

# NOTES ON THE MEDICINES AUSTRALIA PAYMENTS TO PATIENT GROUPS DATABASE

## About payment disclosure reporting requirements:

- Payments are reported on an annual basis to Medicines Australia by member companies
- Reports use a Jan-Dec year (not Australian financial year) and new reports are published on 30 June for the previous year.
- Reporting is required by the Medicines Australia Code of Conduct. The code is currently (at time of writing) on its 20<sup>th</sup> edition (<https://code.medicinesaustralia.com.au/code/>). The section relevant to reporting of payments to patient groups is 14.3:

*“It is reasonable for Companies to provide financial support and/or significant direct or indirect non-financial support to organisations that work to benefit Australian patients, and it is appropriate for these activities to be reported.*

*To encourage consistency in the content and format of these reports, Companies should include:*

- *the name of the patient organisation;*
- *a description of the nature of the support that is sufficiently complete to enable the average reader to form an understanding of the nature of the support; and*
- *the monetary value of financial support and of invoiced costs. For significant non-financial support that cannot be assigned a meaningful monetary value, the published information should describe clearly the non-monetary value that the organisation receives.*

*Medicines Australia will make publicly available on its website the completed reports in accordance with the publishing dates specified in Section 14.4.*

*It is the responsibility of a Company to inform a patient organisation that any sponsorship received by the patient organisation from the pharmaceutical Company, whether sponsorship of the organisation, a specific publication, website or activity, and including the monetary value of the sponsorship, will be publicly disclosed”*

- Reports are published for three years and then removed from the site (<https://www.medicinesaustralia.com.au/code/transparency-reporting/health-consumer-organisation-support-reports/>)

## Creating the database:

- Reports were downloaded from the Medicines Australia website for years 2013-2022, converted from PDF format to Excel spreadsheets, and aggregated into a single spreadsheet.
- We also searched for voluntary disclosures from pharmaceutical companies that were not members of Medicines Australia. The websites of any company that had at least five prescription products on the Australian Register of Therapeutic Goods were searched and additional reports were identified for seven non-member companies.
- Column B: Pharmaceutical company names
  - We have kept company names as they were at the time of the report, and have not made edits for mergers or acquisition
  - Two exceptions:
    - BioCSL was renamed to Seqirus when they acquired Novartis' influenza vaccine business in 2015 and has been referred to as Seqirus (bioCSL) in the database
    - Abbott spun off their pharmaceutical arm to form AbbVie in 2013 and has been referred to as AbbVie (Abbott) in the database
- Column C: Source of disclosure
  - Notes whether the disclosure was retrieved from the Medicines Australia website or from the pharmaceutical company's website
- Column D: Name of patient group/health consumer organisation
  - We have matched patient group names to entries in the ACNC charity register (<https://www.acnc.gov.au/charity/charities>) or their website
  - We used charity annual reports to confirm some name changes and have aimed to use the name that the group operates under, even where that is not their name as registered in the ACNC register
  - When a group had multiple names in the original data, common aliases have been included in brackets – eg Healthy Bones Australia (Osteoporosis Australia)
  - State-based patient groups were kept as separate organisations, we did not combine entries due to group mergers into a national body (eg state Huntington's groups merging to form Huntington's Australia). However, if a group expanded their geographic scope, the latter name was used (eg Parkinson's SA adding in NT- have been referred to as Parkinson's SA/NT)
  - Deleted "The" at the start of group names, and suffixes which denote organisational structure (pty, ltd, incorporated, etc) unless this was required for clarity (e.g. MS Plus (Multiple Sclerosis Ltd), maintained the suffix to distinguish the group from Multiple Sclerosis Australia)
  - See table below for patient group name changes and notes
- Column E: Clinical area of patient group
  - Additional variable coded based on the main area that the group works in. We only included one clinical area per group even if groups span multiple clinical areas.

