

MND AUSTRALIA

ANNUAL REPORT 2019-20



Our vision

A world free of MND

Our mission

To advocate, inform, connect,
and invest in research to
improve the lives of all those
impacted by MND



PRESIDENT & BOARD CHAIR

Report



The period from the beginning of July 2019 to the end of June 2020 was another busy term for MND Australia. The last quarter of this term in particular was most challenging given the COVID-19 influenced restrictions, and I must take this opportunity to thank our CEO, Carol Birks, and all of the MND Australia staff for so capably leading and managing our operations during such a different and unique environment.

Through Carol's leadership the team was able to work positively, flexibly and seamlessly from their homes whilst continuing to support the State Associations, who equally impressed with their ability to effectively support those with MND and their families during this extraordinary period.

During the first half of the 12 month period

our board was able to consider, formulate and deliver our Strategic Plan 2020 to 2023. The final document was approved at our AGM held at Perth in December of 2019.

The 2019 AGM concluded the six year term for David Ali as President. On behalf of the board I would like to again thank David for his commitment, hard work and leadership throughout this period. The board is fortunate that David has remained on the board as a representative of MND Victoria.

At the AGM the board also expressed its appreciation of the significant contributions of Professor Matthew Kiernan as Chair of the Research Committee over five years, and welcomed Professor David Burke as our new Research Committee Chair. David continues our remarkable experience over many years, to have such eminent individuals in this important role.

On behalf of the board I would also like to thank Peter Denham who was a loyal board member for over 10 years as the Queensland representative and pass on our appreciation to Peter and his wife Moya for their contributions to MND Queensland over so many years.

At the 2019 AGM I was honoured to be nominated as President and have been most

impressed with the passion and quality contributions of each of our Board members during a very different and challenging 12 month period.

The board will be more than capable to handle the challenges over the next 12 months so as we can continue to achieve our mission to encourage the strong collaboration amongst our members to:

- promote the very best care outcomes for those with MND and
- enable research that will identify the cause and lead to better care, control and ultimately a cure for MND.

Finally, I would also like to take the opportunity to thank our auditors Charles Pitt and Nga Kwan – and also Australian Healthcare and Hospitals Association for managing MND Australia’s finances.



David Lamperd

PRESIDENT, MND AUSTRALIA

MND Australia Board Directors

30 June 2020

David Lamperd

President

Mark Grey

Vice-President | Independent Director

Andrew Halter

Treasurer | Independent Director

Joyce Schuringa

Secretary | MND Tasmania

David Ali

MND Victoria

Geoff Thomas

MND South Australia

Professor Samar Aoun

MND Western Australia

Professor David Burke AO

Chair, MNDRA Research Committee

Lara Kirchner

MND New South Wales

Jemma Scott

Independent Director

Peter Denham

MND Queensland

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND



CHIEF EXECUTIVE OFFICER

Report



The 2019 – 2020 year started off with much promise for the ALS/MND community culminating in December when we welcomed the international ALS/MND community to Perth for the Annual Meetings of the International Alliance of ALS/MND Associations, ALS/MND Connect meeting, Allied Professionals Forum, 30th International ALS/MND Symposium and many satellite meetings.

These meetings, organised by the International Alliance and the MND Association of England, Wales and Northern Ireland, are usually held in the northern hemisphere. It was therefore wonderful that we were able to organise the first ever Global Walk to d'Feet ALS/MND to take advantage of the warm weather.

People living with MND, family, friends, ALS/MND Association staff and volunteers, researchers and clinicians all gathered on the Perth waterfront wearing t-shirts from their respective ALS/MND Associations to walk in hope and celebration. The promise of the many advances in research leading to effective treatments in the not too distant future was palpable.

Many potential therapies being trialled or coming to trial and novel and innovative trial designs were reported on and there was a sense that 2020 could be a pivotal year for ALS/MND research.

No one could have predicted what was to come. As we said farewell in Perth bush fires were spreading across Australia and then in February the world started to face the daunting reality of a global pandemic. As a vulnerable population there were great concerns for the ALS/MND community globally.

The International Alliance played a vital role in sharing information and hosting webinars to support ALS/MND Associations to respond swiftly and effectively to support and inform their communities.

