mnd Australia

ANNUAL REPORT 2022–23

Our vision

A world free of MND

Our mission

To improve the lives of everyone impacted by MND through advancing research, advocacy and high quality care

A message from our President

Prof Samar Aoun

I have the honour to write the President's Report this year. I was elected President in April 2023 following the departure of Mark Grey. I take this opportunity to acknowledge and thank Mark for his valuable contribution over five and half years as a Board Director of MND Australia including more recently as its President.

During 2022-23, the MND Australia Board and staff continued to work hard to deliver against our Strategic Plan supporting our mission to improve the lives of everyone impacted by MND through advancing research, advocacy and high-quality care.

In doing so we support our members – the six State MND Associations – who provide direct support and services to people living with MND, their carers and families and the health professionals and service providers involved in their care in all states and territories.

Together we are committed to ensuring people living with MND have timely access to:

- care and support to meet their individual needs to enable them to live better, for longer, regardless of their age or postcode
- diagnosis, clinical trials, technologies, and therapies.

Our research arm – MND Research Australia – allocated through the Research Committee $3 million of funds received for research to support new grants commencing in 2024 to discover causes, improve care and find treatments. MND Research Australia has also continued to strengthen its relationships with organisations such as FightMND and MND & Me including through the MND Collective.

In March 2023 the MND Australia Board approved the new ‘Research Strategy 2023-26’ which will drive research that delivers improved quality of care and life for patients and carers, and to find effective treatments and ultimately a cure for MND. This is achieved by being a leader in stakeholder engagement, research grant funding, guiding research directions, facilitating awareness and communication, and advocacy.

During the year the Board established a Governance Committee to oversee the process for changing MND Australia’s legal status from an incorporated association to a company limited by guarantee. A new constitution is currently out for consultation.

As part of the governance changes, MND Research Australia and MiNDAUS will transition to being more integrated with MND Australia which will contribute to improving integration across the care and research spectrums.

MND Australia has been an active contributor to the MiNDAUS Partnership since its inception five years ago. Consideration is being given to the future governance arrangements for MiNDAUS within MND Australia. And on Global MND Day on 21 June 2023, MND Australia held an event at Parliament House in Canberra during which the MiNDAUS Registry was formally launched.

Although outside the reporting period, I would like to mention that the Board reviewed its Strategic Plan and endorsed a new Strategy for 2023-26. The three key objectives are:

- Strengthening awareness and engagement
- Sustaining advocacy to benefit people living with MND
- Funding the sustainability of MND Australia and the sector

I take this opportunity to acknowledge and thank Andy Halter for his great contribution on the MND Australia Board for the past six years including five years as Treasurer. On behalf of the Board I want to express our appreciation for his time and effort. Andy has helped put MND Australia on a solid financial footing.

And I thank Scott Penhall who was the MNDSA Director on the MND Australia Board from November 2022 to early July this year.

Finally, I would like to acknowledge the excellent work of MND Australia’s Board Directors, CEO and staff, the support and work of our members – the State MND Associations – as well as our partners, donors and sponsors.

Prof Samar Aoun

> MND Australia is the national peak body of state organisations that support those living with and impacted by motor neurone disease

A message from our Chief Executive Officer

David Ali

This year MND Australia commenced celebrating its 30th anniversary which will continue until May 2024. This is a time to reflect on our achievements and what still needs to be done.

As the national voice for all those impacted by MND we remain focused on improving the lives of people living with MND through advancing research, advocacy and high quality care.

Everything we do must be person-centred with the paramount focus being on people living with MND and their carers and families. This is reflected in MND Australia's Strategic Plan. We continue to deliver on the key areas of: awareness, support services, advocacy, research, sustainability and strategic partnerships.

During the year MND Australia has always had its members – the State MND Associations – as a central element of what it has done as part of the national network focused on improving the lives of all Australians living with motor neurone disease and advancing research to end MND.

