

MND AUSTRALIA

ANNUAL REPORT 2020-21



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



PRESIDENT & BOARD CHAIR

Report



As I complete my second year as President of MND Australia I reflect on a year like no other. We were beset with the impacts of the COVID-19 pandemic including lockdowns, border closures and other disruptions.

Notwithstanding these, MND Australia continued to deliver against its Strategic Plan to support the State MND Associations, build awareness, to advocate, strengthen information development, support research and reinforce international partnerships. This was an incredible effort by the Board, the MND Australia staff, and our members – the State MND Associations.

Despite being a difficult year, much was achieved. As the peak national body, MND Australia continued its commitment to advancing MND care and research and supporting its members.

Of particular note MND Australia is proud of both MND NSW and MND Victoria for reaching the milestone of 40 years in the provision of care and support to people living with MND. A truly amazing milestone for both Associations.

And the other State Associations continue to go from strength-to-strength in supporting their local MND communities and working closely with MND Australia. The collaboration between the State MND Associations and with MND Australia has flourished even during the challenges of COVID-19.

Our Make Aged Care Fair campaign remains an important focus to influence positive outcomes for people living with MND aged 65 years and over while the gap widens between this cohort and those able to access the NDIS. Submissions, collaborations and community campaigns continued to advocate for access to quality, needs-based services and supports for all people living with MND regardless of age, location or circumstance.

MND Australia developed several trusted information resources for people with MND and health professionals such as fact-sheets, plain language guides, blogs and research updates.

In late 2020 a monthly State of Play webinar

series commenced to give the MND community the opportunity to hear directly from MND Research Australia funded researchers. These have been very popular and will be extended in 2022 to also focus on care.

With funds from a three-year \$1.3 million Information, Linkages and Capacity Building (ILC) National Information Program grant, MND Australia developed MND Connect, which provides resources, information and service linkage for people living with MND, their carers and family, as well as the health professionals and service providers who support them to live well.

I was privileged to be part of the MND Connect launch on Global MND Day at Parliament House on 21 June. The Minister for the National Disability Insurance Scheme, Senator the Hon Linda Reynolds CSC, formally launched MND Connect and also the MND Australia End of Life Guide. We greatly appreciated the Minister's support. And we deeply value the continuing support of Minister Alex Hawke who hosted the Parliamentary event. We also thank Social Services Minister Anne Ruston, Shadow Assistant Minister for the NDIS Senator Kimberley Kitching, Deputy Chair of Joint Standing Committee on the NDIS Senator Carol Brown, John Alexander MP, Ross Vasta MP and others.

We also acknowledge Peter Chambers and Sharon Kirkwood who shared their stories on living with motor neurone disease and the challenges of navigating the service system. It is people like Sharon and Peter and their families and carers who motivate us to do

everything possible to reach our vision of a world without MND.

MND Australia continues to strengthen its relationships with other organisations, either national or international, that will advance MND care and research. For example, MND Australia collaborated with FightMND to host a joint MND Research Summit in November 2020 focussed on developing a national collective approach to research that enables better outcomes for people with MND.

MND Australia has also been a significant partner in the MiNDAUS Partnership which is funded by a five-year NHMRC grant to empower MND patients and their carers; the unification and integration of data collection in MND; and integrated data informing policy development.

International partnerships endure with MND Australia's actively participating in the global alliance of the International Alliance of ALS/MND Associations through its Board, the Scientific Advisory Committee, other committees and working groups.

Our research arm – MND Research Australia – allocated through the Research Committee almost \$2.9 million of funds received for research to support new grants commencing in 2020.

During the year MND Australia had a change of CEOs. After over 14 years as CEO, Carol Birks stepped down. Carol's contribution to MND Australia and the broader MND community has been outstanding, assisted by her commitment, work ethic and passion to support those with MND and their families

within not only Australia but also globally.

The thorough recruitment process that followed Carol's decision to retire ensured we had the opportunity to consider a number of quality candidates and MND Australia subsequently welcomed David Ali as our new CEO in March.