Here in Australia the strength of our national network came to the fore. With the needs of

people living with MND guiding decision making, MND Australia, in partnership with our members, responded swiftly and effectively to adapt service delivery and events and develop information based on the changing situation.

Following a comprehensive review and engagement process, the Strategic Plan 2020 to 2023 was approved at the MND Australia board meeting in December, with a mission to advocate, inform, connect and invest in research to improve the lives of all those impacted by MND.

During 2019 – 2020, our small team delivered a number of key results related to the five areas identified in this plan: *awareness, advocacy, care, research* and *international partnerships* as outlined in this Annual Report.

My sincere and deepest thanks to the MND Australia team, Communications Manager Morag Millington, Information Resource Manager Ben O'Mara, MND Connect Project Manager Ruth Quaken, Admin Assistant Komal Upadhyaya, and research staff, Executive Director Gethin Thomas and Research Coordinator Laura Birks, who have continued as a hardworking, effective and committed team during a year of great disruption.

I would especially like to thank our volunteer Emilie MacIsaac and the many consistent and loyal donors, new supporters, sponsors, social media followers and subscribers who are vital in supporting the work of our small team.

I thank the board and member associations for their continued support, guidance and dedication to the MND cause.

Finally, a heartfelt thank you to our President, David Lamperd, for his sound and collaborative leadership this year.

Together we will end MND.



Carol Birks

CEO, MND AUSTRALIA

EXECUTIVE DIRECTOR, RESEARCH

Report



The second half of 2019 - 2020 saw the world dominated by COVID-19. Lockdowns and business restrictions have significantly impacted incomes and financial resources right across the Australian community and our MND community has not been spared.

In addition, fundraising events have been either cancelled or moved online. Despite this our fantastic community of fundraisers and donors, though hard work and amazing generosity, have again managed to raise almost \$3M for MND research projects commencing in 2021, almost matching our 2020 grant funding.

Our researchers have managed to keep their research efforts rolling on during these times. Through a mix of ingenuity, flexibility and mostly dedication, clinical trials and lab-

based experiments have experienced only minor delays and disruptions.

A new team was established for MND Research Australia (MNDRA) during 2019 - 2020. Our team, consisting of myself, the Executive Director, Research, Professor David Burke, Chair of the Research Committee, and Laura Birks, Research Coordinator, are now well bedded in and through great teamwork we have managed to adapt well to the challenges this year has thrown at us.

Many of you will have seen that we have changed our name from the MND Research Institute of Australia (MNDRIA) to MND Research Australia (MNDRA), which we feel better reflects our role as the National MND Research Organisation and further highlights our symbiotic relationship with MND Australia.

A handwritten signature in black ink, appearing to read 'Gethin Thomas', written in a cursive style.

Gethin Thomas

**EXECUTIVE DIRECTOR, RESEARCH,
MND AUSTRALIA**

TREASURER

Report



MND AUSTRALIA

MND Australia received a total income of \$920,277 in 2019/20 compared to an income of \$845,201 received in the previous 12 months. This difference in income was primarily due to the receipt of a government grant through the NDIS Information, Linkages and Capacity Building (ILC) grant program to deliver the MND Connect Project.

The year saw a downturn in unsolicited online donations received with \$411,780 received in 2019/20 compared to \$581,934 in 2018/19. The devastating bushfires over the summer and the crippling COVID-19 pandemic shifted the demand for donation income towards those who suffered from these extraordinary events. However, this disappointing result from an MND Australia

perspective was offset by:

- the \$80,264 received as jobkeeper and cash flow subsidy payments from the Federal Government in response to the COVID-19 pandemic;
- and the pleasing fundraising results seen across the country thanks to the hard work of our members.

MND Australia has returned a deficit of \$77,876 this year predominantly due to an increase in staff costs related to the engagement of the project manager, the downturn in unsolicited donations, and the unrealised loss on shares.

MND Australia provides administrative support to the Australian MND Registry by processing registry related income and expenses. All donations received by MND Australia that specify they are to be directed to the Australian MND Registry (AMNDR) are committed to support the Registry. No income was received during 2019/20 for this purpose and \$50,000 of registry funds held as funds committed were expended to support an NHMRC partnership grant administered by the University of Sydney.

