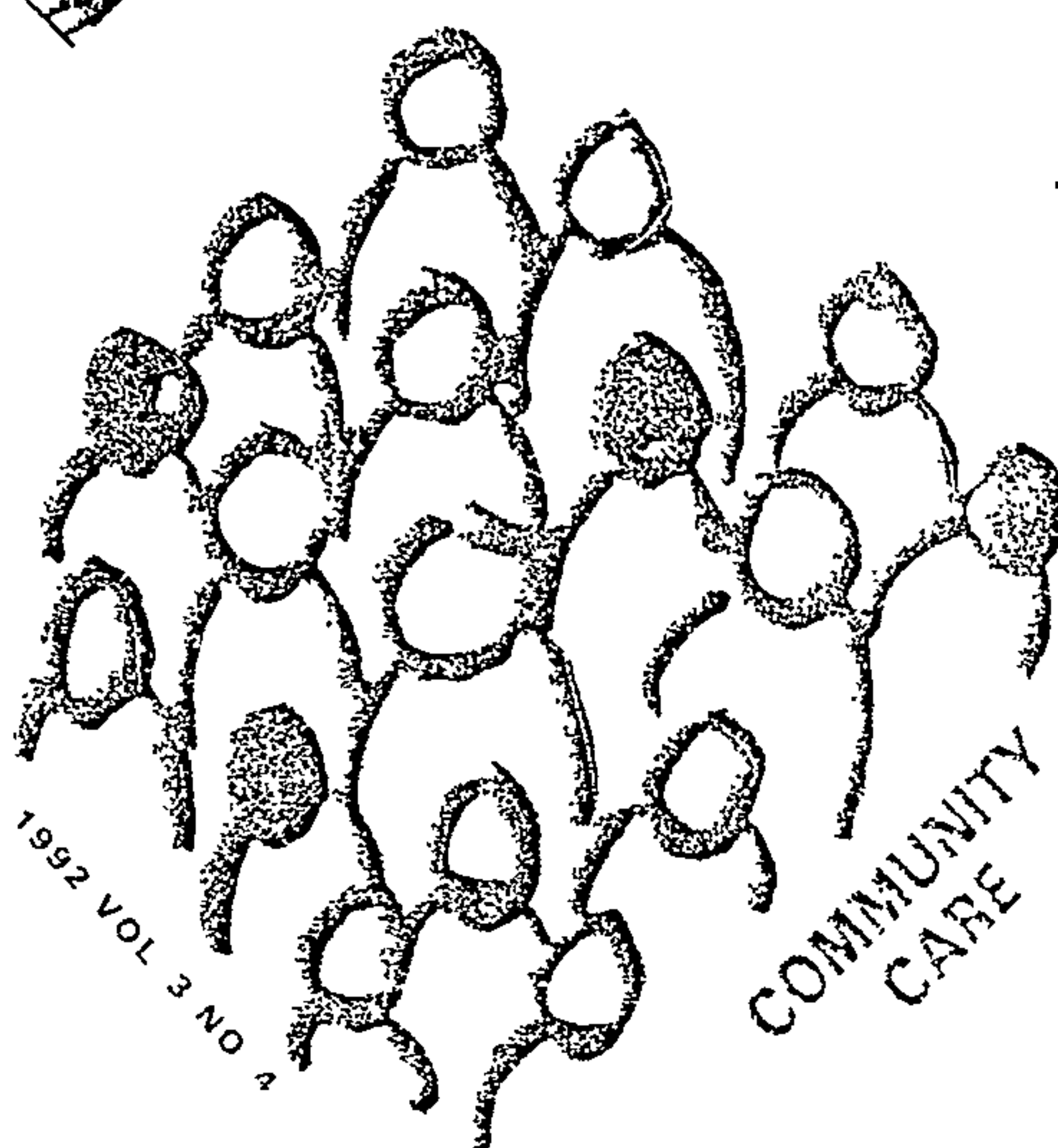
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