David is a very experienced CEO and had been involved with the MND community on a volunteer basis for over 20 years, having previous appointments to the MND Australia Board and also the MND Victoria State Council.

The transition from the solid base that Carol established to the impressive leadership provided by David has been seamless and David has continued his global contributions with his appointments as Vice Chair and Treasurer of the International Alliance of ALS/MND Associations.

Since the 2020 AGM there have been changes at the Board level including:

- the resignation of Deputy President and MND NSW representative Lara Kirchner, who was replaced by Sara Pantzer on 12 November 2020
- the appointment on 12 November 2020 of MND Queensland representative Elyse Maberley
- the resignation of MND Victoria representative David Ali to take on the MND Australia CEO role. Wayne Pfeiffer was appointed MND Victoria representative on 4 March 2021
- the resignation of MND Tasmania representative Joyce Schuringa, who was

replaced by Professor Tracey Dickson appointed on 31 March 2021.

On behalf of the Board, I would like to sincerely thank Lara, Joyce, Elyse and David for their invaluable contributions.

MND Australia has indeed been fortunate to have attracted such high-quality Board members and I take this opportunity to acknowledge the important contributions to date of our newer Board members Sara, Wayne, Tracey and Diana.

In May the Board reviewed its Strategy and consequently released its Strategy 2021-22 with a mission to improve the lives of everyone impacted by MND through advancing research, advocacy and high quality care.

The six Objectives of Awareness, Support Services, Advocacy, Research, Sustainability and Strategic Partnerships will ensure MND Australia is truly the national voice, is more influential and impactful, more collaborative, and more inclusive and patient and carer-centred in everything it does.



David Lamperd

PRESIDENT, MND AUSTRALIA

MND Australia Board Directors

30 June 2021



David Lamperd
President



Mark Grey
Vice-President



Andrew Halter
Treasurer



Jemma Scott
Secretary



Wayne Pfieffer
MND Victoria



Prof Tracey Dickson
MND Tasmania



Geoff Thomas
MND South Australia



Sara Pantzer
MND New South Wales



Prof. Samar Aoun
MND Western Australia



Elyse Maberley
MND Queensland



Prof David Burke
Chair, MNDRA Research Committee



MND Australia is the national voice for people living with MND.

Together with our members, the State MND Associations, and our research arm, MND Research Australia, we strive to improve the lives of everyone impacted by MND.

CHIEF EXECUTIVE OFFICER

Report



It was an absolute pleasure to commence as MND Australia's Chief Executive Officer in March this year. After several years volunteering, it is a privilege to have the opportunity to contribute at an operational level to improve the lives of people impacted by MND today and in the future.

In respect of the 2020-21 reporting period, I can't take credit for almost three-quarters of it. The recognition has to go to my predecessor Carol Birks. Over the year Carol ably led the delivery of the MND Australia Strategy; particularly during a year like no other. Despite the challenges thrown up by the COVID-19 pandemic, Carol's commitment and pragmatism ensured she and the MND Australia team remained focussed on MND Australia having a strong and effective voice for people with motor neurone disease.

During the year, much was achieved against the Strategy focus areas of awareness, care, advocacy, research and international partnerships. MND Australia increased its awareness activities and engagement particularly through our website, social media and the delivery of existing and new offerings such as the monthly State of Play research webinars which have been greatly complimented by many viewers.

We continued our commitment to inform and connect through printed and online information resources, conferences and research. We worked with the State MND Associations and people with MND to develop and update information resources for people living with MND and their families and the health professionals and service providers involved in their care. We share the latest on research and care through MND blogs, fact sheets, plain language guides, monthly newsletters, Advance, International Research Update and more.

We made significant progress during the year on the MND Connect Project funded by a three-year Information, Linkage and Capacity Building (ILC) Grant. This project is funding each State Association to provide the MND Info Line service. The grant also funds the development of an MND Connect website to link the MND community with

accessible MND information and resources.

