

MND AUSTRALIA

# ANNUAL REPORT 2021-22

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# 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



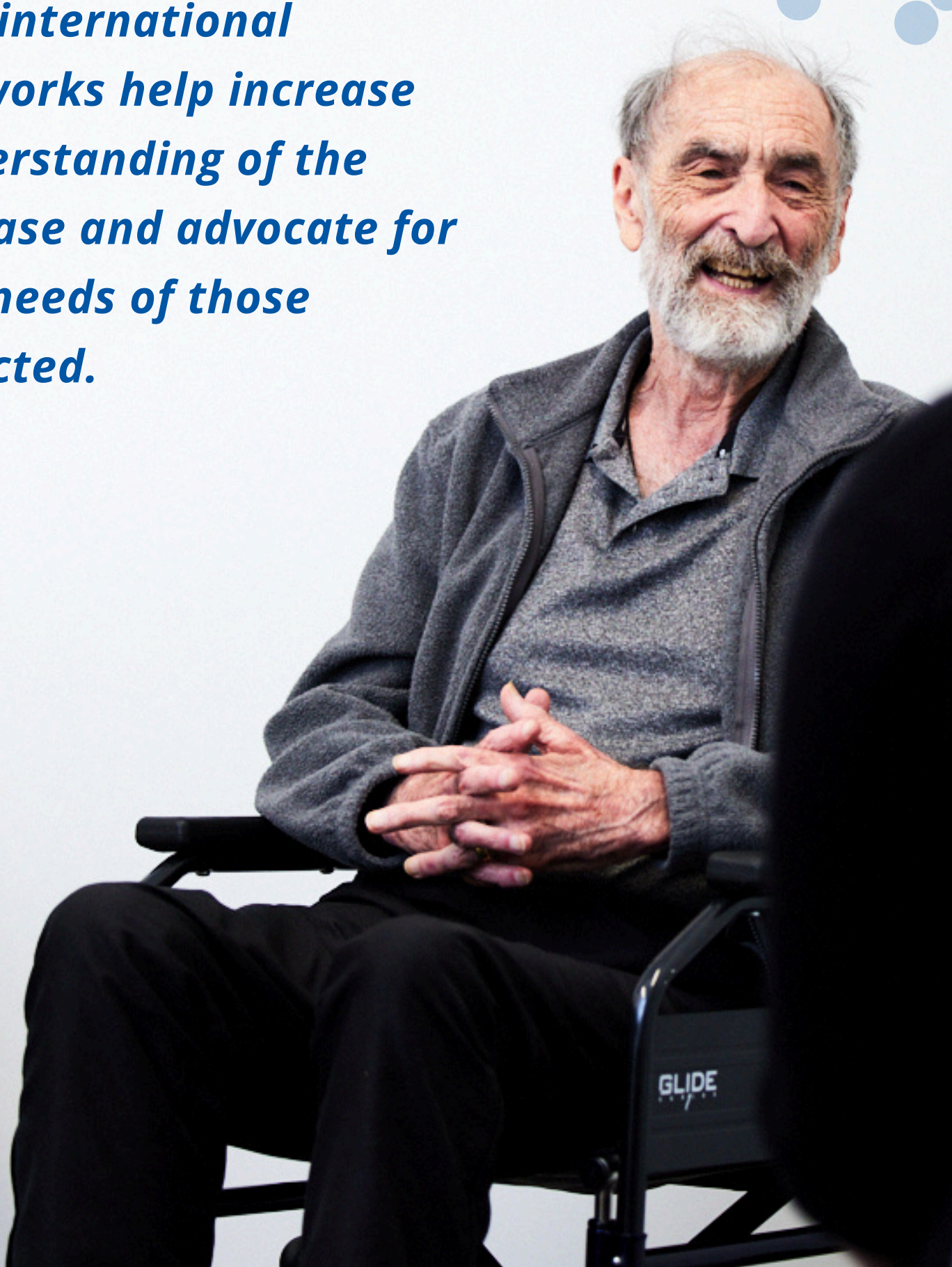


***MND Australia is the national peak body of  
state organisations that support those  
living with and impacted by  
motor neurone disease***





