



ANNUAL REPORT 2023-24

*MND Australia is the peak body
and national voice for motor
neurone disease*



A message from our President



Andrew
Danson

Some 12 months ago, I was privileged to be elected as the President of the MND Australia board. I stepped into this role to continue an agenda of change that had been started by our previous president, Professor Samar Aoun, who initiated an ambitious agenda to propel MND Australia forward over the next 5 years. After 12 months I feel this agenda is well underway and is not only needed but required by our members and community across Australia.

After an exhaustive recruitment process, we welcomed our new CEO, Clare Sullivan taking over from David Ali who sat in the role for 3 years, and we thank David for his service. Clare is an accomplished, passionate and driven leader, and over the past 9 months since, she has made a profound impact on our organisation and cultivated strong relationships with our members.

It has been a year of change and many highlights, our 30th anniversary celebration at Parliament House in the middle of the year offered an opportunity for our board, greater team and community to gather and celebrate the achievements of the association over the previous 30 years.

To commemorate this milestone, MND Australia awarded 30 lifetime achievement medals to Australians who have made significant contributions to the MND community. It was incredibly humbling to meet many of these recipients, whose efforts span vital areas such as MND research, community support, and healthcare. We were also fortunate to hear the NDIS priority eligibility pathway program launched by Bill Shorten, with the NDIS providing 18 assessors accelerating NDIS access to those suffering from the disease.

The event also marked the launch of our advocacy priorities in preparation for the upcoming federal election, along with our new National MND Lived Experience Network. This Network provides an exciting platform for organisations and groups to

engage directly with individuals living with MND, fostering connection and collaboration.

Our commitment to funding research remains steadfast and also a priority to our greater agenda. This year, we invested \$3.1 million in cutting-edge research aimed at developing new treatments, understanding the causes of MND, and improving care for those affected by the disease. In 2024, we proudly supported over 24 new projects that promise to advance our understanding of MND.

The MNDA board and team have ambitious goals and targets and will strive for the absolute best outcomes for both our members and more importantly in our community.

Finally, I would like to express my gratitude to my fellow board members and the dedicated staff of MND Australia. Your unwavering commitment to improving the lives of Australians impacted by MND is inspiring. Together, we strive toward our vision of a world free of MND.

*Together with the
State MND Associations,
we work to advance
motor neurone disease
care, advocacy
and research*



MND Australia board directors

at 30 June 2024



Andrew Danson
President and MND SA



Jemma Scott
Vice-President



Peter Ricketts
Treasurer



Diana Melham
Secretary and MND QLD



Prof Samar Aoun
MND WA



Prof David Burke AC
Chair, Research Committee



Amy Critchley
MND NSW



Prof Tracey Dickson
MND TAS



Wayne Pfeiffer
MND VIC



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 strategy

Objectives



Strengthening awareness and engagement

Through amplifying the strong and united voice for people living with MND, increase awareness, impactful engagement & support the highest impact research to improve the lives of everyone impacted by MND.



Sustaining advocacy to benefit people with MND

Positioning MND Australia as the peak body for MND and to be identified as the foremost advocacy leader for people living with MND on issues that require government, institutional or systemic change through educating, advocating and influencing.



Funding sustainability of MND Australia & the sector

Bolster MND Australia's foundations, income streams and sustainability as well as improve funding to State MND Associations and for MND research.

Values



Collaboration
Empathy
Quality
Inclusion



Person-centred
Equity of access
Extensive knowledge of MND
Established relationships
Membership

Our 23-24 achievements in brief



Launch of the National MND Live Experience Network



\$3.1 million invested in research



43 new or revised information resources



11 e-newsletters sent to our 15K+ subscribers



142,000 website visitors



11th National MND Australia Care Conference



30 awards presented to leaders in MND



24 research projects funded



3 PhD scholarship top-up grants



11 editions of *Research Directions*



30th anniversary celebrations at Parliament House



Seven advocacy submissions to government



Seven *State of Play* research webinars



Over 25,000 social media followers



Launch of *6 Point Plan* for advocacy



3rd AUS/NZ MND Research Symposium

Lifetime achievement medals

In recognition of MND Australia's 30th anniversary, we awarded thirty Australians who have made a significant contribution to the MND community over the last 30 years with lifetime achievement medals