During the year we completed the End of Life Guide for people living with MND, their carers and families. This important resource provides practical information on planning ahead and end of life care for people living with MND, their carers and family members in an easily accessible and friendly format. Our hope is that the guide will help more people with MND be able to achieve a dignified death.

Despite the COVID-19 constraints impacting on face-to-face meetings with members of Parliament and other decision-makers, our advocacy efforts in 2020-21 continued. During the year we maintained our focus on our Make Aged Care Fair Campaign to raise awareness of the increasing gap in access to government-funded services and support for those aged over 64 years compared to younger people with MND accessing the NDIS.

We made several submissions to government, to Parliamentary inquiries and to the Royal Commission into Aged Care Safety and Quality. Some of these included calling on the government to retain the option of telehealth for NDIS participants; providing comments on the National Preventive Health Strategy; NDIS discussion paper on support coordination; pre-budget submission for the Federal Budget 2021-22; NDIS planning policy for personalised budgets and plan flexibility.

Together with the State MND Associations we rigorously advocated to counter the Government's proposed introduction of

independent assessments to the NDIS access and planning processes. Subsequently the Minister for the NDIS announced that independent assessments will not proceed.

We welcomed the recommendations from the Aged Care Royal Commission Final Report released in March which would significantly improve the care and support that older Australians with a disability, like MND, currently receive under the Aged Care system. However, we need to focus on equality for people aged 65 and over and the full implementation by the government of the Royal Commission's recommendations.

In between lockdowns and border restrictions, Executive Director Research Gethin Thomas and I appeared before the House of Representatives Standing Committee on Health, Aged Care and Sport to advocate for the development of clear processes and pathways to support fast track approval of medicines for MND patients, as well as advocate for the introduction of processes to encourage and enable more clinical trials across Australia.

Some of our advocacy efforts are undertaken with Neurological Alliance Australia. We have also supported various campaigns and collaborations such as the COTA Victoria led Assistive Technology for All, the Arthritis Australia led Accessible Product Design Alliance, and the Spinal Life Australia led Disability Doesn't Discriminate Campaign.

MND Australia continues its commitment to supporting research collaborations and partnerships nationally and internationally to

promote and fund research from discovery to health care.

One example is MND Australia's support of the MiNDAUS initiative focused on patient centred care funded by an NHMRC Partnership Grant. Another example is Gethin Thomas working collaboratively with FightMND on a successful joint summit held in November 2020 to start the process for creating national MND research agenda including a national MND Collective.

MND Australia actively participated in the work of the International Alliance of ALS/MND Associations sharing and learning. MND Australia is taking an active role in PACTALS (the Pan-Asian Consortium for Treatment and Research in ALS).

COVID also significantly impacted national campaigns to raise funds and awareness nationally. I take the opportunity to acknowledge the agility of the State MND Associations to pivot to online and virtual events, although I am sure they and many others are looking forward to face-to-face events again.

In May this year the Board reviewed its Strategic Plan and subsequently developed its Strategy 2021-22 with a refreshed mission, values and objectives. The primary areas of focus are awareness, support services, advocacy, research, sustainability and strategic partnerships. Related to this, we commenced a review of our research governance to ensure the optimum model for facilitating research.

There is much excitement about our

directions, and more hard work ahead of us. However, our principles and strengths – person-centred, equity of access, established relationships, membership and extensive knowledge of MND – are at the heart of what we do and will guide us in the successful execution of the Strategy.

I am very appreciative of the Board, its President David Lamperd and to the extraordinary MND Australia team for being so supportive since I sat in the CEO chair. Together we will aim to have a world free of MND. In the meantime, we will continue to be motivated by those inspirational and resilient people who are impacted by MND and we will work hard to improve their lives through advancing research, advocacy and high quality care.