*Since 1983, 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.*





# PRESIDENT AND BOARD CHAIR *Report*



**David Lamperd**

**I have been honoured and privileged to be President of MND Australia for the past three years – due primarily to the resilience and positive manner shown by each of our Board Directors and the team at MND Australia in face of the impacts from COVID-19 that continued to challenge us.**

Our Board worked hard to deliver against the MND Australia Strategy with its mission to improve the lives of everyone impacted by MND through advancing research, advocacy and high-quality care. Our hardworking MND Australia team have been most capably led by our CEO, David Ali, whose leadership and advocacy have influenced a number of impressive outcomes during this past 12 months.

Although outside the reporting period, in September MND Australia successfully facilitated the launch of the Parliamentary Friends of MND Group. Co-chaired by the Hon Alex Hawke MP and Senator the Hon Carol Brown the Group will provide a non-partisan forum for Parliamentarians to interact with MND Australia, health professionals and the wider MND community on matters relating to strongly supporting advancing care, advocacy, and vital research to find better

treatments and eventually a cure for this disease on behalf of those living with MND. The launch at Parliament House was indeed an excellent opportunity for Parliamentarians to learn more about the challenges that many of those living with MND face with the NDIS and the Aged Care programs.

The launch complemented the hard work throughout the year in our advocacy work which took an even greater significance particularly around equity of access for people aged 65 and over in the aged care system compared with those diagnosed with MND under 65 years on the NDIS.

Our research arm – MND Research Australia – allocated through the Research Committee almost \$3.15 million of funds received for research to support new grants commencing in 2021.

MND Research Australia has also continued to strengthen its relationships with organisations such as MND & Me and FightMND, and co-hosted a successful MND Research Symposium with FightMND in April.

Finally, I would like to acknowledge the incredible work of our members, the State Associations, whose tireless efforts continue to significantly assist those living with MND, their carers, family and friends. MND Australia will continue to value and support their efforts as we work together towards a world free of MND.



# MND Australia Board Directors

30 June 2021

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**David Lamperd**  
President



**Mark Grey**  
Vice-President



**Andrew Halter**  
Treasurer



**Jemma Scott**  
Secretary



**Wayne Pfieffer**  
MND Victoria



**Prof Tracey Dickson**  
MND Tasmania



**Geoff Thomas OAM**  
MND South Australia



**Sara Pantzer**  
MND New South Wales



**Prof. Samar Aoun**  
MND Western Australia



**Diana Melham**  
MND Queensland



**Prof David Burke AC**  
Chair, MNDRA Research Committee



# CHIEF EXECUTIVE OFFICER

## Report



**David Ali**

**I have now finished my first full year as MND Australia's CEO and have greatly appreciated the support of the MND Australia Board, our incredibly hard-working team and my CEO colleagues across the State MND Associations.**

In September last year the Board approved the MND Australia Strategy to support our mission to improve the lives of everyone impacted by MND through advancing research, advocacy and high quality care. The key areas of focus in delivering against the Strategy was and continues to be: Awareness, Support Services, Advocacy, Research, Sustainability and Strategic partnerships.

