



CHAIR OF THE RESEARCH SUBCOMMITTEE

RESEARCH SUBCOMMITTEE MEMBERS

DATA, INNOVATION & TECHNOLOGY SUBCOMMITTEE MEMBERS

CANDIDATE INFORMATION
OCTOBER 2025



ABOUT MND AUSTRALIA

MNDA is a nationally recognised charity dedicated to the prevention and control of MND and operating as the national peak body for State and Territory-based MND associations and other interested bodies. Through advocacy, awareness and community support, MNDA has become a powerful voice both nationally and internationally. Central to its mission is a commitment to funding world-class research - building momentum that seeks to improve treatments, enhance care and ultimately, find a cure.

Refer to the MND Australia Strategy 2023-26 at the end of this document.

POSITION: CHAIR OF THE RESEARCH SUBCOMMITTEE

The Chair of the Research Committee plays a critical governance and advisory role, providing strategic leadership and oversight of MNDA's Research Strategy and Research Grant Program. The Committee supports the development, implementation, and evaluation of research projects that align with MNDA's objectives.

The Chair of the Research Committee is also an independent Director on the Board of MNDA, with a tenure of three years, renewable.

As Chair, you will:

- Lead the Research Committee in its strategic deliberations and meetings;
- Ensure that MNDA's Research Strategy and Research Grant Program are aligned with best practice, ethical standards, and community needs;
- Report to the Board in relation to the implementation and outcomes of MNDA's Research Strategy and the Research Grant Program;
- Lead the Committee in the oversight of the Grants Review Panel (which will assess the relative merits of proposals for research funding), and in making recommendations to the Board in relation to proposals to be allocated funding under MNDA's Research Grant Program.

Selection Criteria

Note, you are not required to address all selection criteria in your application – please refer to Application Instructions at the end of this document.

To be considered for the role of Chair of the MNDA Research Committee, applicants must meet the following criteria:

Qualifications

- A postgraduate qualification (Masters or PhD) in public health, health promotion, epidemiology, medical science, behavioural science, or a related field;
- Eligible under Australian charities and corporate law to be a company director;
- Consent to being elected or appointed as an independent Director of MNDA.



Experience

- At least 10 years' experience in health research, public health policy, or applied health promotion research;
- Demonstrated leadership experience in a research or academic setting, such as leading a research group, department, or previous committee work;
- Experience engaging with or advising not-for-profit boards, government agencies, or policy-makers on evidence-based health interventions.

Expertise

- Deep understanding of research methodologies, ethics, and governance within the health or not-for-profit sector;
- Ability to critically assess research proposals and outcomes;
- Understanding of knowledge translation and implementation science as it relates to health promotion.

Skills & Attributes

- Strong leadership, facilitation, and communication skills;
- Ability to work collaboratively within a Committee and a Board and engage effectively with diverse stakeholders;
- A good understanding of ACNC Governance Standards including the duties set out in Standard 5: Duties of Responsible People and its Conflict of Interest provisions;
- Commitment to health equity, social justice, and the values of MNDA;
- High level of integrity, professionalism, and ethical conduct.

POSITION: RESEARCH SUB-COMMITTEE MEMBERS (Multiple roles)

The key responsibilities of the Committee are:

- As requested by the Board, reviewing and revising MNDA's Research Strategy to ensure that it aligns with MNDA's Strategic Plan and strategic direction and advising the Board accordingly;
- Advising the Board on opportunities and strategies to support the implementation of MNDA's Research Strategy, including, but not limited to, sourcing and raising of funds, ensuring that funded research is high impact, collaborating with other organisations and individuals, promotional and marketing opportunities and communication strategies;
- Reviewing, monitoring and reporting to the Board in relation to the implementation of MNDA's Research Strategy;
- Oversight of the Grants Review Panel, which is responsible for assessing the relative merits of research proposals and recommending to the Board which proposals should be allocated funding under MNDA's Research Program;
- Monitoring the progress, quality, and impact of research projects funded under MNDA's Research Program and reporting annually to the Board on the nature and outcomes of MNDA's Research Program for the relevant year;
- As requested by the Board, reviewing and revising MNDA's Research Program to ensure that it aligns with MNDA's Research Strategy and reflects best practice and advising the Board accordingly;
- Ensuring that MNDA's research ethics and governance frameworks reflect best practice and are maintained appropriately and advising the Board accordingly;
- Advising the Board on any research-related matters referred to the Committee by the Board;



- Report at each Board meeting, through the Committee Chair, on matters relating to the Committee's responsibilities;
- Prepare an annual report for the Board summarising the Committee's activities and outcomes and evaluating the Committee's effectiveness;
- Ensure effective communication between the Committee and the Board, as well as with the CEO and other Board Committees where applicable.