David Ali

CEO, MND AUSTRALIA

EXECUTIVE DIRECTOR, RESEARCH

Report



Although the wider world may have still been turned upside down through 2020-2021, MND research continued to progress and our brilliant researchers just kept adapting and developing their projects to ensure their work kept moving.

In a similar vein, our marvellous donors and fundraisers again surpassed themselves despite very few face-to-face events were possible. We were incredibly privileged to be able provide over \$3.1M in research grants this year. Given the challenges faced this is an amazing total and we are very grateful. In the research space it was a big year.

Internationally, a number of important clinical trials were completed and there was mixed news. Amylyx's AMX0035 drug showed very promising Phase 2 results and has now been submitted directly for approval.

Unfortunately, Brainstorm's NurOwn had less clear outcomes and we await to see the path forward for this therapy.

In Australia, we held the first National MND Research Summit, bringing together people with lived experience, researchers, funding bodies, industry and neurologists and allied health providers.

From this we have developed a plan to launch "The MND Collective", which will enable us to focus our research efforts more effectively and ensure the lived experience voice plays a central role in decision making.

A handwritten signature in black ink, appearing to read 'Gethin Thomas'.

Gethin Thomas

**EXECUTIVE DIRECTOR, RESEARCH,
MND AUSTRALIA**

TREASURER

Report



MND Australia

For the year ended 30 June 2021, MND Australia had a net surplus of \$359,666. In 2019-20 MND Australia's financial position was a net deficit of \$77,876. The primary reason for the turnaround was due to the decision this year to revalue the share investments to market value, leading to a revaluation of \$437,540. If the shares had not been revalued, the net result would have been relatively consistent with previous years.

MND Australia received a total income of \$1,295,334 in 2020-21 compared to \$867,766 in 2019-20, partly due to bequest income, JobKeeper and cash flow subsidy payments from the Federal Government in response to the COVID-19 pandemic.

MND Australia received its second 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 establish the MND Connect website which was formally launched by the Minister for the National Disability Insurance Scheme on Global MND Day on 21 June, and to also establish the National MND Info Line service.

Income from unsolicited online donations continued to decline reflecting an ongoing trend in the reduction in donations reportedly due to the COVID-19 pandemic and the 2020-21 summer bushfires. There had been a decline in national fundraising events including the postponement of the Australia Moves for MND campaign from May 2021 to early 2022 which impacted on MND Australia's income for 2020-21. The decline in donation income was offset by a generous bequest of \$250,000 which has enabled MND Australia to continue its work as the national voice for MND and to improve the lives of all those impacted by MND.

Overall expenditure decreased compared to 2019-20 (\$935,668 down from \$945,642 in 2019-20). General expenses decreased significantly however were offset by an increase in employee expenditure from \$534,930 in 2019-20 to \$672,591 in 2020-21 which in part includes the MND Connect

Project Manager funded from the ILC grant as well as employee expenses incurred relating to the exiting Chief Executive Officer.

The net asset position also improved to \$1,020,287 compared to \$660,622 in 2019-20, mainly due to the revaluation of the shares. This relatively strong net equity position means MND Australia is able to meet all of its financial commitments as they fall due.

The Finance Audit and Risk Management Committee is focussed on strengthening and building on the foundations of MND Australia to resource and achieve our strategic priorities to improve outcomes for people with MND. One example is the development of investment strategies for MND Australia and MND Research Australia to achieve better returns than the miniscule returns on bank term deposits.

MND Research Australia

The Treasurer of MND Australia is also the Treasurer of 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 received by MND Australia specified for research are passed on in full to 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 income to offset some of the operational costs of running our research arm.

MND Research Australia had a deficit for the

year of \$2,484, which is an improvement of \$88,292 deficit in 2019-20. The change is due to the revaluation of listed investments amounting to \$133,824. This revaluation was offset by a decrease in donations and bequest income for the financial year, although further donations were received after the end of the financial year. Usually the 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 \$3,121,037 available for grants to be allocated by the Research Committee in November 2021.