Dr Peter Allcroft

Professor Samar Aoun

The Hon Guy Barnett

Professor David Berlowitz

Carol Birks

Dr Paul Brock AM

Professor David Burke AC

Neale Daniher AO

Judith Durham AO

Mavis Gallienne

Dr Kirsten Harley

Marjorie Harrap

Rod Harris

Dr Anne Hogden

Professor Matthew Kiernan AM

David Lamperd

Dr Graham Lang

A/Professor Susan Mathers

Janet Nash

A/Professor Shu Ngo

Professor Garth Nicholson

A/Professor Roger Pamphlett

Ian Rodwell AO

Professor Dominic Rowe AM

Helen Sjardin

Dr Derik Steyn

Professor Paul Talman

Geoff Thomas OAM

Ralph Warren

Professor Justin Yerbury AM



Our research grants program funds world-class research for better treatments, improved care, and ultimately a cure



2024 MND research grants

Research Fellowships

Daniel McLoone MND Research Prize

Dr Chien-Hsiung (Alan) Yu – University of Melbourne

Investigating TDP-43-associated immune activation to map the causes of MND

Jim Zissimopoulos MND Postdoctoral Fellowship

Dr Nicole Sheers – University of Melbourne

Developing a new exercise therapy to improve breathing and cough in people living with MND

David Deguara MND Postdoctoral Fellowship

Dr Thais Sobanski – University of Queensland

Boosting sugar breakdown to halt the progression of motor neurone disease

Bill Gole MND Postdoctoral Fellowship

Dr Rachel Atkinson – University of Tasmania

Freezing motor neurone disease in its tracks



Innovator Grants

Charcot Award

Dr Adekunle Temitope Bademosi

University of Queensland

Investigating the role of synaptic proteins in MND neurodegeneration

Peter Stearne Familial MND Research Grant

Dr Ianthe Pitout

Murdoch University

Developing a new drug candidate for C9ORF72-linked MND

Jenny Simko MND Research Grant

Dr Luke McAlary

University of Wollongong

Deep mutational scanning to define and predict the pathogenicity of existing and future SOD1 mutations

Doug Parry MND Research Grant

A/Prof Marco Morsch

Macquarie University

Targeting the nucleus: Is TDP-43 supplementation in the nucleus enough to delay disease progression?

Dr Paul Brock MND NSW Research Grant

Dr Rachel Tan

University of Sydney

Accessible disease-specific biomarkers for sporadic MND

NTI MND Research Grant

Dr Rebecca San Gil

University of Queensland

Targeting protein aggregation in motor neuron disease

Bruce Catto MND Research Grant

Dr Cindy Maurel

Macquarie University

Probing molecular drivers of TDP-43 phase transition: the influence of lysine modifications

Daniel McLoone MND Research Grant

Dr Wei Luan

University of Queensland

Synaptic mechanisms of non-motor dysfunction in MND

Fat Rabbit MND Research Grant

Dr Hazel Quek

The Council of the Queensland Institute of Medical Research

Microglia diversity in ALS: Impact on disease and drugs

Peter Gregory & Fore Group MND Research Grant

A/Prof Richard Gordon

Queensland University of Technology

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

Col Bambrick MND Research Grant

Dr Andrew Tosolini

University of Queensland

Connecting the dots between the powerhouse of the motor neuron and their vulnerability in MND

Superball XVI MND Research Grant

Dr Samantha Barton

University of Melbourne

Could Schwann cells be exacerbating motor neuron dysfunction in MND?

Run MND NSW Research Grant

Dr Sayanthoran Saravanabavan

Macquarie University

Examining the pathogenic roles of circular RNAs in genomic instability in ALS

Murray Geale MND Research Grant

Dr Alain Wuethrich

University of Queensland

Developing a new nanotechnology to track ALS

Daniel Veysey MND Research Grant

Dr Mouna Haidar

University of Melbourne

Assessing the therapeutic impact of chemogenetic stimulation of neuropeptide Y cortical interneurons in ALS mouse models

Daniel McLoone MND Research Grant

Prof Yuling Wang

Macquarie University

Investigating the role of extracellular vesicles (EVs) membrane

Daniel McLoone MND Research Grant

Dr Sarah Rea

Murdoch University

Antisense oligonucleotide induced clearance of cytoplasmic TDP-43 aggregates to prevent disease progression in ALS

Daniel McLoone MND Research Grant

Dr Benjamin Trist

University of Sydney

Partnering with industry to develop new assays for improving diagnosis, understanding and treatment of ALS