- As examples:
  - The Children's Cancer Institute has been coded as a cancer group, though they could also be considered to fit into children's health
  - The Lung Foundation has been coded as a respiratory group even though they also engage in lung cancer advocacy
- Column F: Description and/or Purpose of Support – contains raw text from disclosure reports
- Column G: Nature of support – contains raw text from disclosure reports
- Column H: Financial support (cleaned – AUD) – for entries with a monetary value, we have included only the value of this payment. Have also converted any payments reported in other currencies to AUD using the average exchange rate for that year retrieved from the Reserve Bank of Australia's website (<https://www.rba.gov.au/statistics/historical-data.html>)
- Despite our best efforts at cleaning there may still be errors/duplicates in the database

## Changes to patient group names during data cleaning

Patient group – Name used in final database	Name(s) pre-cleaning	Note	Change to financial totals
Access Australia (Access Australia Group)	Access Australia	Name in charity register is "Access Australia Group Limited"	nil
Access Australia (Access Australia's National Infertility Network)	Access Australia	Name in charity register is "Access Australia's National Infertility Network Limited"	nil
ACON Health (AIDS Council of NSW)	AIDS Council of NSW; ACON Health		\$56,274 from ACON Health \$1500 from AIDS Council of NSW
Arthritis Foundation of Australia (Osteoarthritis Australia)	Arthritis Foundation of Australia; Osteoarthritis Australia		\$10,000 from Osteoarthritis Australia \$3,087,458.12 from Arthritis Foundation of Australia
AS Victoria (Ankylosing Spondylitis Victoria)	AS Victoria	Name in charity register is "Ankylosing Spondylitis Victoria Inc"	nil
Australasian Hepatology Association	Australian Hepatology Australia	Incorrect name in disclosure report	\$2000 added to Australasian Hepatology Association
Australian Atherosclerosis Society	Australian Atherosclerosis Society; FH Australasia Network	FH Australasia Network is a program of the Atherosclerosis society	\$21,635 from Australian Atherosclerosis Society \$15,000 from FH Australasia Network
Australian Pain Society	Australian Pain Society; Pain Australia	Three entries for Pain Australia named the Australian Pain Society in the description as the recipient group	\$88,363 from Australian Pain Society \$291,000 from Pain Australia
Australian Scleroderma Interest Group (Australian Rheumatology Association)	Australian Scleroderma Interest Group	Part of the Australian Rheumatology Association	nil
BEAT Bladder Cancer Australia	BEAT Bladder Cancer; Bladder Cancer Australia	Have assigned Bladder Cancer Australia to BEAT Bladder cancer as a best guess	\$113,500 from BEAT Bladder Cancer, \$10,000 from Bladder Cancer Australia

<b>Patient group – Name used in final database</b>	<b>Name(s) pre-cleaning</b>	<b>Note</b>	<b>Change to financial totals</b>
Better Foundation (Blacktown and Mount Druitt Hospitals Foundation)	Better Foundation	Name in the charity register is "Blacktown and Mount Druitt Hospitals Foundation Ltd"	nil
Blepharospasm Australia (BEB Western Australian Support Group)	BEB Western Australian Support Group		\$2900 assigned to this group - 2 payments
Bowel Cancer Australia (Bowel Cancer & Digestive Research Institute Australia)	Bowel Cancer Australia	Name in the charity register is "Bowel Cancer & Digestive Research Institute Australia"	nil
Can Too Foundation	Can Too; CanToo		\$2,400 from Can Too \$200 from CanToo
Cherish Women's Foundation (Gynaecological Cancer Foundation)	Cherish Women's Foundation	Name in the charity register is "Gynaecological Cancer Foundation Ltd."	nil
Children's Cancer Institute	Children's Cancer Council	Have assigned to Children's Cancer Institute as best guess	\$918 added to Children's Cancer Institute
Chris O'Brien Lifehouse	Chris O'Brien Lifehouse; The Trustee for Lifehouse Australia Trust	Multiple names, have merged	\$2,000 from Chris O'Brien Lifehouse \$10,636.36 from Trustee for Lifehouse
Congenital Adrenal Hyperplasia Support Group Australia		Name in the charity register is "CAH Support Group Australia Incorporated"	nil
Creaky Joints Australia (Global Healthy Living Foundation)	Creaky Joints Australia; Global Healthy Living Foundation	Creaky Joints is a part of GHLF. Most payments name Creaky Joints or talk about arthritis/inflammation in the description.	\$157,500 from Creaky Joints \$468,500 from Global Healthy Living Foundation
Crohn's & Colitis Australia (Australian Crohn's and Colitis Association)	Australian Crohn's and Colitis Association; Crohn's & Colitis Australia		\$2,026,339.27 from Australian Crohn's and Colitis Association \$384,220.77 from Crohn's & Colitis Australia

