DECEMBER 2018

ADVANCE

Investing in innovation, partnering for progress

The Motor Neurone Disease Research Institute of Australia (MNDRIA) was established in 1986 to foster MND research in Australia. From the first grant of $19,046 awarded in 1987, MNDRIA has grown and established a rigorous process for distribution of donations received. In 2018 MNDRIA has awarded almost $4million for new research projects. The primary objective of MNDRIA is to promote research excellence by supporting only the best research that has the greatest chance of finding effective treatments and improving the care of people living with MND.

MNDRIA is working to achieve that objective by **investing in innovation** through**:**

1. Innovator Grants. This year, 'grants-in-aid' have been replaced by 'Innovator Grants' to better reflect their purpose around seed funding new ideas for innovative projects with a clear relevance to MND. Projects must meet at least one of three priority areas identified after extensive consultation with researchers, health professionals, community and MND Australia's State MND association members: (i) advance MND research to understand its causes; (ii) foster the treatment development process and clinical trials; (iii) enhance clinical research and the evidence-base for clinical practice. *(page 4)*

2. Attracting and developing outstanding researchers by supporting researchers at all stages of their careers. Postdoctoral fellowships and PhD top-up grants attract and support early-career researchers. A special grant to promote a mid-career researcher has been established with the Betty Laidlaw Prize. Innovator grants support the best researchers at all stages of their careers. *(page 6)*

MNDRIA is maximising the impact of every dollar spent by **partnering for progress** through:

1. Collaborations and partnerships
Application guidelines encourage collaborative research. The MNDRIA-funded SALSA-SGC collaboration ($1 million) has led directly to NHMRC partnership funding ($2.5 million). *(page 5)*

2. Participation in national and international meetings *(pages 2, 6)*
Meetings facilitate information exchange between researchers and establishment of collaborations and the opportunity to meet people with MND who inspire the urgency to change the future.

14th annual MND Australia Research Conference
Representatives of MND Australia, board members, MNDRIA research committee, presenters and researchers funded by MNDRIA at The Florey Institute, Melbourne in November 2018

Objectives of the MND Australia Research Conference are to:

- promote sharing of expertise amongst MND researchers in Australia
- enable interaction of researchers to foster collaborations
- provide feedback to a wide audience about the latest developments in MND research
- demonstrate the value of the funded research to donors to encourage their continuing support.

The MND Australia Research Conference will not be held in 2019 as it would coincide with the International Symposium on ALS/MND which will be held in Perth. *(see page 2)*

MND Australia is relocating

As the national organisation representing all Australians who share the vision of a world without MND, MND Australia, together with its research arm the MND Research Institute of Australia, is relocating to Canberra. Located in Deakin, the new office is close to other not-for-profit organisations as well as being conveniently located for meetings at Parliament House.

The new postal address from 1 January 2019 is

PO Box 117, Deakin West, ACT 2600

All mail sent to PO Box 430, North Sydney NSW 2059 will be redirected to the ACT address throughout 2019.

Telephone numbers will not change:
T (MND research): +61 2 8287 4989
T (MND Australia): +61 2 8287 4980

mnd Research Institute of Australia

Executive Director Research Report 2018

Funds available for MNDRIA research grants continue to grow each year, thanks to the generosity of the Australian community. This is not only due to a wider understanding of the need to accelerate research discoveries, but also acknowledges the successful outcomes of many of the projects and the people whose research is only possible because of funding from MNDRIA. New researchers are continually turning their attention to MND research, not only because of available funding but also because of the exciting opportunities new discoveries have opened up. It is hard to count exactly how many researchers are currently focused on MND research in Australia, but MNDRIA is funding projects in 14 institutions across Australia in 2019 so we estimate that team members in these and other centres would account for well over 100 MND-focused researchers.