Our advocacy efforts during the year were brought into sharper focus with the creation of a new National Advocacy and Policy Manager position.

We have continued to build on our relationships with other MND organisations, in particular the Fight MND and the MND and Me Foundation, as well as many other organisations including through our involvement in the Neurological Alliance of Australia. Internationally we have actively supported the work of the International Alliance of ALS/MND Associations.

A snapshot of activities to support the delivery of our Strategic Plan during the year include:

- supporting our members – the State MND Associations – as part of a strong national network
- implementing person-centred approaches and lived experience voices into everything MND Australia does
- co-ordinating and developing public policy advocacy including supporting advocacy, research and submissions, and media
- together with MS Australia, refreshed the Neurological Alliance Australia to be a strong and recognised driving force.
- developing and managing linkages and partnerships with other national and international non-government organisations and alliances, including scientific researchers and clinicians
- preparing a funding submission to develop MND Care Guidelines, together with the State MND Associations and other stakeholders
- the official launch of the Parliamentary Friends of MND Group

MND Australia has facilitated opportunities to leverage the unique strengths of the national MND and international ALS/MND communities to maximise complementarity to achieve positive outcomes for people living with MND and to avoid duplication.

I take the opportunity to thank our loyal donors, supporters, sponsors, partners and others who are vital in supporting the work we do. I thank the Board and member State MND Associations for their continued support, guidance and dedication to the MND cause.

Finally, I express my sincere thanks to the Board Presidents I worked closely with during 2022-23: David Lamperd, Mark Grey and Prof Samar Aoun. I have greatly appreciated their support during the year.

And finally, my deepest thanks go to the MND Australia team for their incredible hard work over the year. They are all steadfast in their commitment to making a difference for people living with MND.

David Ali

> *Since 1993, we have been the voice for the MND community.*
>
> *Our national and international networks help increase understanding of the disease and advocate for the needs of those affected.*

MND Australia Board Directors

at 30 June 2023

Prof Samar Aoun
President & MND WA

Amy Critchley
Secretary & MND NSW

Diana Melham
MND Queensland

Jemma Scott
Vice-President

Scott Penhall
MND SA

Prof David Burke AC
Chair, MNDRA Research Committee

Andrew Halter
Treasurer

Prof Tracey Dickson
MND Tasmania

Wayne Pfieffer
MND Victoria

MND Australia Staff

at 30 June 2023

David Ali
Chief Executive Officer

Laura Birks
Research Coordinator

Frances Quan Farrant
National Policy & Advocacy Manager

Dr Gethin Thomas
Executive Director, Research

Maddie Catlin
Executive Officer

Morag Millington
Communications Manager

Ruth Quaken
Project Manager

Komal Upadhyaya
Administration Officer

Dr Ben O'Mara
Information Resources Manager

A message from our Executive Director, Research

Dr Gethin Thomas

The last 12-months have seen many ups and downs in the MND research arena.

In the treatment area, Tofersen, a drug developed by Biogen that specifically targets mutations in the SOD1 gene, was approved in the US. We also saw encouraging results from Phase 2 trials for low-dose IL2 (MIROCALS Trial) and for Clene's treatment CNM-Au8.

Although we are yet to see a curative treatment come through the pipeline, increasing numbers of "disease-modifying" treatments are showing promising results.

Interestingly, with many of these disease modifying treatments, the effects are greater with longer treatment duration which will hopefully inform clinical trial design going forward. With a complex disease like MND, it is critical we have a wide-range of treatment options that can be customised to each patient's specific situation.

In Australia, Edaravone was approved for use in Australia and we are currently awaiting the outcomes of the application for inclusion of the drug on the PBS so it will be affordable for MND patients.

There are also three trials underway that have come from Australian research and are being run in Australia. This is fantastic to see and shows the strength of Australian MND research.