Our advocacy focus during the year have been on:

- equity of access in the Aged Care system to provide timely access to needs based in-home funding and support for people with MND
- calling on the Federal Government to establish a separate funding stream for assistive technology in aged care
- fast-track access to effective treatments and devices for MND
- improve equity of access to genetic services for Australians with MND

A snapshot of other activities during the year include:

- supported the State MND Associations as part of a strong national network
- advocated to counter the Government's proposed introduction of independent assessments to the NDIS access and planning processes
- developed a communications strategy and an advocacy strategy, and developing a research strategy
- improved governance including research governance and commenced review of the Constitutions
- made several submissions to government and to Parliamentary inquiries
- continued to enhance the MND Connect website with new and updated information resources for people living with MND and health professionals
- continued to strengthen our relationship with several partners and explored new partners
- with MS Australia, revamped Neurological Alliance Australia
- active partner on the MiNDAUS project
- hosted the successful 10th National MND Australia Conference co-hosted with MND NSW in September 2021; the Support Services Day in February 2022; the MND Research Symposium co-hosted with FightMND in April 2022
- participated in the work of the International Alliance of ALS/MND Associations sharing and learning and took an active role in PACTALS (the Pan-Asian Consortium for Treatment and Research in ALS) through its September conference.



# MND AUSTRALIA STRATEGY 2021-23

## 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

## Our values

### Collaboration



We work collaboratively on behalf of our national network of member MND Associations to foster promotion and sharing of best practice information and care for the benefit of all who live with MND, including their families and friends, regardless of where they live



### Empathy

We are motivated by those inspirational and resilient people who are impacted by MND

### Inclusion



We believe in fair and equitable access to government health, disability and aged care programs to improve the lives of all people living with MND



### Quality

We strive to fund only the highest calibre research and innovation to move us closer to effective treatments for MND and to support high-quality care services for people living with MND

## Our objectives

1

### Awareness

As the national voice for MND, raise awareness about the disease and share knowledge and stories on care and research

2

### Support Services

Support the State MND Associations to provide best practice care and support services for people living with MND regardless of where they live in Australia.

3

### Advocacy

Present a strong national voice representing people living with MND and State MND Associations, and to collaborate with others on issues that require government, institutional or systemic change through educating, advocating and influencing.

4

### Research

Promotion and facilitation of research into understanding the cause of MND, effective treatments and improved care for people with MND, and fundraising to support MND Research Australia.

5

### Sustainability

Strengthen and build on the foundations of MND Australia to resource and achieve our strategic priorities to improve outcomes for people with MND.

6

### Strategic partnerships

Strengthen collaborative partnerships and alliances nationally and internationally to create innovative opportunities in research, treatments and care.

# To achieve our Vision, Mission and Objectives we need:

## CRITICAL ENABLERS

Collaborative leadership as the national voice for the MND community



Multistakeholder involvement, engagement and influence



High quality and evidence-based information and national data on care and research



Funding



State, national and international partnerships



## Principles and Strengths

*at the heart of what we do*

### Person centred

Everything we do must be person-centred with the paramount focus being on people living with MND and their carers and families.

### Equity of Access

Irrespective of age, geographical location, or ability to pay, all people living with MND should have access to services they need during their disease progression.

### Established Relationships

Our relationships with health professionals, researchers, government and other peak bodies enable us to focus our efforts on improving the lives of people with MND and on research most likely to lead to effective treatments and best practice care.

### Membership

Our national member Association network and our membership of the International ALS/MND Alliance place us at the heart of unrivalled knowledge sharing, capability building and an advocacy and research network that maximises the opportunity for higher quality MND care and research.

### Extensive knowledge of MND

For almost 30 years we have together with our State Association members developed a deep understanding of the needs, expectations and aspirations of people living with MND across Australia.

## To achieve progress we need to:

- 1 Further develop MND Australia as the national peak organisation for motor neurone disease
- 2 Build on existing strengths and capability of the national network of member MND Associations
- 3 Promote and share best practice information and care for the benefit of all who live with MND, including their families and friends, regardless of where they live
- 4 Continue to be motivated by those inspirational and resilient people who are impacted by motor neurone disease
- 5 Fund only the highest calibre research and innovation to move us closer to effective treatments for MND and to support high-quality care services for people living with MND
- 6 Advocate for fairness and equitable access to government health, disability and aged care programs to improve the lives of all people living with MND.