<b>Patient group – Name used in final database</b>	<b>Name(s) pre-cleaning</b>	<b>Note</b>	<b>Change to financial totals</b>
Diabetes NSW (Australian Diabetes Council)	Diabetes NSW; Australian Diabetes Council	Name change (nb Australian Diabetes Council is not the same as Diabetes Australia)	\$387,940 from Diabetes NSW \$5,500 from Australian Diabetes Council
Diabetes Victoria	Diabetes Victoria; Diabetes Australia - Victoria		\$41,000 from Diabetes Victoria \$30,000 from Diabetes Australia - Victoria
Fabry Australia (Fabry Support Group Australia)	Fabry Australia; Fabry Support Group Australia		\$52,275 added to Fabry Australia
FAST Australia (Foundation for Angelman Syndrome Therapeutics Australia)	FAST Australia	Name in the charity register is "Foundation for Angelman Syndrome Therapeutics Australia Limited"	nil
Gastroenterology Society of Australia	Gastroenterology Australia Research & Education.	The description of payment names the Gastroenterology Society.	nil
Gaucher Association of Australia & New Zealand		Not currently active - does not appear to have been a registered charity	nil
GI Cancer Institute (Australasian Gastro-Intestinal Trials Group)	GI Cancer Institute	Name in the charity register is "Australasian Gastro-Intestinal Trials Group"	nil
HAE Australasia	HAE Australasia; Australasian Patient Organisation for Hereditary Angioedema		\$293,312.37 from HAE Australasia \$11000 from Patient Organisation for Hereditary Angioedema
Haemophilia Foundation Australia	Haemophilia Foundation Australia; Heamophilia Foundation Australia	Typo in one of the entries (heamophilia)	\$50,000 added to Haemophilia Foundation Australia
Health Equity Matters (Australian Federation of AIDS Organisations)	Australian Federation of AIDS Organisations		nil

<b>Patient group – Name used in final database</b>	<b>Name(s) pre-cleaning</b>	<b>Note</b>	<b>Change to financial totals</b>
Healthy Bones Australia (Osteoporosis Australia)	Osteoporosis Australia; Healthy Bones		\$365,874.22 from Healthy Bones \$3,222,800 from Osteoporosis Australia
HeartKids (HeartKids Australia)	HeartKids Australia; HeartKids	Prior to 2016 there was a national organisation and separate state organisations. Federated in 2016. Have combined pre-2016 HeartKids Australia and post-2016 HeartKids entries. Pre-2016 state organisations remain separate	\$45,000 from HeartKids Australia \$22,600 from HeartKids
Huntington's NSW & ACT	Huntington's New South Wales & ACT; Australian Huntington's Disease Association New South Wales	State Huntington's groups (except Victoria) merged in 2023 forming Huntington's Australia.	\$558 added to Huntington's NSW & ACT
Juvenile Arthritis Foundation	Juvenile Arthritis Foundation; Juvenile Arthritis Fundraiser	Assigned Juvenile Arthritis Fundraiser payment to the Juvenile Arthritis Foundation as a best guess.	\$3960 from Juvenile Arthritis Foundation \$2500 from Juvenile Arthritis Fundraiser
Kidney Health Australia (Australian Kidney Foundation)	Kidney Health Australia; Kidney Health Australia Western Australia (WA); The Australian Kidney Foundation		\$1,967,947.58 from Kidney Health Australia \$350 from Kidney Health Australia WA \$452,409.40 from The Australian Kidney Foundation
Liver Foundation	Liver Foundation; The Australian Liver Foundation; Liver Foundation of Western Australia (WA)	Liver Foundation WA payment was for the West Coast Liver Meeting which is run by the Liver Foundation.	\$10000 from The Australian Liver Foundation \$85000 from Liver Foundation \$2500 from Liver Foundation WA
LiverWELL (Hepatitis Victoria)	Hepatitis Victoria; LiverWELL		\$272,715 from LiverWELL \$8780 from Hepatitis Victoria
Living Positive Victoria (People living with HIV/AIDS Victoria)	Living Positive Victoria; People living with HIV/AIDS Victoria	Name in charity register is "People living with HIV/AIDS Victoria". Have combined entries	\$67,000 from Living Positive Victoria \$28,600 from People Living with HIV/AIDS Victoria