Less encouraging was the failure of several trials, including: a genetic therapy targeting C9ORF72 (Wave-C9); pegcetacoplan, targeting neuro inflammation; and reldesemtiv that aimed to increase muscle function.

We funded 23 grants to support research in 2023 to the tune of $5 million, which was a combination of fantastic fundraising from a host of community organisations, great support from the State Associations and MND and ME and a very generous request from the estate of David McLoone.

Of special note was Daniel McLoone Major Research Initiative. These grants funded outstanding innovative and collaborative projects that have the capacity to make a significant impact on Australian MND research. MNDRA worked with FightMND to double the amount available for this grant program enabling us to jointly fund two projects. Each project will receive a total of $1M over four years.

The two projects funded are are led by Dr Thanuja Dharmadasa and Professor Bradley Turner, both from The Florey at the University of Melbourne.

In 2022 we ran our inaugural *Australian Clinical Research Learning Institute* and the *MND Research Collective* continues to build momentum. The Lived Experience, Discovery Research and Clinical Care Expert Driving teams are now well-established and meeting monthly to build collaborations and ensure the lived experience voice is central to everything we do.

I had the great opportunity to attend the first face-to-face MND/ALS International Alliance meeting for three years in San Diego in December 2022. It was a great opportunity to connect with my peers and Alliance members from around the world.

I have now also been Chair of the Alliance Scientific Advisory Council for a year now and have very much appreciated the increased interactions with MND organisations and companies developing treatments.

Further illustrating the standing of our MND researchers, Professor Matthew Kiernan received the 2022 Ramaciotti Medal for Excellence in October 2022 and Professor Samar Aoun was named the 2023 WA Australian of the Year in recognition of her work in research and advocacy for end-of-life care.

On a very sad note, the MND research community lost a giant of research and a staunch advocate with the passing of Professor Justin Yerbury in July 2023. Refusing to give in to this cruel disease that afflicted him and took many of his family members, Justin forged a brilliant research career leading an amazing team at the University of Wollongong developing new treatments for MND.

As a mark of his huge contribution, earlier in the year, he received the Eureka Prize for Scientific Research and the Excellence in Medical Biological Sciences Prize in the 2022 NSW Premier’s Prizes for Science & Engineering.

Gethin Thomas

2023 MND RESEARCH GRANTS

Daniel McLoone Major Research Initiative

Dr Thanuja Dharmadasa – The Florey, University of Melbourne

Exploring disease heterogeneity across MND clinical phenotypes using a multimodal, multicentre neuroimaging approach

Daniel McLoone Major Research Initiative

Professor Bradley Turner – The Florey, University of Melbourne

Australian Preclinical Research ALS (APRALS) Network: a roadmap for effective translation of therapeutics for sporadic MND

Beryl Bayley MND Postdoctoral Fellowship

Dr Alison Hogan – Macquarie University

The RNA-binding protein SFPQ offers a novel avenue to understand disease mechanisms and identify therapeutic targets in MND

Bill Gole MND Postdoctoral Fellowship

Dr Jeremy Lum – University of Wollongong

Identifying drivers that contribute to the loss of neuronal connections in the early stages of ALS

Daniel McLoone MND Research Prize

Dr Catherine Blizzard – University of Tasmania

A collaborative multivariable approach to prevent the spread of corticomotor dysfunction in ALS

Charcot Award

Prof Trent Woodruff

University of Queensland

Linking C9orf72 dipeptides to inflammation in MND

Peter Stearne Familial MND Research Grant

Dr Sonam Parakh

Macquarie University

Nucleoredoxin (NRX), a novel gene therapy target against TDP-43 multifaceted pathogenic mechanisms