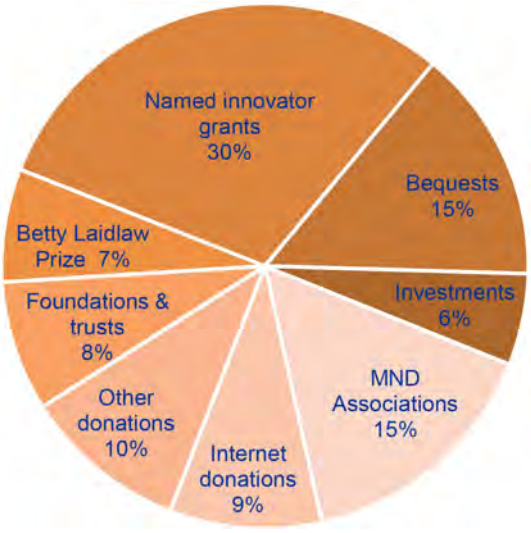
MNDRIA is indebted to the time provided by the fifteen expert members of the Research Committee. Review of the application assessment process has ensured that each application for funding is reviewed by committee members with the most appropriate expertise. A spokesperson is appointed for each application to lead discussions at the annual grants allocation meeting.

MNDRIA is committed to encouraging participation in research conferences, both national and international. This provides the opportunity to gain presentation skills, disseminate outcomes of current research, hear breaking news of the latest findings, mix with other researchers and discuss opportunities for collaborations and partnerships. The annual MND Australia Research Conference, intended largely for a research audience, moves between states each year to allow easier participation of people in all locations. The 13th MND Australia Research Conference was held at the Charles Perkins Institute at the University of Sydney in November 2017. The 14th MND Australia Research Conference was held at the Florey Institute, University of Melbourne in November 2018. Both meetings were followed by a community day, MND Connect, with research presentations for the broader MND community. Read reports on pages 6-8.

The International Symposium on ALS/MND is the world's largest medical and scientific conference on ALS/MND. Experts from research and medical communities as well as ALS/MND associations and people living with ALS/MND come together each year to share new understandings about ALS/MND. The International Symposium will be held in Perth in 2019 (see below). It is hoped that all Australian MND-focused researchers will make every endeavour to participate.

Donations for named innovator grants have grown from 14% of all donations received in 2017 to 30% of all donations received in 2018. New named grants have come from bequests (Andrew Butcher, Janette Hamilton), funding organisations and foundations (Neil and Norma Hill Foundation, Lord Mayor's Charitable Foundation, MSWA) and foundations and groups who have increased the level of their previous funding to $50,000 or more to provide a named grant (Gross Foundation, NTI). Other named grants come from ongoing sponsors and from the state MND associations.

Donations received by MNDRIA in 2018 for new grants commencing in 2019.



We welcome Laura Birks who has recently joined MND Australia as Research Manager and is already working from the new MND Australia office in Canberra. All operations of MND Australia will move to Canberra to join her in January 2019.

During 2018 MND Australia lost two highly valued members of the research team. Rachel Rizk gave invaluable support in her roles in communications and information and then as Research Manager before moving on to a new challenge in February. In just two years, including 12 months as Executive Director Research, Dr Stephanie Williams achieved great changes to move MNDRIA forward with development of rigorous processes and policies regarding MND research priorities, grant applications, grant review, conflict of interest, collaborations and partnerships, clinical trials and research strategy. We were very sorry to lose Stephanie at the end of May 2018 and, since that time, I have stepped back into the role as acting Executive Director Research until the right person is recruited for this exciting role.

Janet Nash
Acting Executive Director Research
MND Australia

30th International Symposium on ALS/MND, Perth, Australia, 2019.

MND Australia, in partnership with MND WA, is proud to host the International ALS/MND meetings in Perth in 2019. This will be an opportunity for the Australian MND community to come together with their peers and leading international researchers from around the world to present and debate key innovations in their respective fields.

The Symposium is preceded by the International Alliance of ALS/MND Associations annual meeting, an Ask the Experts session and the Allied Professionals Forum. Save the dates:

- Sunday 1 December — International Alliance of ALS/MND Associations Annual Meeting
- Monday 2 December — Ask the Experts
- Tuesday 3 December — Allied Professional Forum
- Wednesday 4 – Friday 6 December — 30th International Symposium on ALS/MND

Call for abstracts will be announced on social media channels early in 2019.