AMNDR Registry

MND Australia provides administrative support to the Australian MND Registry by processing registry related income and expenses. Registry funds are administered in a registry account within MND Australia's MYOB accounting system. 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 2020-21. As at 30 June 2021, MND Australia held \$232,531 as funds committed to the Registry. Although outside this reporting period, it should be noted that the Committee members of the AMNDR Registry unanimously approved at an Extraordinary General Meeting on 8 October 2021 that the Committee be wound up. Expenses of \$50,000 had been transferred to the University of Sydney for the Registry as the fourth contribution to the NHMRC Partnership Grant.

The Committee agreed the balance be divided with two more payments of \$50,000 each required to be made to the University of Sydney; \$80,000 to continue the employment of the Registry Data Manager and \$2,530 be provided to MND Australia to cover the costs of winding up.

Acknowledgments

On behalf of MND Australia and MND Research Australia I thank our members – the State MND Associations – for working with us to ensure a strong and effective national network. I also sincerely thank our 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 improve the lives of everyone impacted by MND through advancing research, advocacy and high quality care.

I acknowledge and thank my fellow Finance Audit and Risk Management Committee members including Mark Grey, David Lamperd and Jemma Scott. They together with then CEO Carol Birks (and CEO David Ali since March 2021) and Executive Director Research Gethin Thomas, have devoted significant time and energy over the past financial year to oversight MND Australia's budget and financial management.

Finally, I take the opportunity to thank the Australian Healthcare and Hospitals Association for the provision of financial management and other consulting services,

and thank our new auditors – the Banks Group Assurance Pty Ltd – in particular Andrew Fisher and Dominique Leung.

Andrew Halter

TREASURER, MND AUSTRALIA

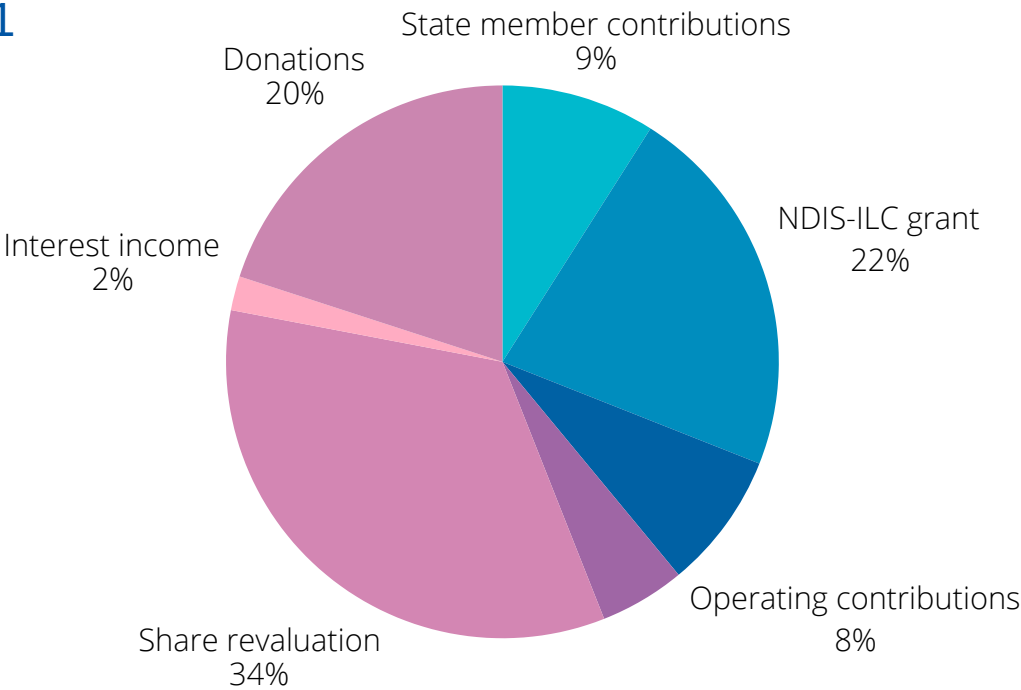
Financial statements for [MND Australia](#) and [MND Research Australia](#) are available on the ACNC website