Jenny Simko MND Research Grant

Dr Duncan Crombie

University of Melbourne

Preventing toxic protein aggregation in cells by targeting stress granules

Mavis Gallienne and Graham Lang MND Victoria Research Grant

Dr Brooke-Mai Whelan

University of Queensland

Save Our Speech (SOS) Study

Dr Paul Brock MND NSW Research Grant

Dr Shu Yang

Macquarie University

Characterising CHCHD10-mediated TDP-43 mitochondria entry in MND

NTI MND Research Grant

Dr John Lee

University of Queensland

Therapeutic potential of targeting one of the core players of inflammation (Inflammasome) in MND

MonSTaR MND Research Grant

A/Prof Mary-Louise Rogers

Flinders University

Refinement of p75 ECD measurement as a biomarker for clinical trials for MND

Daniel McLoone MND Research Grant

Dr Fleur Garton

University of Queensland

An Australian sporadic ALS transcriptome resource

Fat Rabbit MND Research Grant

Dr Margreet Ridder

University of Queensland

Drug controlled gene therapy for MND

Ian Sneddon Two Rivers Run MND Research Grant

Prof Mark Wilson

University of Wollongong

Identifying new drugs from Australian native plants and animals to treat motor neuron disease

Col Bambrick MND Research Grant

Dr Adam Walker

University of Queensland

Finding enzymes to remove MND pathology from neurons

Superball XV MND Research Grant

Prof Aaron Russell

Deakin University

Investigating the role of neurturin (a specific protein) as a therapeutic strategy to delay ALS disease progression

Run MND NSW Research Grant

Dr Jennilee Davidson
Macquarie University

Characterising the interactome of sequestosome-1 (p62) – the peacemaker between protein homeostasis and dysfunction

Murray Geale MND Research Grant

Dr Derik Steyn
University of Queensland

Decoding disease impact on the hypothalamus across the ALS-FTD spectrum of disease

Daniel Veysey MND Research Grant

Dr Rosie Clark
Flinders University

Releasing inhibitions – a novel approach to determine targets of inhibitory dysfunction in ALS

Daniel McLoone MND Research Grant

A/Prof Peter Noakes
University of Queensland

Stabilising neuromuscular signalling in MND

Daniel McLoone MND Research Grant

Dr Rita Mejzini
Murdoch University

Development of RNA-like precision therapies to reduce toxic MND protein in the neuron

Daniel McLoone MND Research Grant

A/Prof Sean Millard
University of Queensland

Understanding how the ALS risk factor, GGNBP2, impairs a cellular process defective in many people with ALS

PhD Scholarship Top-Up Grant

Elise Kellet
University of Queensland

The role of post-translational modification of TDP-43 in disease pathology

PhD Scholarship Top-Up Grant

Kathryn Maskell
University of Tasmania

Do upper and lower motor neurons need different treatments to effectively stop neurodegeneration in ALS?

PhD Scholarship Top-Up Grant

Aida Viden
University of Melbourne

Investigating the anatomical origins of MND

> We fund world-class research for better treatments, improved care, and ultimately a cure.

A report from our Treasurer

Andrew Halter

MND Australia

MND Australia had an operating surplus of $520,294 in the year ended 30 June 2023 compared to a deficit of $136,741 in 2021–22.

This was in part due to a significant increase in income. During the 2022–23 year, MND Australia received total income of $1,545,376, compared to $1,056,435 in 2021-22. MND Australia had received income totalling $1,067,094 in donations and bequests, up from $837,688 in 2021–22.

MND Australia received an extension of funding from the Department of Social Services as part of the Information, Linkages and Capacity Building (ILC) grant program to continue to deliver the MND Connect Project to further enhance the MND Connect website with new information resources, and to also support the National MND Info Line service.

Overall expenditure for 2022-23 was $1,025,082 ($1,193,176 in 2021-22) due to continuing efforts on minimising expenditure despite increases in work activity during the year.

Total assets increased from $1.4m in 2021-22 to $2,279,575 in 2022-23. The net asset position increased to $1,403,841 ($883,547 in 2021-22), due to an increase in cash at bank. MND Australia is in a much stronger net equity position than 2021-22.