MNDRIA Grants in 2019

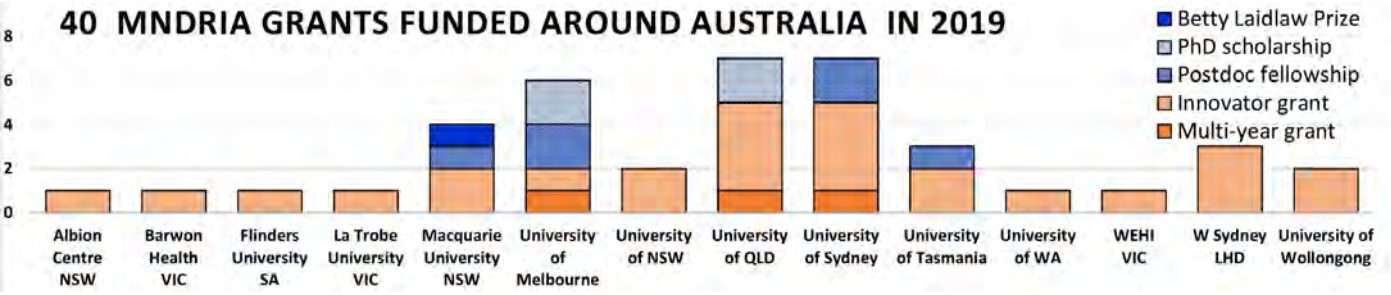
The Motor Neurone Disease Research Institute has supported the best research that has the greatest chance of changing the future of MND with grants of $30 million in the 31 years since the first grant was awarded in 1987.

In 2018 the MNDRIA Research Committee reviewed 90 grant applications and has allocated almost $4 million for new research projects commencing in 2019. Grants were awarded only to the best projects that met at least one of three strategic priorities identified after consultation with the community as the most important areas of research:

1. Advancing MND research to understand its causes
2. Fostering the treatment development process and clinical trials
3. Enhancing clinical research and the evidence-base for clinical practice

Together with 10 multi-year grants continuing from previous years, MNDRIA will fund 40 projects across all Australian states in 2019. Provision has been made for PhD Scholarship top-up grants to be awarded early in the new year.

The annual funding rounds continue to develop capacity, capability and collaboration with the ultimate vision of finding effective treatments that will lead to a world without MND.



Promoting research excellence by supporting only the best research that has the greatest chance of finding effective treatments and improving the care of people living with MND

John Laidlaw AO and Marco Morsch

Betty Laidlaw MND Research Prize 2019

Dr Marco Morsch
Macquarie University, NSW

Investigating how proteins, which are normally located in the nucleus of the cell, get transferred to the periphery, where they accumulate and are believed to initiate MND.

Betty Laidlaw has been cared for at home by her husband John since she was diagnosed in 1984 with primary lateral sclerosis, a slowly progressive form of MND. This prize is a gift from John and Betty Laidlaw to acknowledge an outstanding mid-career researcher. The grant is for an innovative and collaborative project to advance understanding of MND, with a clear potential for effective treatments for MND.

Bill Gole MND Postdoctoral Fellowship 2019 – 2021

Dr Rosemary Clark
The University of Tasmania

Do the nerve cells responsible for regulating inhibition in the central nervous system contribute to clinical differences in ALS/MND?

Bill Gole died from MND in 2003. Thanks to the Rodwell Foundation, the Bill Gole MND Postdoctoral Fellowship has been awarded in memory of Bill each year since 2005.
The fellowship encourages early-career researchers to focus their study on MND. It leaves a momentous legacy. About 90 percent of recipients continue to work in the field of MND and/or neurological diseases with several recipients rising to be among Australia's leading MND researchers. Dr Rosemary Clark is the 15th person to receive this prestigious award.

Beryl Bayley MND Postdoctoral Fellowship 2019 – 2021

Dr James Hilton
The University of Melbourne

Investigating the role of an iron-related pathway in motor neurone death.

Beryl Bayley, a regular MNDRIA donor, died in Sydney in 2013. After distributions to a friend and a family member, the balance of her Estate was directed to MNDRIA for the purpose of MND research. This bequest of over $2 million will provide a 3-year postdoctoral fellowship each year until all the funds from the bequest have been spent.

Charcot Grant

Professor Julian Gold
The Albion Centre, Sydney

Clinical trial of the antiretroviral drug Triumeq in patients with MND to test whether there is an improvement in survival and function.

Jean-Martin Charcot is known as the Father of Neurology.
Born in France in 1825, he was the first person to describe amyotrophic lateral sclerosis (ALS) in 1874.