Daniel McLoone MND Research Grant

Prof Yuling Wang

Macquarie University

Investigating the role of extracellular vesicles (EVs) membrane

Daniel McLoone MND Research Grant

Dr Benjamin Trist

University of Sydney

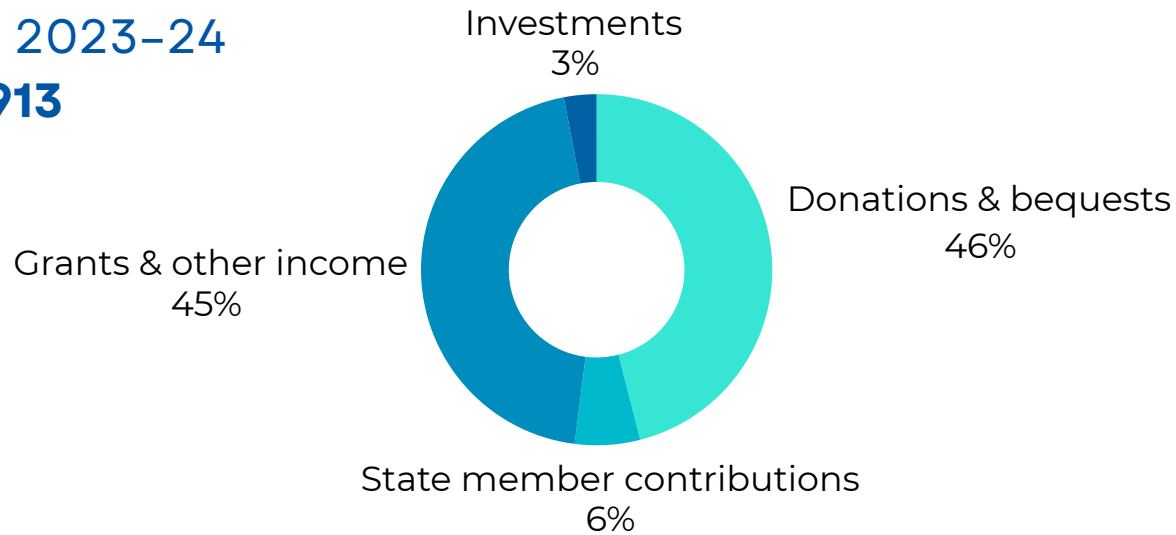
Partnering with industry to develop new assays for improving diagnosis, understanding and treatment of ALS

PhD Scholarship Top-Up Grants

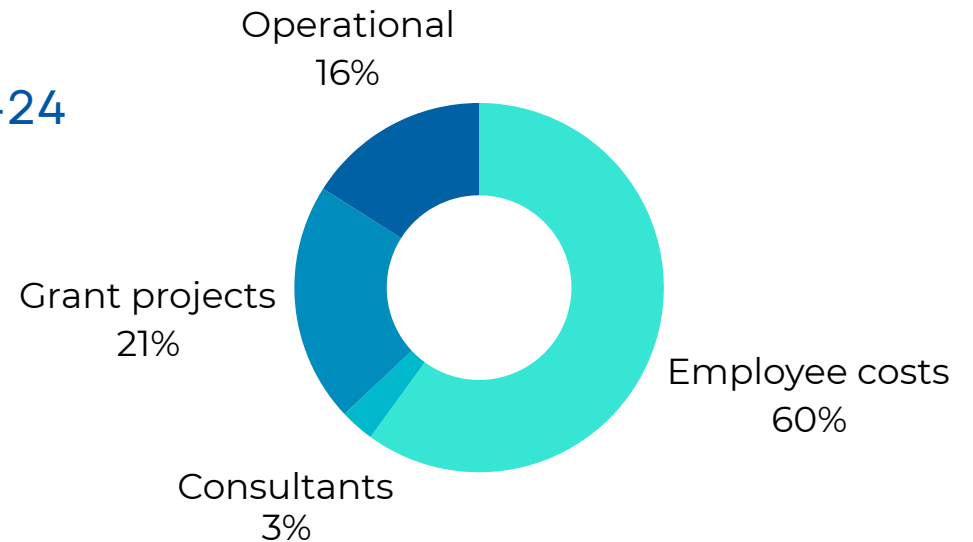
- **Stephanie Howe**, University of Queensland
- **Andrew Quattrocchi**, University of Melbourne
- **Flora Cheng**, Macquarie University

Income and expenditure

INCOME 2023-24
\$2,033,913



EXPENDITURE 2023-24
\$1,748,178



MND Australia

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