The Board's Finance Audit and Risk Management Committee is continuing to strengthen the foundations of MND

Australia to resource and achieve our strategic priorities to improve outcomes for people with MND.

In 2021 the Committee had budgeted for a deficit in 2021-22 and planned and budgeted a break-even in 2022-23 (with a surplus in 2023-24 and future years). With the half million-dollar surplus in 2022-23, MND Australia is performing better than expected.

To continue to strengthen MND Australia's income streams and financial sustainability, the Board recently developed a Revenue Strategy focussed on increasing membership fees for the 2024-25 year and out years; a coordinated and targeted donation income-raising, eg national corporate sponsorship; prioritising pursuit of Commonwealth Government and other grants; continuing current lower risk, low fee diversified passive asset strategy; and building the financial capacity to fund future year initiatives.

MND Research Australia

All funds received by MND Research Australia (MNDRA) to support research come from donations, fundraising and bequests. MNDRA does not receive any government funding.

All funds and donations received by MND Australia specified for research are passed on in full to MNDRA to fund vital research. An administration contribution is transferred to MND Australia to offset some of the operational costs of running the research arm.

MND Research Australia had a deficit for the year of $1,784,979, compared to a surplus of $2,302,923 in 2021-22.

Notable changes were that bequests received in 2022–23 were $348,270 compared to $3.9m in the previous year in which MNDRA had received a significant and generous bequest from the estate of Daniel McLoone.

The decrease in bequests was partially offset by an increase in donations received in 2022–23 being $3,158,1535 ($1.9m in 2021-22). Dividends were down to $14,121 ($35k in 2021–22) and interest received were also up at $142,514 ($15k in 2021-22).

Funds available for research grants are generally received between 1 September and 31 August each year. Grants are made available for research commencing the following year. There was a total of $3.142m made available for grants to be allocated by the Research Committee in late 2023.

Regarding the Balance Sheet, as at 30 June 2023 there were $9,093,347 in total assets. This is slightly down from $9.7m as at end June 2022.

MNDRA's investment strategy includes funds invested in conjunction with advice from Danny McMahon, the Principal of Planning Forward financial planners, through the BT Panorama investment platform.

Overall investments totalling $6.76m have returned $194k in income during 2022-23, giving a return of 2.86 per cent before fees of $2,086. Total cash return from term deposits and cash management account totalled $138k.

In regard to Listed Securities, there are shares donated to MNDRA from various bequests over the years. MNDRA's Securities portfolio now total $1.463m.

During 2022-23, $36k was received in income from the portfolio. During the year MNDRA invested in several managed funds which provided $19k in income from $1.125m in holdings and also gained $15k in value. Performance has been variable, again possibly reflecting a turbulent year for the stock market.

Acknowledgments

On behalf of MND Australia and MND Research Australia I thank our donors and supporters for their generosity. Their support is vital to enable us continue our work to improve the lives of everyone impacted by MND through care, advocacy and research.

I thank my fellow Finance Audit and Risk Management Committee members including Jemma Scott, Amy Critchley and Andrew Danson.

I also thank former Board members Mark Grey and Scott Penhall who were also members of the Committee during the year. They, together with our CEO and Executive Director Research, have devoted significant time and energy over the past year to oversee MND Australia's budget, financial and risk management.

Finally, I thank our auditors the Banks Group Assurance Pty Ltd, and also Assisted Innovations for their support.