The Charcot Grant is awarded each year to the top-ranking Innovator Grant to acknowledge the high regard of the research committee for the research project, the track record of the researcher and the relevance of the project to MND.

Investing in innovation— Innovator Grants for 2019

1. Advancing MND research to understand its causes

Neil and Norma Hill Foundation MND Research Grant
Dr Rebekah Ahmed, The University of Sydney
Physiological changes along the frontotemporal dementia amyotrophic lateral sclerosis spectrum – The hypothalamus where eating, metabolism and neurophysiology meet.

MNDRIA Innovator Grant
Professor Roger Chung, Macquarie University, NSW
Revealing the role of protein clearance pathways in sporadic ALS.

Janette Hamilton MND Research Grant
Dr Anthony Cook, The University of Tasmania
Identifying how changes to the TDP-43 protein spread in ALS using human stem cells.

Jenny Barr Smith MND Research Grant
Associate Professor Peter Crouch,
The University of Melbourne
Does iron contribute to death of motor neurones in MND?

Lady (Mary) Fairfax MND Research Grant
Associate Professor Kay Double, The University of Sydney
Investigation to find out how chemical changes to a healthy protein results in the protein becoming toxic, potentially killing nerves in both inherited and non-inherited forms of MND.

Peter Stearne Familial MND Research Grant
Dr Jennifer Fifita, Macquarie University, NSW
A search for large structural changes in DNA of people with MND to identify new MND genes.

Jenny Simko MND Research Grant
Associate Professor Nimeshan Geevasinga
Western Sydney Local Health District
Using novel MRI techniques to learn more about MND.

Col Bambrick MND Research Grant
Dr John Lee, The University of Queensland
Investigating the beneficial effects of the protein C3aR on glucose metabolism in immune cells in MND.

Superball XI MND Research Grant
Associate Professor Seth Masters
Walter and Eliza Hall Institute of Medical Research, VIC
Turning off inflammation caused by a specific immune pathway that is accidentally activated in ALS.

Jenny Simko MND Research Grant
Professor Pamela McCombe, The University of Queensland
Immunogenetics of motor neurone disease - a pilot study.

MNDRIA Innovator Grant
Dr Parvathi Menon, Western Sydney Local Health District
Understanding ALS progression using multiple techniques to study brain dysfunction which may underlie disease causation.

Fat Rabbit MND Research Grant
Dr Sean Millard, The University of Queensland
Identifying how combinations of sporadic ALS risk factors lead to neurodegeneration.

MSWA MND Research Grant
Dr Sarah Rea, The University of Western Australia
Characterising the interaction between two ALS-linked proteins to identify a therapeutic target for MND.

Andrew Butcher MND Research Grant
Dr Mary-Louise Rogers, Flinders University, SA
How does Triumeq work as an MND treatment? A study to determine the relationship between endogenous retrovirus, TDP43 pathology and inflammatory signals in MND.

Benalla Act to d'feet MND Research Grant
Dr Rachel Tan, The University of Sydney
The role of toxic proteins that are highly resistant to destruction in causing the death of motor neurons in MND.

MNDRIA Innovator Grant
Dr Mehdi van den Bos, Western Sydney Local Health District
Observing effects on brain waves by magnetic pulses to understand the origins and spread of ALS.

NTI MND Research Grant
Associate Professor Trent Woodruff
The University of Queensland
Investigating the role of a protein, Free Fatty Acid Receptor 2 (FFAR2), on immune cells that may protect neurons from damage in MND.

Dr Paul Brock MND NSW Research Grant
Associate Professor Justin Yerbury
The University of Wollongong
Mutations in the gene called UBA1 cause spinal muscular atrophy; does it play a role in MND?

2. Fostering the treatment development process and clinical trials

Gross Foundation MND Research Grant
Dr Catherine Blizzard, The University of Tasmania
The role of estrogen in MND: Investigating how estrogen may be protective and have therapeutic value in MND.

Charcot Grant
Professor Julian Gold, The Albion Centre, NSW
Clinical trial of the antiretroviral drug Triumeq in patients with MND to test whether there is an improvement in survival and function.

MonSTaR MND Research Grant
Dr Fiona McKay, The University of Sydney
Does the immune-modulating multiple sclerosis therapy, dimethyl fumarate (tradename Tecfidera), currently being trialled in Australia in ALS patients, enhance neuroprotective immune and metabolic pathways in these patients?

