



# ANNUAL REPORT 2023-24

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*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 Pfieffer**  
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**

## Strengths

# 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 Sayanthooran 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

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Macquarie University

*Investigating the role of extracellular vesicles (EVs) membrane*

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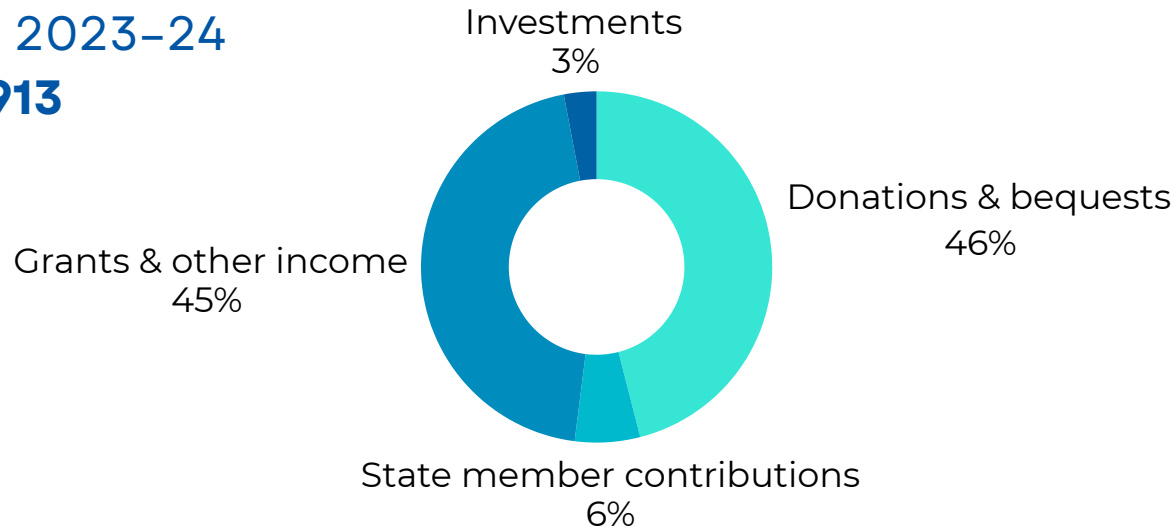
*Partnering with industry to develop new assays for improving diagnosis, understanding and treatment of ALS*

## PhD Scholarship Top-Up Grants

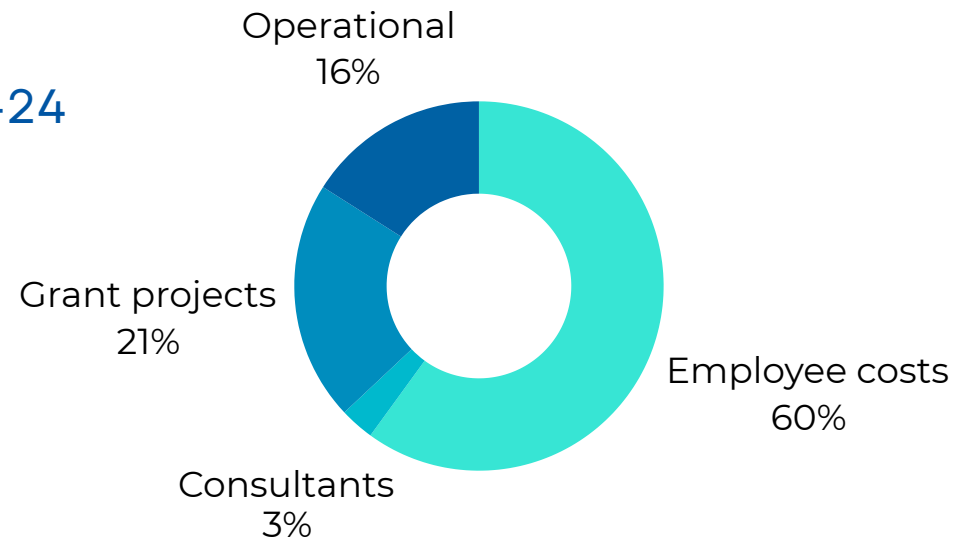
- **Stephanie Howe**, University of Queensland
- **Andrew Quattrocchi**, University of Melbourne
- **Flora Cheng**, Macquarie University

# Income and expenditure

## INCOME 2023-24 **\$2,033,913**



## EXPENDITURE 2023-24 **\$1,748,178**



*Extract from Audited Financial Statements*

## **MND Australia**

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Philip ACT 2606  
[mndaustralia.org.au](http://mndaustralia.org.au)