Expertise, Skills & Attributes

- Strong leadership, facilitation, and communication skills;
- Ability to work collaboratively within a Committee and a Board and engage effectively with diverse stakeholders;
- A good understanding of ACNC Governance Standards including the duties set out in Standard 5: Duties of Responsible People and its Conflict of Interest provision;
- Commitment to health equity, social justice, and the values of MNDA;
- High level of integrity, professionalism, and ethical conduct;
- Experience in the oversight of research grant review panels and evaluation of research impact;
- Expertise in health research ethics and governance frameworks.

Applications are also welcome from people living with MND, current family carers, or former family carers (if their family member died from MND within the last two years) - who demonstrate a genuine interest in contributing valuable recent lived experience to this important subcommittee work.

POSITION: DATA, INNOVATION AND TECHNOLOGY COMMITTEE MEMBERS

The key responsibilities of the Committee are:

MiNDAUS Registry and National MND Platform

- Provide governance and oversight of MiNDAUS Registry operations, including advice on:
 - (i) Increasing patient and clinician engagement;
 - (ii) Strengthening approval processes for data collection, access, use, and disclosure;
 - (iii) Maintaining and strengthening MNDA–MiNDAUS Partner relationships.
- Advise on strategies to evolve the MiNDAUS Registry into a National MND Platform that empowers people living with MND and their families, supports research, and informs better health and care outcomes (MNDA Constitution 3.2.10).

Data Governance and Strategy

- Advise on the development and enhancement of MNDA's data governance framework.
- Monitor implementation for compliance with privacy and health data laws, including the Privacy Act 1988 (Cth).
- Oversee ethical data use and identify existing MND-related databases in Australia, assessing their relevance to MNDA's strategic objectives.

Digital Strategy and Innovation

- Advise on digital transformation and innovation aligned with MNDA's strategic objectives, including:
 - (i) Generative AI adoption;
 - (ii) Developments in genomics, robotics, and brain-computer interfaces.



- Support evaluation of emerging technologies and promote a culture of innovation and continuous improvement.

IT and Cybersecurity

- Monitor MNDA's IT performance and risks, recommending enhancements to mitigate cyber threats.
- Review and recommend policies on information security, cybersecurity, and business continuity.
- Oversee cybersecurity framework implementation and assess relevance of enhancements for State/Territory MND organisations.

Risk and Compliance

- Identify and assess digital and technological risks, ensuring mitigation strategies.
- Advise on effectiveness of digital/data initiatives, risk exposures, and innovation outcomes.
- Ensure alignment with ACNC Governance Standards and other regulatory requirements.

Expertise, Skills & Attributes

- Strong leadership, facilitation, and communication skills;
- Ability to work collaboratively within a Committee and a Board and engage effectively with diverse stakeholders;
- A good understanding of ACNC Governance Standards including the duties set out in Standard 5: Duties of Responsible People and its Conflict of Interest provisions;
- Commitment to health equity, social justice, and the values of MNDA;
- High level of integrity, professionalism, and ethical conduct;
- Development and implementation of health data governance and ethics frameworks;
- Emerging technologies including generative ai, genomics and robotics;
- IT and cybersecurity infrastructure, governance and risk management.

Applications are also welcome from people living with MND, current family carers, or former family carers (if their family member died from MND within the last two years) - who demonstrate a genuine interest in contributing valuable recent lived experience to this important subcommittee work.

APPLICATION INSTRUCTIONS

Applications for **ALL** positions should be submitted **by Tuesday, 4 November 2025** and should:

- State clearly which position and subcommittee you are applying for;
- Be submitted via henderconsulting.com.au and include a cover letter (max 2 pages) and CV uploaded as a single PDF document.

Chair of Research Subcommittee applicants should also address the following in their cover letter:

- Do you hold current or previous approval by the National Health and Medical Research Council as a person suitable to assess health research?
- Are you involved directly or indirectly in the governance of an MND Association which is a Member of MNDA?
- Do you have any actual or perceived conflicts of interest relating to your performance of this role and if so, indicate how you will manage these conflicts, if selected for the role?

Confidential enquiries for all positions are welcome to Andrew Reed and Bernie Dyer at Hender Consulting on (08) 8100 8830.

MND AUSTRALIA STRATEGY 2023 – 26



Our vision

A world free of MND

Our values

Our mission

To improve the lives of everyone impacted by MND through advancing high quality care, advocacy and research



Collaboration

We work collaboratively with and on behalf of our national network of member MND Associations to foster promotion and sharing of best practice information and care for the benefit of all who live with MND, including their families and friends, regardless of where they live.



Empathy

We are motivated by those inspirational and resilient people who are impacted by MND.



Quality

We strive to fund only the highest calibre research and innovation to move us closer to effective treatments for MND and to support high-quality care services for people living with MND.



Inclusion

We believe in fair and equitable access to government health, disability and aged care programs to improve the lives of all people living with MND

Our objectives



Strengthening awareness and engagement

Through amplifying the strong and united voice for people living with MND, increase awareness, impactful engagement and 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.

Our strengths



Person-centred



Equity of access



Extensive knowledge of MND



Established relationships



Membership