MonSTaR MND Research Grant
Professor Mark Wilson, The University of Wollongong
Rapid Screening of thousands of chemicals for their effects in a cellular model of MND, to identify potential new drugs to treat people with MND.

3. Enhancing clinical research and the evidence-base for clinical practice

MSWA MND Research Grant
Professor Samar Aoun, La Trobe University
Best practice in end-of-life care and bereavement support: A national survey of bereaved family carers of people with MND.

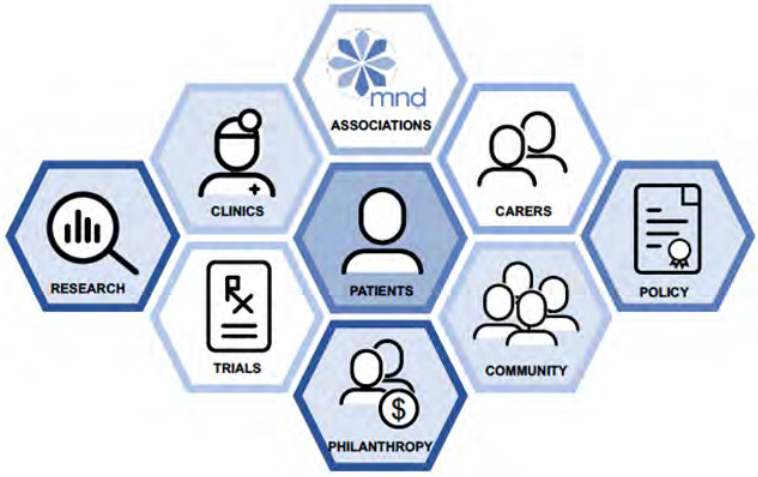
Lord Mayor's Charitable Foundation
Associate Professor Paul Talman, Barwon Health, VIC
The Australian Motor Neurone Disease Registry.

Mavis Gallienne & Graham Lang MND Victoria Research Grant
Professor Julian Trollor, University of New South Wales
Understanding the mental health needs of people with MND by using information from health services.

MNDRIA Innovator Grant
Dr Michelle Farrar, University of New South Wales
Investigation of the value of available therapies for treatment of MNDs, particularly spinal muscular atrophy (SMA), in terms of their clinical usefulness, costs and desirability.

Partnering for impact, driving collaboration and innovation along the research pipeline and the healthcare system

Motor Neurone Disease: Patient centred care for a progressive neurological disease — evidence driving policy



Building on a long history of collaborations between MND clinics, researchers and community groups, a national MND network was successful this year in its application for a National Health and Medical Research Council (NHMRC) Partnership grant which aims to consolidate these efforts under one umbrella. The new 5-year project "**Motor Neurone Disease: Patient centred care for a progressive neurological disease— evidence driving policy**" is led by Professor Matthew Kiernan (University of Sydney), neurologist and NHMRC Practitioner Fellow.

A cornerstone of the successful application was the national MND research framework established through the sporadic ALS Australia systems genomics consortium (SALSA-SGC). This consortium, established in 2016 and funded through the MND Australia Ice Bucket Challenge Grant, had the goal to facilitate genomics research in those with sporadic ALS. Although the focus is genomics the framework for consistent data collection that has been implemented across the MND clinics nationally builds a resource that underpins all patient-based research and management. The biological samples can contribute to new biomarker and systems genomics research. This national approach contributes to Australia being viewed as a destination for international clinical trials. Under the Partnership we plan an amalgamation of the Australian Motor Neurone Disease Registry (AMNDR) with the SALSA database, to have a one stop shop for readily available data for MND biological and policy research.

A key aim is to provide evidence-based, data-driven evaluations of MND health and disability care to inform national and state policy and drive high quality, nationally equitable care to those with MND. An App that will be developed will have the dual purpose of allowing patients and family carers to better monitor their own disease trajectory and needs, while simultaneously providing data on use of support services to inform future health policy. This will ensure an improved person-centred approach to future MND health and social care in Australia.

The Partnership includes the national and state MND Associations, as well as key community and philanthropic groups. These groups bring essential perspectives to priorities for policy. The Partnership is open to all in the MND community since we must all pull together to manage this disease. We are just in the early stages of establishing the work plan of the Partnership, but there will be opportunities for all stakeholders to contribute.