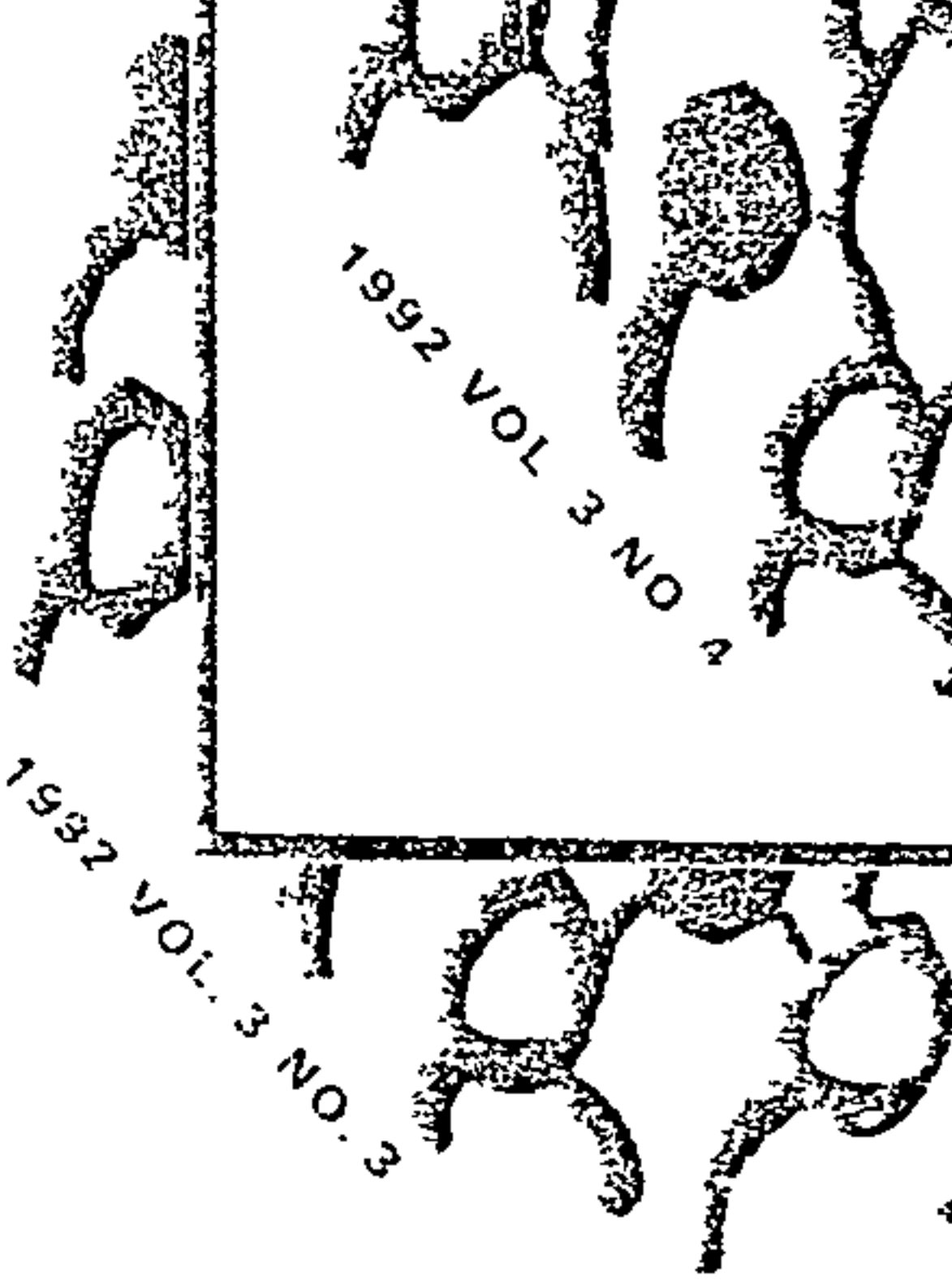
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Mental Handicap