<b>Patient group – Name used in final database</b>	<b>Name(s) pre-cleaning</b>	<b>Note</b>	<b>Change to financial totals</b>
Lung Foundation Australia	Lung Cancer Central; Lung Foundation Australia	Assigned Lung Cancer Central to the Lung Foundation as a best guess	\$2000 added to the Lung Foundation
Melanoma Tasmania (Skin Cancer Tasmania)	Melanoma Tasmania	Name in the charity register is "Skin Cancer Tasmania" - note, charity merged with Melanoma Institute Australia in 2022	nil
Mito Foundation (Australian Mitochondrial Disease Foundation)	Australian Mitochondrial Disease Foundation; Mito Foundation		\$1163 from Mito \$500 from Australian Mitochondrial Disease
MPS Australia (Mucopolysaccharide & Related Diseases Society)	MPS Australia	Name in the charity register is "Mucopolysaccharide & Related Diseases Society"	nil
MS Australia (Multiple Sclerosis Australia)	MS Australia; Multiple Sclerosis Australia	note – MS Australia and MS Research Australia merged in 2021, have kept as separate organisations in the database	\$1,625,672.23 from MS Australia \$27,839 from Multiple Sclerosis Australia
MS Plus (Multiple Sclerosis Ltd)	Multiple Sclerosis Ltd; MS Plus	MS Plus is the NSW, VIC, TAS, ACT branch of MS Australia	\$3,727 from MS Plus \$539,979 from Multiple Sclerosis Ltd
Musculoskeletal Australia (Arthritis Foundation of Victoria; MOVE Muscle, Bone & Joint Health; MSK Australia)	Arthritis Foundation of Victoria; MOVE Muscle, Bone & Joint Health; Musculoskeletal Australia; MSK Australia		\$32,391 from Arthritis Foundation \$60,000 from MOVE \$10,000 from MSK \$164,097.65 from Musculoskeletal
Myasthenia Alliance Australia		This is a collaboration between "Myasthenia Gravis Association of Queensland" and "The Australian Myasthenic Association in NSW"	nil
Myeloma Australia (Myeloma Foundation of Australia)	Myeloma Australia; Myeloma Foundation Australia		\$2,926,482 from Myeloma Australia \$160,000 from Myeloma Foundation Australia

<b>Patient group – Name used in final database</b>	<b>Name(s) pre-cleaning</b>	<b>Note</b>	<b>Change to financial totals</b>
NeuroEndocrine Cancer Australia (Unicorn Foundation)	NeuroEndocrine Cancer Australia; Unicorn Foundation		\$314,345 from NeuroEndocrine Cancer \$436,316.35 from Unicorn Foundation
Neuromuscular WA (Muscular Dystrophy Western Australia)	Muscular Dystrophy Western Australia		nil
Northcott Disability Services (The Northcott Society)	Northcott Disability Services	Name in the charity register is "The Northcott Society"	nil
One Door Mental Health (Schizophrenia Fellowship Of New South Wales)	Schizophrenia Fellowship; One door mental health		\$30,000 from One Door Mental Health \$20,524.30 from Schizophrenia Fellowship
Pancare Foundation	Pancare Foundation; Pancreatic Cancer Support Australia	Have assigned a Pancreatic Cancer Support Australia payment to Pancare as a best guess	\$30,000 from Pancreatic Cancer Support Australia \$60,000 from Pancare Foundation
Parkinson's SA/NT (Parkinson's South Australia; THRF Group – Parkinson's; Fighting Parkinsons)	Parkinson's South Australia; Parkinson's South Australia and Northern Territory	Parkinson's South Australia expanded to included Northern Territory. They have since joined the Hospital Research Foundation Group and may also be referred to as Fighting Parkinsons	\$2,000 from Parkinson's South Australia and Northern Territory \$73,153.63 from Parkinson's South Australia
Parkinson's Australia	Parkinson's Australia; Parkinson's Passports Reprints - Parkinson's Disease Australia		\$20,705 added to Parkinson's Australia
Parkinson's New South Wales	Parkinson's New South Wales; Parkinson's Support Group Wagga Wagga; Parkinson's Unity Walk	Payment description for Parkinson's Unity Walk appears to be for the NSW group. The Wagga Wagga support group also appears to be a part of the larger NSW group.	\$1300 from Parkinson's Support Group Wagga Wagga \$500 from Parkinson's Unity Walk
Rotarians Against Malaria		This is a sub-group of "Rotary Australia World Community Service Limited"	nil
RULE Prostate Cancer (Australian Prostate Centre)	Australian Prostate Centre		nil
Zest Healthcare Communications (Nexus Australasia)	ZEST Health Strategies; Nexus Australasia		\$5000 from Nexus Australasia and \$39886 from Zest