The Partnership is an exciting new development for the MND community, but will take time to bring everything together.
As we start the process of further developing the Partnership we have some clear guiding principles:

Do what is best for those with MND, or those who are diagnosed with MND in the future.
Do what is best for the use of funds raised by tax payers, community fund-raising and philanthropy.
Do what is best for the use of the data and biological samples gifted by those with MND, recognizing that it is unethical to not make the most of those gifts.

In both the short and long-term we hope that the new Partnership will benefit the MND community in multiple ways.

Watch this space!

Professor Naomi Wray
University of Queensland

Investing in innovation—attracting and developing outstanding researchers by supporting researchers at all stages of their careers

Tasmania is Australia's smallest state but two adjoining institutes in Hobart at the University of Tasmania consistently attract grant funding from the MND Research Institute of Australia for an ever-growing team of productive researchers who are working their way up the ladder of research success.

From Professor Tracey Dickson at the **Menzies Institute of Medical Research:**

For the central nervous system to work properly there must be critical regulation of the millions of connections, or synapses, between nerve cells. Researchers at Menzies have shown that in MND this regulation is missing, leading to abnormal activity and ultimately neuron dysfunction and degeneration. With this new knowledge, we are now trialling ways to stop this cascade – and stop MND !

From Associate Professor Anna King at the **Wicking Centre:**

A key focus of our MND research is on neuroprotective strategies, particularly those that focus on the nerve cell processes or axons, which are responsible for transmitting signals. Our research has two key areas; understanding why these nerve cell processes degenerate and understanding how they degenerate. By answering these questions we are identifying new therapeutic targets for MND, which we hope will maintain the function of the motor neurons.

The list of MNDRIA grants and awards to the University of Tasmania in recent years is impressive, with grants awarded to researchers at all stages of their careers. Five of the fifteen hotly contested Bill Gole MND Postdoctoral Fellowships awarded since 2005 have gone to Tasmania to a continuing spectrum of promising early-career researchers.

MND Australia Research Conference Poster Prize— encouragement for students to participate in meetings and develop presentation skills:

Rosemary Clark (runner up): 2015
Emily Handley (winner): 2018

PhD top-up grants—to attract students to choose motor neurone disease as the focus of their research:

Rosemary Clark 2013-2015
Jayden Clark 2013-2015

Bill Gole MND Postdoctoral Fellowships—to provide three years of salary for early-career researchers to establish a track record with research publications that will help them to achieve further funding for their research:

Dr Roger Chung: 2005 (now Professor)
Dr Anna King: 2008-2010 (now Associate Professor)
Dr Catherine Blizzard: 2011-2013
Dr Jacqueline Leung 2014-2016
Dr Rosemary Clark: 2019-2021

Grants-in-aid / innovator grants—to enable researchers at all stages of their career to work on novel ideas and grow their data so they are in a position to apply for government funding for large project grants to further develop their work:

Professor James Vickers: 2007
A/Prof Anna King: 2009, 2013, 2014, 2017, 2018
Dr Meng Inn Chuah: 2010
Dr Catherine Blizzard: 2014, 2016
Professor Tracey Dickson: 2016
Dr Jacqueline Leung: 2017
Dr Anthony Cook: 2019

Betty Laidlaw Prize —a reward for an outstanding mid-career researcher to work on an innovative and collaborative project:

Dr Catherine Blizzard: 2017

Research Committee Members—giving something back in an honorary role—recognition of achievement and expertise in a specialised area of MND research:

Professor James Vickers: 2006-2013
Professor Tracey Dickson: 2014-present

MND Australia Research Conference

Dr Frederik Steyn (The University of Queensland) reports on the 14th annual MND Australia Research Conference held at The Florey Institute of Neuroscience and Mental Health in Melbourne in November 2018

The MND research community met on 9 November at The Florey Institute of Neuroscience and Mental Health (Melbourne) for the 14th MND Australia Research Conference. This meeting offers Australian MND-focussed researchers an opportunity to share discoveries and to develop ideas to improve our understanding of, and capacity to treat, MND. The focus of 2018 was *investment in innovation and partnering for progress.* Following the welcoming address by David Ali (President, MND Australia), Professor Steven Petrou (Director, Florey Institute) launched the meeting. Prof Petrou commented on progress made by MND researchers at The Florey, and how philanthropic support is instrumental. Marco Morsch (Macquarie University) was awarded the Betty Laidlaw MND Research Prize, Julian Gold (The Albion Centre, Sydney) received the Charcot Grant, and Russel Higgins, Louise Mogg and Stephen Giles (the trio behind the Superball Grants) were recognised for their many years of raising funds to support MND research.