Registry funds are administered in a registry account within MND Australia's MYOB accounting system. As of 30 June 2020,

MND Australia has \$232,531 of funds committed to support the Registry in 2020/21 and beyond.

While MND Australia's income, apart from membership fees and grants, is dependent on year to year donations, operational expenditure is closely monitored and managed. Once again we were disciplined with our administration costs. Staff costs relate exclusively to delivering our core objectives. The MND Australia team consists of six, mostly part time staff, with a total of 4.2 FTE which includes 1.6 FTE to run our research arm MND Research Australia. A project manager (0.8 FTE) was recruited in March 2020 funded through the NDIS ILC Grant. MND Australia continues to rent office space and receive professional accounting services provided through the Australian Health and Hospital Association (AHHA).

MND RESEARCH AUSTRALIA

The Treasurer of MND Australia is also the Treasurer of MND Research Australia. All funds received by MND Australia specified for research are passed on in full to our research arm, MND Research Australia (MNDRA), to fund vital research. All donations received by MNDRA are directed to fund research. A small administration contribution is transferred to MND Australia from bank interest and share dividend income to offset some of the operational costs of running our research arm. All funds received by MNDRA to support research come from donations, fundraising and bequests. MNDRA does not receive any government funding.

The funds available for grants are measured by reference to those received between 1 September and 31 August each year. Grants are made available for research commencing the following year.

Although MNDRA received \$2,852,453 in the financial year 2019-2020, the board was able to approve \$2,896,474 for allocation at the October 2019 Research Committee meeting in Sydney. This was awarded in full to grants commencing in 2020.

We sincerely thank our members for working with us to ensure a strong and effective national network, the many donors and supporters for their generosity, and the people with MND past and present who inspire their communities to donate, raise funds and leave bequests. Your support is vital to MND Australia and MNDRA in continuing our work to advocate, inform and connect to improve the lives of all Australians living with MND and advance and fund research to end MND.

My personal thanks to Carol Birks, David Lamperd, Mark Grey, Jemma Scott and Gethin Thomas. Your quality efforts have delivered great value to the Finance Audit Risk Management Committee in 2020. I'm truly humbled to be blessed with your support.