# MND Australia staff

30 June 2021

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**David Ali**  
Chief Executive Officer



**Dr Gethin Thomas**  
Executive Director, Research



**Laura Birks**  
Research Coordinator



**Morag Millington**  
Communications Manager



**Nicole Merrick**  
Project Manager



**Dr Ben O'Mara**  
Information Resources  
Development Manager



**Ruth Quaken**  
Project Manager



**Komal Upadhyaya**  
Administration Officer



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





# EXECUTIVE DIRECTOR, RESEARCH

## Report



**Dr Gethin Thomas**

### **It's been another busy year both in the Australian and international MND research Communities.**

At home in Australia we funded 26 grants to support research in 2022 to the tune of \$3.1M which was a combination of fantastic fundraising from a host of community organisations, the State MND Associations and MND and ME and generous bequests.

After two years of delays due to COVID, we were finally able to hold the inaugural Australian and New Zealand MND Research Symposium in Brisbane in April 2022. We had well over 200 participants to hear about a range of topics in basic, clinical and healthcare research as well as hosting our community focussed MND Connect Research session.

Two national research collaborations have continued to grow and prosper; MiNDAUS and The MND Collective.

MiNDAUS provides a web-based platform for a unique and innovative disease Registry amalgamating the original AMNDR Registry and the SALSA Genetic database. They are now

enrolling patients with all 11 National specialist MND clinics collecting data by the end of 2022 and 80% of incident cases of MND enrolled within three years.

The MND Collective provides a platform for researchers across the MND spectrum to collaborate and share resources. A strong lived experience voice drives the Collective and the first objective is to produce a living database of research resources and projects to enable researchers to identify opportunities to collaborate and share resources.

Internationally, the first new MND treatment since 2017 was approved for use in the US and Canada. MND Australia is now working to bring the treatment, AMX0035 (RELYVRIO) from Amylyx to Australia. Two other treatments are also under review by the FDA but the decision are not due until 2023.

Further strengthening MND Australia's international profile, I will have the privilege of taking over as Chair of the International ALS/MND Alliance Scientific Advisory Council (SAC) in December 2022.

In preparation for this, I attended the Alliance Board Strategy meeting in Edinburgh in June. This was a fantastic opportunity to work with Alliance Board members, to make a significant contribution to the direction of the Alliance going forward, and to ensure that Australia keeps abreast of current best practice.

# 2022 MND RESEARCH AUSTRALIA GRANTS

## **Betty Laidlaw MND Research Prize**

**Associate Professor Parvathi Menon, University of Sydney**

Improved Understanding of Brain Excitability in ALS/MND

## **Bill Gole MND Postdoctoral Fellowship**

**Dr Fiona Bright, Macquarie University**

Exploring undefined regions & novel functions of the TDP-43 protein - The molecular pursuit to uncover the cause and ultimately find a cure for MND

## **Beryl Bayley MND Postdoctoral Fellowship**

**Dr Mouna Haidar, Florey Institute of Neuroscience and Mental Health**

A novel gene therapy approach targeted to overactive brain motor neurons

## **Nancy Gray MND Postdoctoral Fellowship**

**Dr Marnie Graco, Institute for Breathing and Sleep**

Optimising quality of life and survival in motor neurone disease by improving the use of overnight breathing support

## **Scott Sullivan MND Research Scholarship**

**Dr Fleur Garton, University of Queensland**

An investigation into MND biomarkers and genetic risk mechanisms to improve diagnosis/tracking and therapeutic avenues for sporadic ALS

## **Charcot Award**

**Dr Emma Devenney, University of Sydney**

Harnessing Artificial Intelligence Computer Models in MND: a novel pathway to improve patient outcomes

## **Peter Stearne Familial MND Research Grant**

**Dr Lyndal Henden, Macquarie University**

Sex and ancestry – a recipe for gene discovery in MND

## **NTI MND Research Grant**

**Dr Frederik Steyn, University of Queensland**

Preclinical validation of macimorelin, a ghrelin mimetic, as a treatment for amyotrophic lateral sclerosis (ALS)