INCOME & EXPENDITURE

2020 – 2021

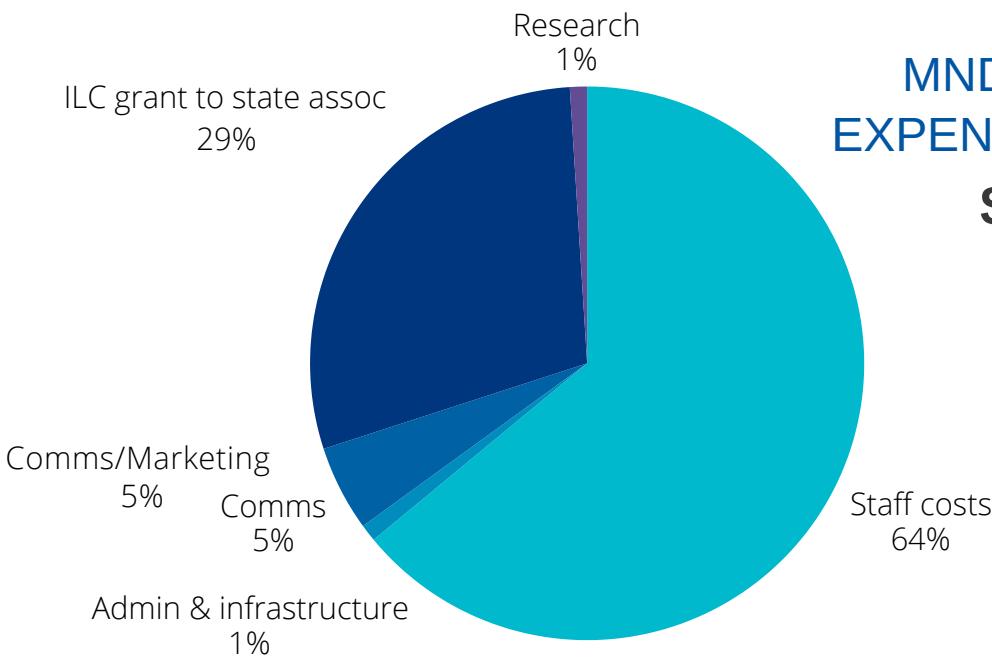
MND AUSTRALIA INCOME 2020-21

\$1,295,334



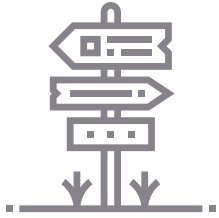
MND AUSTRALIA EXPENDITURE 2020-21

\$935,668



HIGHLIGHTS & IMPACT

2020–21



Launched the End of Life Guide at Parliament House on Global ALS/MND Day



Held the inaugural Australian MND Research Summit, in partnership with FightMND



Hosted a Global ALS/MND Day event at Parliament House, attended by key decision makers, including the minister for the NDIS



Launched the State of Play webinar series, to showcase and connect Australian MND research with wider community



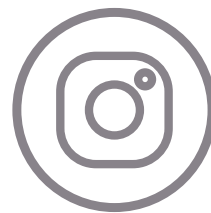
Outgoing CEO Carol Birks awarded the International Alliance Humanitarian Award



First National Walk to D'Feet held on 3 May 2020 for MND Week 2022



\$3 million in research grants awarded by MND Research Australia



MND Australia joined Instagram and is building a following on the platform



Continued campaigning to 'Make Aged Care Fair' for Australians aged 65+ with MND



Over 11 submissions, responses and consultation papers made to Government for issues affecting people with MND



Collaborative advocacy wins, including Aged Care Royal Commission recommendations, extension of telehealth and halting NDIS independent assessments.