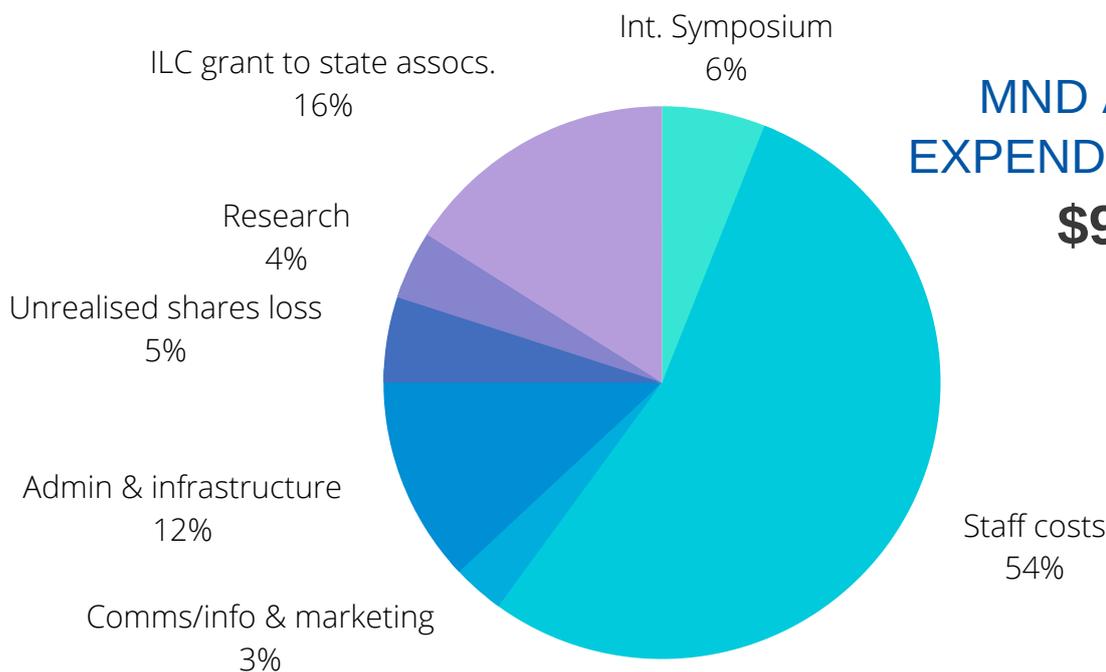
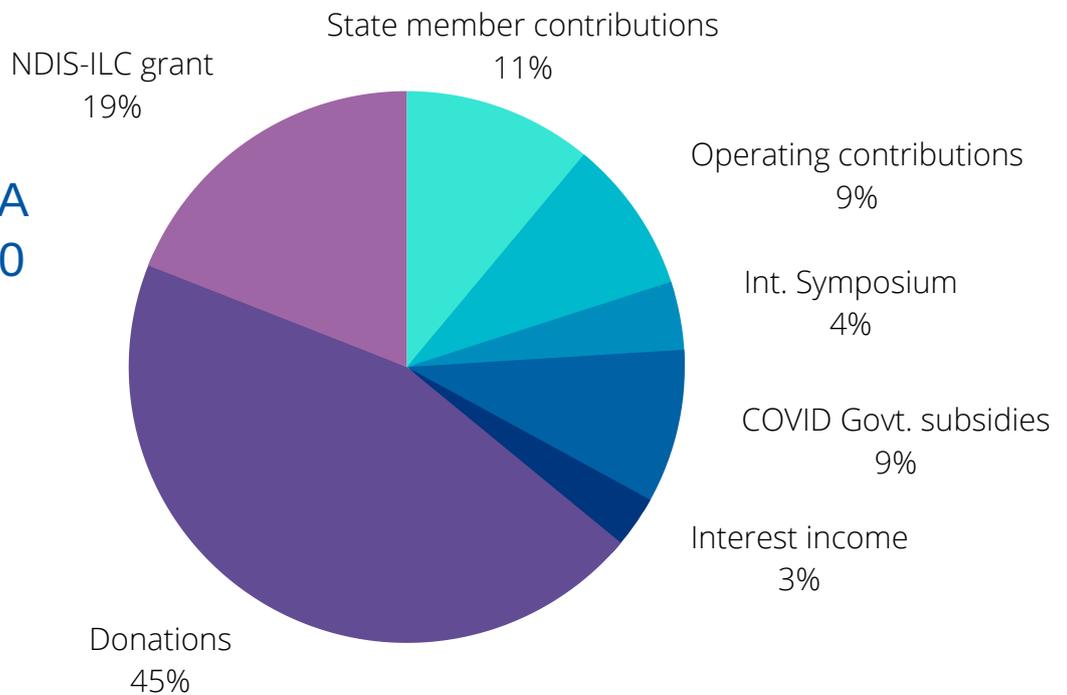


Andrew Halter

TREASURER, MND AUSTRALIA

INCOME & EXPENDITURE 2019-20

MND AUSTRALIA
INCOME 2019-20
\$920,227



MND AUSTRALIA
EXPENDITURE 2019-20
\$998,153

MAKE YOUR MOVE



#AM4MND



AWARENESS

With our members, we **unify** and **magnify** the impact of the national network of MND Associations

Australia Moves for MND #AM4MND

3 May-21 June 2020

- First national fundraising campaign, involving entire national network of MND associations
- Over **\$220,000** raised
- Virtual campaign in response to global COVID pandemic restrictions
- Launched on the first day of MND Week 2020 in May and concluded on Global ALS/MND Awareness Day on 21 June 2020
- Over 180 participants across Australia
- am4mnd.org.au

Global ALS/MND Awareness Day

21 June 2020

- High levels of social media engagement globally. MND Australia's Global Day Facebook posts reached over 134,000 people.
- Senators and MPs demonstrated their support of the MND community in Parliament House by wearing cornflowers provided by MND Australia

CARE

Developing high quality information materials for members, people living with MND, health professionals and care providers to drive best practice care

\$1.3 million ILC Grant

In November 2019, MND Australia was awarded a \$1.3 million Information, Linkages and Capacity Building (ILC): National Information Program grant, funded by the National Disability Insurance Agency.