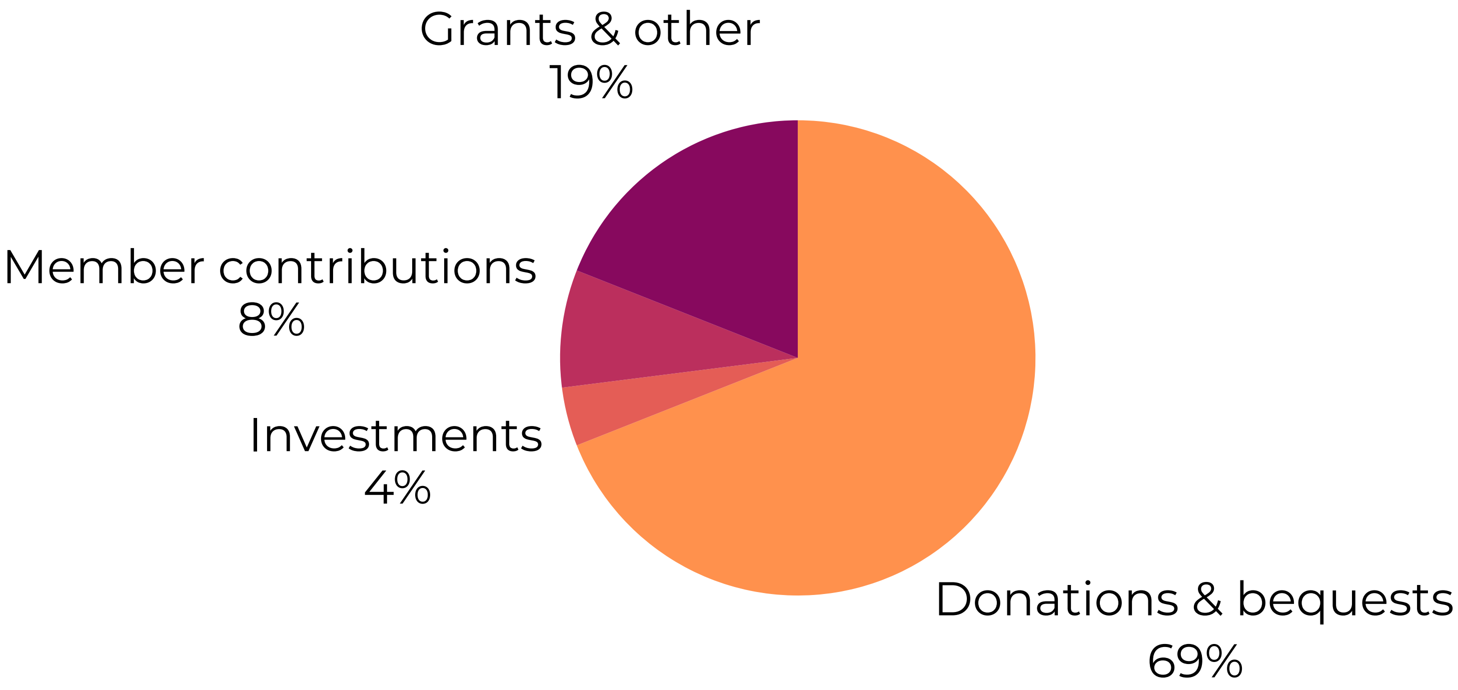
Although outside the reporting year, I do want to acknowledge and thank MND Victoria for their meticulous preparation in the lead up to taking over the provision of financial management and payroll services for MND Australia from 1 July 2023.