The Conference commenced with two keynote presentations showcasing the commitment of the MNDRIA in building research capacity across Australia. As the first recipient of the Betty Laidlaw Prize (2017), Catherine Blizzard presented discoveries made possible through the support of the Laidlaw family. She has established a research program that investigates how changes at the postsynaptic junction may contribute to MND pathogenesis. Her studies show that TDP-43 is important in maintaining the integrity of the postsynaptic junction, and that changes in the folding and function of this protein might impact the function and survival of neurons. Naomi Wray (The University of Queensland) next presented an update on progress made in establishing a nationwide platform for the collection and storage of MND samples and data. With support from the MND Australia Ice Bucket Challenge Grant (2015-2018), and working alongside researchers across Australia, Prof Wray established the sporadic ALS Australia systems genomics consortium (SALSA-SGC).

This program was awarded a 5-year NHMRC Partnership Grant (2018-2022) to take their work forward. Prof Wray shared her thoughts on the need for collaborative research.

Following a brief morning-tea break, there were a series of talks focussing on *Advancing MND Research to understand causes*. Justin Rubio (The University of Melbourne) discussed the role of precision genomics. Working with post-mortem tissues, A/Prof Rubio's team has embarked on an ambitious project to improve our understanding of the genetic roadmap of individual motor neurons in MND. Kelly Williams (Macquarie University) discussed progress in the genetics of sporadic MND and how pathways that arise from retroviral activation and enrichment of protein clearance could contribute to MND risk. Lezanne Ooi (The University of Wollongong) transitioned discussions towards breakthroughs in understanding of fundamental processes unique to MND. MND is a disease of the entire neuro-motor circuit; the neurons that originate in the brain and spinal cord, and the connections that they make with other neurons and the muscle. Using the mouse as a model of MND, Dr Ooi presented evidence for factors that contribute to hyperexcitability of motor neurons, and how this can change with age. Moving down the neuron, Justin Yerbury (The University of Wollongong) discussed the complexity of protein interactions at the synaptic terminal, and how the proteome at nerve endings could be vulnerable to the effects of MND. Conducting studies on muscle biopsies obtained from people living with MND, Peter Noakes (The University of Queensland) directed our attention to muscle, and the connections between muscles and neurons. A/Prof Noakes showed how connections or synapses between the muscle and the neuron change very early in disease. The session concluded following a discussion on environmental causes for MND. β-N-methylamino-L-alanine (or BMAA) is a cyanobacterial neurotoxin. Exposure and aggregation of this toxin can lead to pathophysiology that closely resembles MND, leading many to believe that BMAA is an environmental trigger for MND. Edwin Lim (Macquarie University) presented his work on BMAA, and how exposure to this toxin can impact the neuron, and how BMAA might spread between neurons. Dr Lim's discoveries raised compelling talking points, in time for a lunch break.

Following lunch we turned our attention to discoveries made across the clinic and the lab. Roger Chung (Macquarie University) started the session with insights into the role of protein degradation pathways in MND pathogenesis, and the potential to target Cyclin F to clear pathological protein aggregates. Presenting data from cell and zebrafish models, Angela Laird (Macquarie University) showed that drugs that target the removal of toxic proteins from neurons might be used to treat MND. Trent Woodruff (the University of Queensland) showed that multiple drugs could be used to target the innate immune system to protect neurons not already impacted by MND, thereby slowing the progression of disease. Mary-Louise Rogers (Flinders University) spoke of the potential of compounds that target genes to slow MND progression, and their use of immunogenes encoding human IGF-I (hIGF-1) and human GDNF (hGDNF). Building on recent discoveries of the potential of CuII(atsm) to slow MND disease progression, Peter Crouch (The University of Melbourne) introduced ferroptotic stress (leading to a type of iron-dependent cell death) and how this might be targeted to slow disease progression. The session concluded with an overview of findings from The Lighthouse Project, and the use of Triumeq (an antiretroviral medication) in treating MND. Dominic Rowe (Macquarie University) presented data from a Phase-1 safety and tolerability study conducted by Julian Gold (The Albion Centre, Sydney). Their data show that Triumeq is safe to use in MND and provides a strong foundation for a larger international study to address the potential for treatment. The session concluded on this high note.