The grant will deliver a national 'MND Info Line' service and fund the development of an 'MND Connect' section of our website, to provide people with MND, their families and carers, as well as the health professionals and services providers involved in their care, access to immediate, accessible and consistent MND-specific information.

Partnership with HealthDirect

In June 2019, MND Australia entered into a information partnership with HealthDirect Australia, a Government owned NFP that provides trusted health information and advice.

As part of the partnership, MND Australia provides Healthdirect with up-to-date and accurate information about motor neurone disease for their website and other communication channels





ADVOCACY

A photograph of four women standing in front of a world map. The woman on the far left is wearing a white cap and a floral top. The woman next to her is also wearing a white cap and a floral top. The woman in the center is wearing a dark blazer over a light-colored top. The woman on the far right is wearing a dark blazer over a blue top and has a name tag. They are all smiling and looking towards the camera.

Optimising access to quality needs-based government funded supports for all people living with MND, regardless of age or location

Engaging with Government

In 2019 the 'MND Genies' along with the CEO of MND NSW, joined us for a round of meetings with key Government decision makers. Some of our key meetings over 2019-20 included:

- The Minister and Shadow Minister for the NDIS
- The office of the Minister for Health
- The Shadow Minister for Aged Care
- The National Disability Insurance Agency
- The Shadow Minister for Health

Submissions, responses and statements included:

- Royal Commission into Aged Care Quality & Safety
- Pre-budget submission

- NDIS (pricing review, planning review, Tune review)
- Joint position statements with Neurological Alliance Australia regarding telehealth

Make Aged Care Fair

Our advocacy focus for 2019-20 was the Make Aged Care Fair campaign. Stories of older Australians with MND struggling with the Aged Care system led the campaign during MND Week 2020. We received strong engagement with the wider MND community through our social media channels, raising awareness of the issue and encouraging people to take action by contacting their federal MP and senators.



RESEARCH

Delivering the MND Research Australia Strategy: to increase capacity, encourage excellence, foster collaboration & strengthen partnerships

\$2.8 million in research grants

In October 2019, MND Research Australia awarded 25 grants, totalling over \$2.8 million, to Australian MND researchers, for research projects commencing at the beginning of 2020.

The grants were awarded to high quality research projects with the best chance of discovering the causes, finding treatments and improving care for people living with MND.

Collaborations & partnerships

MND Australia CEO and the Executive Director Research, participated in the *Gold Coast Consensus Meeting*, a gathering of experts from across the world, with the aim to simplify ALS/MND diagnostic criteria and improve early diagnosis of ALS/MND.

MND Research Australia and MND Australia continue to contribute funding and in-kind support to the NHMRC Partnership Grant Consortia, MiNDAUS, as partner organisations. This project will bring existing MND registries together and support the development of a website.

2020 MND RESEARCH AUSTRALIA GRANTS

Betty Laidlaw MND Research Prize

Dr Shyuan Ngo, University of Queensland

From the nucleus to the powerhouse: investigating how TDP-43- mitochondrial interactions wreak havoc in MND

Bill Gole MND Postdoctoral Fellowship

Dr Luke McAlary, University of Wollongong

Targeting Prion-Like Strains of TDP-43

Beryl Bayley MND Postdoctoral Fellowship

Dr Mehdi van den Bos, Westmead Hospital

Deep learning as a tool to advance the diagnosis and pathophysiological understanding of ALS

Charcot Grant

A/Prof Bradley Turner

Development of a novel splice-switching molecular therapy for MND

Peter Stearne Familial MND Research Grant

Prof Julie Atkin, Macquarie University

Novel mechanisms of neurodegeneration induced by dysfunctional actin dynamics in MND

Jenny Simko MND Research Grant

Dr Samantha Barton, Florey Institute of Neuroscience and Mental Health

Could abnormal myelin composition be exacerbating neuronal dysfunction in MND?