## **Jenny Simko MND Research Grant**

**Professor Jacqueline Wilce, Monash University**

Preventing toxic protein aggregation in cells by targeting stress granules

## **Dr Paul Brock MND NSW Research Grant**

**Professor Julie Atkin, Macquarie University**

New mechanisms exploring the relationship between aging and motor neuron disease

## **Run MND NSW Research Grant**

**Dr Alison Hogan, Macquarie University**

RNA transport in Motor Neuron Disease - an investigation into dysfunction of the pathway and its potential for therapeutic intervention



## **Mavis Gallienne and Graham Lang MND Victoria Research Grant**

**A/Prof Rebekah Ahmed, University of Sydney**  
Sleep and autonomic function across the ALS-FTD spectrum

## **MonSTaR MND Research Grant**

**Dr Shu Yang, Macquarie University**  
Preclinical assessment of the therapeutic potential of CHCHD10 in the removal of insoluble protein

## **Phyllis Diana Seman MND Research Grant**

**Dr Albert Lee, Macquarie University**  
Using proteomics to reveal the components of protein aggregates to understand MND biology and identify potential therapeutic targets

## **Superball XIV MND Research Grant**

**Professor Coral Warr, La Trobe University**  
Developing new models to help us understand the cause of variability in MND clinical presentation

## **Fat Rabbit MND Research Grant**

**Dr Tanya McDonald, University of Queensland**  
Investigating energy balance in the progression of MND

## **Col Bambrick MND Research Grant**

**Dr Gabriel Trajano, QLD University of Technology**  
High-density electromyography as a new tool to monitor motor neurone changes in MND

## **Nancy Gray MND Research Grant**

**Dr Andrew Phipps, University of Tasmania**  
Understanding why nerve fibres are vulnerable in MND

## **Nancy Gray MND Research Grant**

**A/Prof Mary-Louise Rogers, Flinders University**  
Uncovering a panel of urinary proteins present in people with MND that can be used to indicate stages of disease

## **Nancy Gray MND Research Grant**

**Dr Jessica Collins, University of Tasmania**  
Developing blood tests to diagnose and monitor MND

## **Nancy Gray MND Research Grant**

**Prof Tracey Dickson, University of Tasmania**  
Rebalancing excitability dysfunction in MND by targeting non-neuronal cells

## **Nancy Gray MND Research Grant**

**Dr Jeffrey Liddell, University of Melbourne**  
How corrupted glial cells perpetrate the death of neurons

## **MNDRA PhD Scholarship Top-Up Grant**

**Jeryn Chang, University of Queensland**  
Decoding the loss of appetite and pathophysiology of the brain in motor neuron disease

## **MNDRA PhD Scholarship Top-Up Grant**

**Sean Keating, University of Queensland**  
TDP-43 and protein clearance in the pathogenesis and treatment of MND

## **MNDRA PhD Scholarship Top-Up Grant**

**Katherine Lewis, University of Melbourne**  
Characterising Myelin Changes in Motor Neuron Disease

## **MNDRA PhD Scholarship Top-Up Grant**

**Jianina Marallag, University of Queensland**  
The potential role of CXCR2 activation in motor neuron disease

# TREASURER

## Report



**Andrew Halter**

### **MND Australia**

MND Australia had an operating deficit of \$136,741 in the year ended 30 June 2022 compared to a surplus of \$359,665 in 2020-21 (boosted by the decision last year to mark the share investments to market value, leading to a revaluation uplift of \$437,540).

MND Australia received total income of \$1,056,435 in 2021-22 compared to \$1,295,334 in 2020-21. Although MND Australia had received the residual of a bequest in February 2022 and donations had increased compared to 2020-21, this was offset with a decrease in investment value due to the vagaries of the share market.