## Changes to pharmaceutical company names

Name used in final database	Full name(s) pre-cleaning	Notes
A. Menarini	A. Menarini Australia Pty Ltd	
AbbVie (Abbott)	Abbott/AbbVie Pty Ltd AbbVie Pty Ltd Abbott Australasia Pty Ltd	AbbVie formed from the pharmaceutical arm of Abbott
Actelion	Actelion Pharmaceuticals Australia Pty Ltd	Acquired by Johnson & Johnson in 2017
Alcon	Alcon Australia	Was a Novartis Subsidiary until 2019
Alexion	Alexion Pharmaceuticals Australasia Pty Ltd	Subsidiary of AstraZeneca
Allergan	Allergan Australia Pty Ltd	Acquired by AbbVie in 2020
Amgen	Amgen Australia Pty Ltd	
Astellas	Astellas Pharma Australia Pty Ltd	
AstraZeneca	AstraZeneca Pty Ltd	
Bayer	Bayer Australia Limited	
BeiGene	BeiGene Pty Ltd	
Biogen	Biogen Australia Pty Ltd Biogen Idec Australia Pty Ltd	
Boehringer Ingelheim	Boehringer Ingelheim Australia Pty Ltd Boehringer Ingelheim Pty Ltd	
Bristol-Myers Squibb	Bristol-Myers Squibb Australia Pty Limited	
Camurus	Camurus	Not a member of Medicines Australia, disclosure reports published on Camurus website
Celgene	Celgene Pty Limited	Acquired by Bristol-Myers Squibb in 2019
CSL Behring	CSL Behring	Subsidiary of CSL Ltd
Eisai	Eisai Australia Pty Ltd	
Eli Lilly	Eli Lilly Australia Pty Limited	
Gilead	Gilead Sciences Pty Ltd	
GlaxoSmithKline	GlaxoSmithKline Australia Pty Ltd	
Grifols	Grifols	Not a member of Medicines Australia, disclosure reports published on Grifols website
Indivior	Indivior Pty Ltd	Not a member of Medicines Australia, disclosure reports published on Indivior website

<b>Name used in final database</b>	<b>Full name(s) pre-cleaning</b>	<b>Notes</b>
Ipsen	Ipsen Pty Ltd	
Janssen	Janssen	Pharmaceutical arm of Johnson & Johnson
Kyowa Kirin	Kyowa Kirin Australia Pty Ltd	Recent member of Medicines Australia, reports for 2020-2022 published on Kyowa Kirin website
Lundbeck	Lundbeck Australia	
Merck Serono	Merck Serono Australia Pty Ltd Merck Healthcare Pty Ltd	Pharmaceutical arm of Merck
MSD	MSD Australia	Merck Sharp & Dohme. Former US subsidiary of Merck, but separated in 1917. Trades as Merck & Co in the US and Canada.
Mundipharma	Mundipharma Pty Limited	
Mylan EPD	Mylan EPD BGP Products Pty Ltd Trading as Mylan EPD	Formed in 2014 from a merger with Abbott Merged with Upjohn in 2021 to form Viatris
Norgine	Norgine Pty Limited	
Novartis	Novartis Pharmaceuticals Australia Pty Ltd	
Novo Nordisk	Novo Nordisk Pharmaceuticals Pty Ltd	
Pfizer	Pfizer Australia Pty Ltd	
Roche	Roche Products Pty Limited	
Sanofi	Sanofi-Aventis Australia Pty Ltd	
Seqirus (bioCSL)	Seqirus (Australia) Pty Ltd bioCSL	Subsidiary of CSL Ltd. Name changed from bioCSL to Seqirus in 2015 when they acquired Novartis' influenza vaccine business. Disclosures from 2019 onwards published on Seqirus website.
Servier	Servier Laboratories (Aust) Pty Ltd	
Shire	Shire Australia Pty Limited	Acquired by Takeda in 2019
Takeda	Takeda Pharmaceuticals Australia	
UCB	UCB Australia UCB Pharma	
Vertex	Vertex Pharmaceuticals	Not a member of Medicines Australia, but has published disclosure reports on the Medicines Australia website
ViiV	ViiV Healthcare	Created as a joint venture of GSK and Pfizer. Not a member of Medicines Australia, disclosure reports published on ViiV website