Andrew Halter

Income & expenditure

INCOME 2022–23

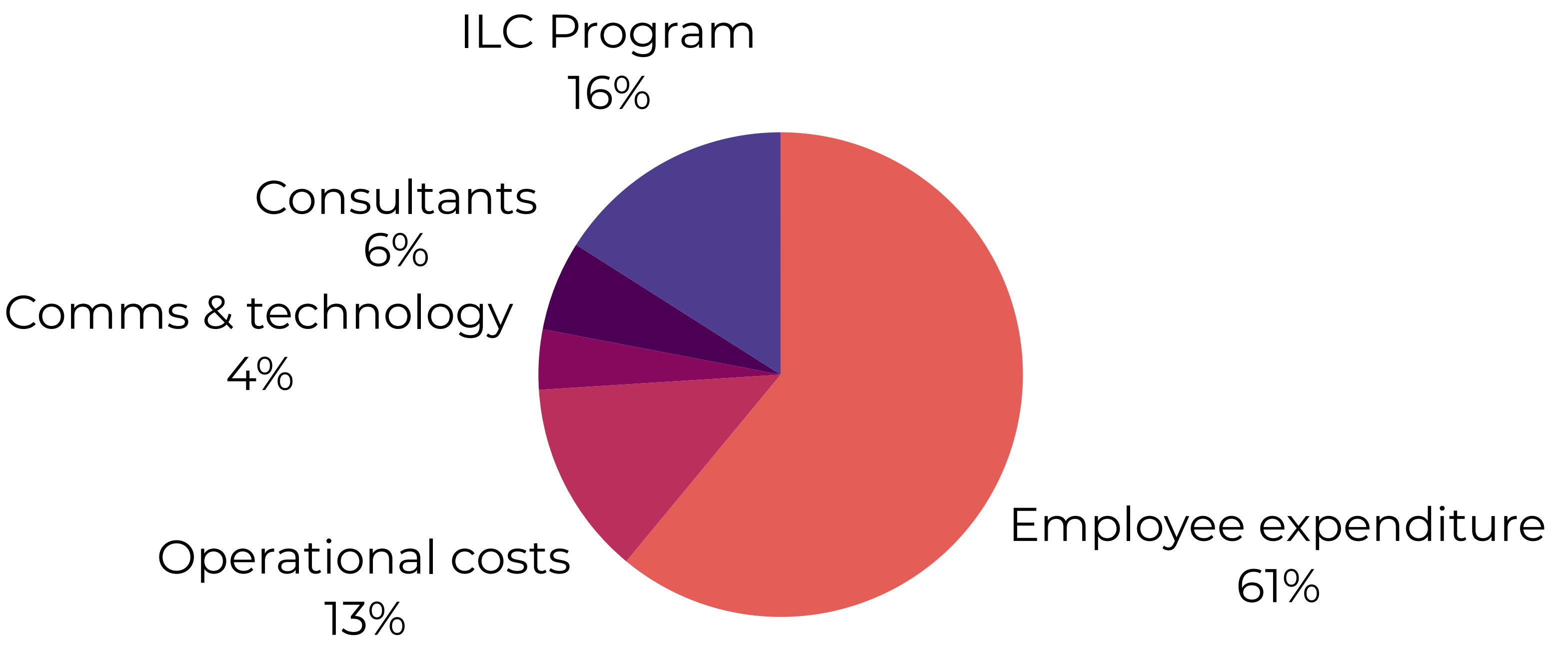
$1,545,376



Income & expenditure

EXPENDITURE 2022–23

$1,025,082



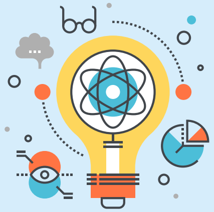
MND Australia Highlights

23

MND research projects funded in Australia

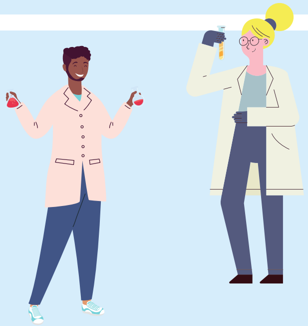
101,000

website visitors



8

editions of Research Directions



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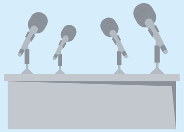
PhD scholarship top-up grants