Col Bambrick MND Research Grant

Dr Richard Gordon, University of Queensland

Targeting inflammasome-driven neuropathology and motor neuron death in MND using a clinically approved cancer drug

Mavis Gallienne and Graham Lang MND Victoria Research Grant

Prof David Berlowitz, Austin Health/ University of Melbourne

NIV@Home

MNDRA Innovator Grant

Dr Albert Lee, Macquarie University

Clearance of TDP-43 by PROteolysis Targeting Chimera (PROTAC) dual targeting to treat amyotrophic lateral sclerosis (ALS)

MNDRA Innovator Grant

Dr John Lee, University of Queensland

Investigating the therapeutic inhibition of CXCR2 as a disease modifying treatment for motor neurone disease

MNDRA Innovator Grant

Dr Fiona McKay, University of Sydney

Natural Killer cells in ALS

MonSTaR MND Research Grant

Dr Marco Morsch, Macquarie University

The unexplored posttranslational modification (SUMOylation) of TDP43 affects aggregate formation and localisation

MNDRA Innovator Grant

Prof Pamela McCombe, University of Queensland

Possible gut derived toxins in ALS: prevalence and effects on outcome

Superball XI MND Research Grant

Dr Susan Mathers, Calvary Health Care Bethlehem/Monash University

Identifying and responding to the health literacy needs of people living with MND/ALS – a coordinated national approach

Benalla Act to d'feet MND Research Grant

A/Prof Lezanne Ooi, University of Wollongong

Targeting cortical hyperexcitability and neurodegeneration in amyotrophic lateral sclerosis

MNDRA Innovator Grant

Dr Mary-Louise Rogers, Flinders University

Urinary Neopterin as a candidate biomarker that can be used to test disease progress in clinical trials for Motor Neurone Disease

Fat Rabbit MND Research Grant

Dr Frederik Steyn University of Queensland

Tipping the Scales on MND: Preclinical testing of a compound with multiple actions to slow disease progression in MND

MNDRA Innovator Grant

A/Prof Trent Woodruff, University of Queensland

Transcriptomic and Functional Evaluation of Immune-Activated Monocytes in MND

MonSTaR MND Research Grant

Dr Sicong Tu, University of Sydney

Utilising multi-modal connectivity and artificial intelligence to track disease progression in ALS/MND

Run MND NSW Research Grant

Dr Kara Vine, University of Wollongong

Non-invasive drug delivery across the blood brain barrier: Improving the bioavailability of drugs for MND

MNDRA Innovator Grant

Dr Adam Walker, University of Queensland

New mouse models of TDP-43 pathology

NTI MND Research Grant

A/Prof Anthony White, QIMR Berghofer Medical Research Institute

Boosting microglia phagocytosis as a therapeutic approach to treat MND

Robert Turnbull MND Research Grant

Dr Kelly Williams, Macquarie University

Comprehensive transcriptome analysis of neuroanatomical regions with variable pTDP-43 pathology in sporadic ALS patients

MNDRA PhD Scholarship Top-Up Grant

Courtney Clark, University of Tasmania

Inhibitory Regulation of Motor Neurons: A new target mechanisms for MND

MNDRA PhD Scholarship Top-Up Grant

Laura Reale, University of Tasmania

Can we stop the spread of TDP-43 pathology in ALS?



**Dr Shyuan Ngo, 2020 Betty
Laidlaw MND Research
Prize winner**

INTERNATIONAL *Partnerships*

Leveraging the international ALS/MND community to maximise understanding of MND, research, treatment and best-practice care in Australia

International ALS/MND Meetings

PERTH, DECEMBER 2019

MND Australia, in partnership with MND Western Australia, welcomed over 1,000 delegates from the international ALS/MND community to Perth as hosts of the 2019 international meetings and programs, including:

- 30th International Symposium on ALS/MND
- ALS/MND Connect
- Patient Fellows
- Allied Professionals Forum
- Inaugural Global Walk to D'Feet ALS/MND
- Meeting of the International Alliance of ALS/MND Associations
- Pan-Asian Consortia for the Treatment of ALS (PACTALS)

International Alliance

MND Australia is an active member of the **International Alliance of ALS/MND Associations**. In 2019-20, MND Australia was represented by board director, David Ali, who continued serving on the Alliance board, and Gethin Thomas, who was invited to join the Scientific Advisory Committee.





MND Australia

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