MND Australia received its third year of funding from the Department of Social Services as part of the Information, Linkages and Capacity Building (ILC) grant program to deliver the MND Connect Project. The funding was used to further enhance the MND Connect website with new information resources, and to also establish the National MND Info Line service.

Overall expenditure for 2021-22 was \$1,193,176 compared to \$935,668 in 2020-21 due to increased salary, technology, travel and other costs.

The net asset position decreased to \$883,547 compared to \$1,020,287 in 2020-21, mainly due to the drop in value of the shares and a reduction in cash at bank. Despite this MND Australia remains in a relatively strong net equity position and is able to meet all of its financial commitments as they fall due.

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. The Committee had planned and budgeted for a deficit in 2021-22 and plans to break-even in 2022-23 and expects a surplus in 2023-24 and future years.

### **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 our research arm.

MND Research Australia had a surplus for the year of \$2,302,923 compared to deficit of \$2,484 in 2020-21. The change is due to an increase in donation income and a significant and generous bequest from the estate of Daniel McLoone.

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 is a total of \$4.316m available for grants to be allocated by the Research Committee in late 2022.

### AMNDR Registry

In the past MND Australia has provided administrative support to the Australian MND Registry (AMNDR) by processing registry related income and expenses. All donations received by MND Australia that specify they are to be directed to the AMNDR are committed to support the Registry.

No income was received during 2021-22. At an Extraordinary General Meeting on 8 October 2021, it was unanimously approved the AMNDR Registry be wound up. This was formally confirmed by NSW Fair Trading on 22 April 2022. MND Australia held \$232,531 as funds committed to the Registry and most of the funds were disbursed during 2021-22 with \$100,000 transferred to the University of Sydney for the Registry as contributions to the NHMRC Partnership Grant; \$60,000 to Deakin University to continue the employment of the Registry Data Manager; \$20,000 to the University of Queensland for data costs and \$2,530 to MND Australia to cover the costs of winding up. The balance of \$50,000 will be paid to the University of Sydney during 2022-23 as the final contribution to the NHMRC Partnership Grant.

### 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 Mark Grey, David Lamperd and Jemma Scott. They together with our CEO and Executive Director Research, have devoted significant time and energy over the past year to oversight MND Australia's budget, financial and risk management.

I thank the Australian Healthcare and Hospitals Association and later Assisted Innovations for the provision of financial management and other services, and also I thank our auditors the Banks Group Assurance Pty Ltd.