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MENTAL HANDICAP Research

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Vol 6 No 3 1993

Bulletin

SPEAKING UP FOR CITIZENS

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What's the problem with allowing
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British Journal of Learning Disabilities

Formerly MENTAL HANDICAP

Editor: John Harris

Some of the topics covered in this multidisciplinary publication are: Current trends in residential and day care services; integration, rehabilitation and quality of life; education and training; employment and occupation; recreation and leisure; advocacy and rights; family and carers; adoption and fostering; prevention, causes and management of specific syndromes; staff training; new technology in practice. In addition there are usually reviews of books and training materials and a Letters section.

Papers published in Recent and forthcoming issues include:

- THOMAS, P. R.: Anorexia Nervosa in People with Severe Learning Disabilities.
- ALBORZ, A.: Parental Input in Education: A Case Study of an Autistic Child.
- HARRIS, P. and THOMSON, G.: The Staff Support Questionnaire: A Means of Measuring Support Among Staff Working with People with Challenging Behaviour.
- MILNE, K.M.: The Role of the Specialist Health Visitor in Aberdeen for People with a Mental Handicap.
- WILLIAMS, A.G.: A Social Competence Curriculum for School Leavers.
- PRASHER, V.P., and KRISHNAN, V.H.R.: Hypothyroidism Presenting as Dementia in a Person with Down Syndrome. A Case Report.
- CLARKE, D.J. and MACLEOD, M.: Recurrent Brief Depression and Mild Learning Disability: Successful Community Management.
- FARRELL, P.; McBRIEN, J. and FOXEN, T.: Introducing the Second Edition of EDY: Training Staff in Behavioural Methods.
- BAHLINGER, V. and WALSH P.G.: A View from the Inside (A Day in the Life of Tom W.).
- BOOTH, W. and BOOTH, T.: Family Undoing.
- SIGAFOOS, J.; KEER, M.; ROBERTS, D. and COUZENS, D.: A Review of Individual Service Plan Goals for Learners with Challenging Behaviours.
- TODD, S.; SHEARN, J.; BEYER, S. and FELCE, D.: Reflecting on Change: Consumers' Views of the Impact of the All Wales Strategy.
- FENWICK, A.: Sexual Abuse in Adults with Learning Difficulties; 1) A Review of the Literature.
- TOOGOOD, S.; SINCLAIR, C.; BELL, A.; JÄQUES, H. and LEWIS, S.: Meeting the Challenge in Clwyd The Intensive Support Team.
- LINDSAY, W. R.; MICHE, A. M.; STAINES, C.; BELLSHAW, E. and CULROSS, G.: Client Attitudes Towards Relationships - Changes Following a Sex Education Programme.
- THE GREAT INTEGRATION DEBATE.; A series of articles each by a well known author.

Mental Handicap Bulletin

This quarterly reprint publication is an easy and efficient way of keeping up-to-date with research and innovation in practice. Key articles are selected from a wide range of UK and international sources and are reprinted here for easy reference. It has a general appeal to professionals of all disciplines; a typical recent issue included:

Speaking up for Citizenship & Rights; Guest Editor Ken Simons

- Exchanging Charity for Rights: The Challenge for the Next Decade; *Marcia H. Rioux.*
- Speaking Out; *Julie Gosling.*
- Finding a New Way to Live/ Make Your Own Choices; *Sarah Cookson & Tim Hart.*
- Back to Basics: What is Advocacy; *Citizens North West.*
- A Chance to Speak; *Ken Simons.*
- Double Jeopardy: Women with Disabilities Speak about Community and Relationships; *Peggy Hutchinson, Linda Beechey, Claudette Foerster & Barb Fowke.*
- Assertiveness Training for People with Mental Handicap; *Claire Winchurst, Biza Stenfert Kroese & Jay Adams.*
- Partners in Policymaking: Empowering People; *Thomas J. Zirpoli, David Hancox, Colleen Wieck & Edward Skarnulis.*

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