2021 MND RESEARCH AUSTRALIA GRANTS

Betty Laidlaw MND Research Prize

Associate Professor Yazi Ke, Macquarie University

Novel therapeutic strategies targeting TDP-43 in Motor Neuron Disease

Bill Gole MND Postdoctoral Fellowship

Dr Thomas Shaw, University of Queensland

Ultra-High Field MRI of Spinal Cord Tissue in Motor Neurone Diseases

Beryl Bayley MND Postdoctoral Fellowship

Dr Emily McCann, Macquarie University

Investigating the role of complex genomic variation in MND

Marisa Aguis MND Postdoctoral Fellowship (2021–23)

Dr Nicholas Geraghty, University of Wollongong

High-throughput flow cytometry drug screen to discover new treatments for MND

Charcot Award

Dr Shyuan Ngo, University of Queensland

MND in space and time: deciphering the spatio-temporal landscape of cell-autonomous and non-cell-autonomous drivers of motor neuron death in MND

Peter Stearne Familial MND Research Grant

Prof Ian Blair, Macquarie University

Genome-wide detection of short tandem repeats that are expanded in ALS

Dr Angela Worthington MND Research Grant

Dr Colin Mahoney, University of Sydney

Establishing the role of high definition-density EEG in the diagnosis and monitoring of MND

Mavis Gallienne and Graham Lang MND Victoria Research Grant

Prof David Berlowitz, University of Melbourne

REPAIR MND: REDuced PATient – ventilator asynchrony with Artificial Intelligence assisted Respiration in MND

Col Bambrick MND Research Grant

Dr Robert Henderson, University of Queensland

A Novel PET Imaging Marker of Astrocytes and Glutamate Reuptake in Brain and Spinal Cord in ALS

Jenny Simko MND Research Grant

Dr Nirma Perera, The Florey

Autophagy in Neuroglia: a hidden player in abnormal MND proteostasis

MonSTaR MND Research Grant

Dr Frederik Steyn, University of Queensland

Targeting NAT1 to improve metabolism and slow disease progression in MND

Jack and Joan Thompson MND Research Grant

Dr Mouna Haidar, The Florey

Will reducing abnormal cortical activity in MND have a therapeutic effect?

Superball XIII MND Research Grant

A/Prof Bradley Turner, The Florey

Defining upper motor neuron markers using translational RNA profiling

Judy Mitchell MND Research Grant

Dr Victor Anggono, University of Queensland

Molecular mechanisms underlying the cytoplasmic aggregation of the RNA binding protein, SFPQ, in ALS

Fat Rabbit MND Research Grant

Dr Adam Walker, University of Queensland

Defining the involvement of ubiquitin-2 in MND

Dr Paul Brock MND NSW Research Grant

Dr David McKenzie, University of Sydney

Development of an amperometric biosensor for the detection of TARDNA binding protein 43 (TDP-43) in MND

Robert Turnbull MND Research Grant

Dr Christopher Bye, The Florey

Next generation pre-clinical modelling for MND

Run MND NSW Research Grant

Prof Pam McCombe, University of Queensland

Revisiting excitotoxicity in ALS: how does this occur?

MNDRA PhD Scholarship Top-Up Grant

Natalie Grima, Macquarie University

Investigating novel genomic and transcriptomic features of sporadic MND

MNDRA PhD Scholarship Top-Up Grant

Dr Anna Ridgers, Austin Health

Virtual Ventilation: An evaluation of the utility of ventilator-recorded data to titrate ventilator settings in comparison to non-invasive ventilation polysomnography

MNDRA Linda Rynalski Bridge Funding Grants

Professor Julie Atkin, Macquarie University

Dr Richard Gordon, University of Queensland

Dr Albert Lee, Macquarie University

Dr Nicole Fewings, University of Sydney

Dr Marco Morsch, Macquarie University

A/Prof Mary-Louise Rodgers, Flinders University

Dr Kara Vine, University of Wollongong

Dr Trent Woodruff, University of Queensland

MND Australia

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