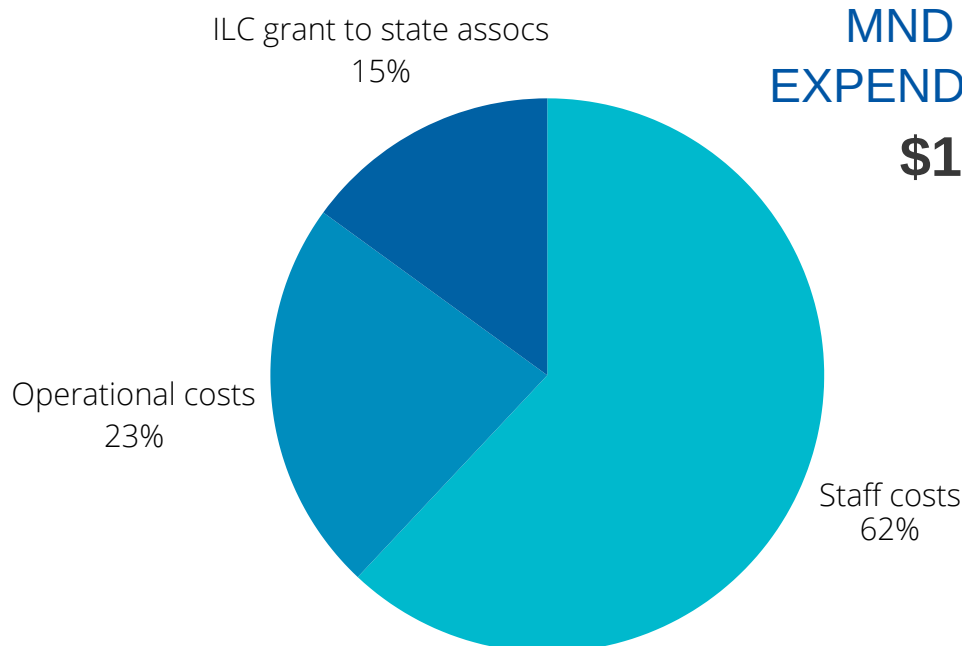
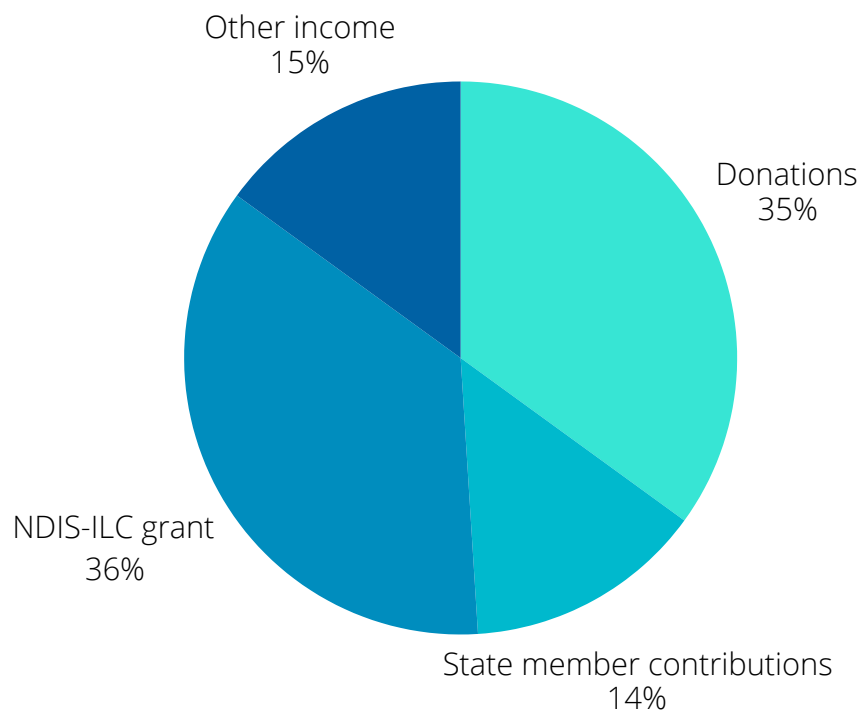
### Andrew Halter

Treasurer and Chair Finance Audit and Risk Management Committee  
16 November 2022

# INCOME & EXPENDITURE

## 2021 – 2022

MND AUSTRALIA  
INCOME 2021–22  
**\$1,056,434**



MND AUSTRALIA  
EXPENDITURE 2021–22  
**\$1,217,364**



# HIGHLIGHTS & IMPACT

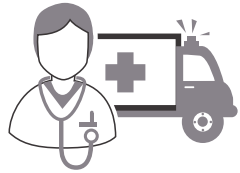
## 2021-22



**Launched the MND Connect website and refreshed MND Australia website**



**Launched the MND Australia 2021-23 Strategy**



**Partnered with the College of Paramedicine to create a paramedics MND tool**



**Over \$3.1 million in research grants awarded by MND Research Australia**



**Held the 10th National MND Australia Conference, attended by over 200 MND professionals**



**Campaigned to improve Aged Care, the NDIS and access to novel medications during the 2022 Federal election**



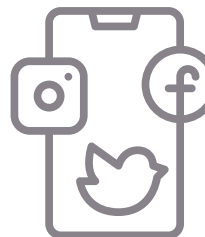
**MiNDAUS online patient registry launched**