The final session focused on breakthroughs in the clinic and research to improve duration and quality of life. Dominic Rowe started with a captivating overview of discoveries in brain imaging that could be used as a diagnostic tool and biomarker for MND. Continuing with the theme of clinical biomarkers, Dominic Hare (The University of Melbourne) presented their approach on the "elemental" signature of MND. A/Prof Hare's team is using technology to identify a unique signature associated with early chemical processes specific to MND. Frederik Steyn (The University of Queensland) showed that loss of weight and body fat is associated with faster disease progression, and that loss of appetite contributes to weight loss and possibly progression. Vicki Flood (The University of Sydney) continued conversations on diet and their pilot study on swallowing exercises and use of olive oil to slow weight loss and disease progression. Developing results show that dietary intervention with olive oil (to increase energy consumption) is well-tolerated and may support weight maintenance. Nicole Sheers (The University of Melbourne) presented an overview of studies on breathing in MND and provided an update on progress of their studies on the benefit of breathing exercises and lung volume recruitment to slow the progression of respiratory insufficiency. The session concluded with use of technology to recover movement in progressive neurodegenerative diseases. Sam John spoke on behalf of Thomas Oxley (The University of Melbourne) on their use of a brain/machine interface to restore movement. This technology could one day allow patients to control devices with thought.

The day culminated with a busy poster session. Discoveries in the lab, clinical observations that inform our understanding of treatment and care, and new insights to help make sense of the heterogeneity of disease were some of the highlights. The best student poster award was presented to Emily Handley (The University of Tasmania).

MND Connect 2018

The 4th annual MND Connect meeting was held in Melbourne on 10 November and showcased the remarkable MND research currently being undertaken in Australia. People living with MND, carers, family, friends, researchers and health professionals from the broader MND community were invited to attend . Ron Grima, who is living with MND, attended the conference with his wife, Debbie. Ron has provided the following report:

Having only recently been diagnosed with MND, I didn't know what to expect from the 4th MND Connect meeting. From the opening address by David Ali, MND Australia President, to the closing panel discussion, I found the conference interesting, informative and enlightening.

"MND: one disease, many faces" was the theme of the conference, and Maria Nanfra highlighted this when she shared with us her amazing story from 'a carer's perspective'. Maria encouraged all carers to 'take time out for yourself'; a very important message for all devoted carers.

One of the presentations I found interesting was "Breathing Life into MND" by Professor David Berlowitz who showed evidence of a 20-year research program tracking the effect of non-invasive ventilation (NIV) on survival. The research indicated that NIV improves overall survival by a median of 13 months.

The value of the MND Connect conference was highlighted by the diversity in the research presentations, including:

- *Cognition and behaviour and MND*
- *The role of stem cells in screening drugs as potential therapies*
- *Genes and the environment: the different causes of MND*
- *Clinical trials update*

It was clear that those involved with MND research are all inspired to achieve one goal: to live in a world without MND. A huge thank you to everyone involved in putting this important meeting together. A special mention to the volunteers from MND Victoria; the Florey Institute; MND Australia CEO, Carol Birks and Shyuan Ngo and Derik Steyn from The University of Queensland.

MND Connect provides a unique opportunity for those affected by MND to learn more about MND research and care strategies. If you would like to watch the PowerPoint and video presentations from MND Connect 2018, these are available on the MND Australia website.

Governance

MND Australia is the principal member of the MND Research Institute of Australia.

The governance and operations of both organisations are the responsibility of MND Australia.

Directors

The board of MND Australia consists of an independent elected President and a nominated representative from each member MND Association board, the chair of the MNDRIA Research Committee and up to three independent directors.

Research Committee

The MNDRIA Research Committee reviews research grant applications and determines the distribution of funds within the set policies and criteria for scientific assessment.

Research Committee Members
Chairman: Professor Matthew Kiernan, NSW
Professor Samar Aoun, WA
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