1st Australian & NZ MND Research Symposium, in collaboration with FightMND

11

e-newsletters sent to our **15,000** subscribers

Social media following

18,600
Facebook

860
Instagram

1,070
LinkedIn

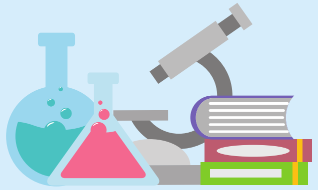
3,180
X

6

State of Play webinars

$5M

in research grants towards cause, care and cure



5

advocacy submissions

10

new digital resources

The National Network of MND Associations

2022-2023

110

information sessions for people with MND

2,146

people with MND registered with the State Associations

218

support groups, for people with MND, their carers and family

7,854

volunteer hours gratefully received by the MND Network

790

people newly diagnosed with MND in 22–23

747

people with MND received NDIS CoS through State Associations

256

education sessions for health professionals & service providers

1,505

people received assistive technology or equipment loans

8,570

total pieces of assistive technology in State Association equipment libraries

22

Indigenous Australians living with MND

120

staff across the six State Associations

Celebrating 30 Years of care, advocacy & research

In May 2023, we launched our 30th anniversary celebrations, which included a '30th' logo and a #MilestoneMondays social media campaign, highlighting key milestones in MND Australia's first 30 years.

mnd Australia
30 YEARS OF CARE, ADVOCACY & RESEARCH

> This October I've had MND for 6 years. I enjoy getting out in my veggie garden with the help of my carer Katrina, especially on a sunny day. I love a sneaky pub lunch and socialising with my family and friends.
>
> My wife and kids are my world and I'm forever grateful for the help and support they give me. I might be confined to my wheelchair now, but I'm not going down without a fight. Life is worth living! #MNDNeverGiveUp

Jason,
living with MND

mnd week
18 – 25 June 2023

> Our Mum, Vijay was diagnosed with MND in 2019. Mum still managed to give my brother and I her advice, insight, and understanding whenever we felt overwhelmed, despite living with the cruelty of MND.
>
> On 19 June 2020 our Mum passed away peacefully in her sleep. Losing a parent is visceral, it is gut wrenching, and it quickly turns what were once stable foundations into rubble. Although, she will never really leave, my mind is filled with fond memories.

Let's hope a cure is found so no one will need to suffer from this cruel, evil disease anymore.

Raksha,
lost her mum to MND

mnd week
18 – 25 June 2023

> I have had MND for 14 years now. My friends always express to me that I have a very positive attitude with a happy face and I do not let this terrible disease take over my life. It's true, I make sure I go out as much as I can from going to the Opera to a game of NRL.
>
> I am a French cook, I cannot use my hands but I can still share my skills to my carers and friends by explaining how to cook and share my French recipes.

I was told I changed many people's lives being me and I'm happy with that. Try your best, don't give up!

Chantal,
living with MND

mnd week
18 – 25 June 2023

> My dad, my hero, the courage and bravery he had. He was so strong I will never forget when dad was diagnosed with MND in August 2022 our lives had been turned up side down.
>
> This horrible disease took my dad from us in February 2023. In just 6 months it just rapidly progressed so fast that everything changed & very quickly. Watching him struggle was heartbreaking.

How brutal MND is there are no words to describe it. I cannot wait for the day that there is a cure. I miss him so much & my heart breaks for everyone who is going through the battle.

Jess,
lost her dad to MND

mnd week
18 – 25 June 2023

> I am in my seventh year of living with MND. Considering I was given two to five years I am very grateful for every day. Once a fit and healthy fitness trainer I have lost everything, head, arm, leg strength and the ability to speak but I maintain positivity and purpose to keep me going.

I am very grateful for all my support team who help me every minute of every day.

Leanne,
living with MND

mnd week
18 – 25 June 2023

> I was told I had six months to 12 months to live because mine was one of the more progressive types of MND (PBP) and that there was no cure. But almost 3½ years later I'm still living my best life!
>
> Incredibly, with the help of family and friends, I've raised more than $130,000 for Motor Neurone Disease and I'll keep going until my last breath.

#NeverGiveUp

Jo,
living with MND

mnd week
18 – 25 June 2023

MND Australia

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mnd Australia

30 YEARS
OF CARE,
ADVOCACY
& RESEARCH