**Hosted the online National Support Services Day with State MND Association staff**



**Co-hosted the inaugural Aus & NZ Research Symposium in Brisbane, in collaboration with FightMND**



**Over 38,000 people follow us on our social media channels or subscribe to our e-newsletter**



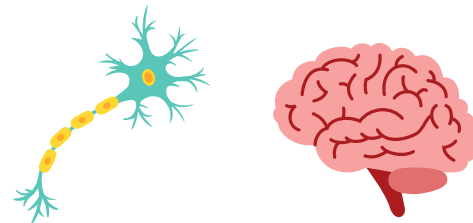
# FEDERAL ELECTION STATEMENT

MND Australia seeks three key election commitments during the 2022 federal election campaign to ensure equity of access to improve the lives of all Australians impacted by motor neurone disease (MND):

- 1. End age discrimination in provision of disability supports and services for people with MND**
- 2. Ensure the NDIS is not weakened**
- 3. Fast-track access to effective novel therapies for MND**

*Motor neurone disease (MND) is a progressive neurodegenerative condition that takes away a person's ability to walk, move, swallow, speak and breathe. Average life expectancy from diagnosis is only 27 months.*

# WHAT IS MOTOR NEURONE DISEASE (MND)?



MND attacks the motor nerves that send signals from the brain, causing the muscles to stop working

Your lifetime risk of developing MND is 1 in 300



A third of people with MND die within one year of diagnosis, and over half die within two years



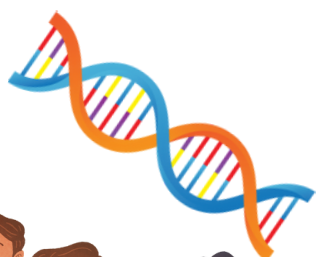
Every day, two people are diagnosed with MND in Australia



There are no effective treatments and no cure



People with MND can lose the ability to move, talk, swallow and breathe



90% of MND cases are sporadic or random

10% are caused by a familial inherited gene

There is hope on the horizon – researchers are working hard to find treatments



MND Australia, together with the state associations, forms a strong network

The economic impact of MND in Australia is over \$2.3 billion per year





# DIGITAL RESOURCES

## 2021–22

- [State of Play: How can research in allied health help build better models of care?](#)
- [Biomarkers in MND](#)
- [Pain management with MND \(factsheet\)](#)
- [Pain management with MND \(plain language\)](#)
- [Overview of the Australian and NZ MND Research Symposium](#)
- [Physiotherapists: a vital part of a MND care team](#)
- [Paramedics MND tool](#)
- [Sexuality and intimacy with MND \(factsheet\)](#)
- [Sexuality and intimacy with MND \(plain language\)](#)
- [MND GP diagnostic tool \(updated\)](#)
- [State of Play: What goes wrong with nerve cells?](#)
- [Maintaining independence at home with MND \(video\)](#)
- [Non-invasive ventilation \(NIV\) in MND \(video\)](#)
- [MND Research Australia \(video\)](#)
- [Why video games matter for MND these holidays](#)
- [How an ethical approach to working with animals helps MND research](#)
- [MND Connect Research Live: from basic science through to advancing treatments and innovative care](#)
- [State of Play: Disease heterogeneity in MND – why is every patient different?](#)
- [State of Play: New drugs from old - drug repurposing and drug delivery in MND](#)
- [Physical activity and MND \(factsheet\)](#)
- [Physical activity and MND \(plain language\)](#)
- [Maintaining weight for health with MND \(factsheet\)](#)
- [Maintaining weight for health with MND \(plain language\)](#)
- [Advance: December 2021](#)
- [Advance: June 2022](#)
- [International Research Update: September 2021](#)
- [International Research Update: December 2021](#)
- [International Research Update: March 2022](#)
- [International Research Update: June 2022](#)

## **MND Australia**

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