

Program

MND Clinical Research Learning Institute

Day 1 (Friday 11th November)

- 9:30 AM **Welcome Remarks and Introductions**
Terry Heiman-Patterson, MD Temple University, US
and MND Aus-GenieUs
- 9:45 AM **Why We Need MND/ALS CRLI**
Richard Bedlack, MD, PhD Duke University, US
- 10:15 AM **The Australian MND research ecosystem**
Gethin Thomas, MND Australia
- 10:35 am **Small Group Exercise 1- Personal Experiences with Research**
Share your experiences with MND research
studies - Breakout Rooms
- 11:05 AM **Networking Break (Breakout Rooms): Grab your coffee**
- 11:30 AM **Ethics and Informed Consent**
Anjali Henders, University of Queensland
- 12:00 PM **Statistics**
Allan McRae, University of Queensland
- 12:30 PM **Genetics**
Sam Brennan, GenieUs and Marcel Dinger, University of NSW
- 1:00 PM **MND Treatment Pipeline and Clinical Trial Design - Challenges
and Opportunities in MND**
Colin Mahoney, University of Sydney Brain and Mind Centre
- 1:45 PM Adjourn



Day 2 (Saturday 12th November)

- 9:30 AM **Welcome to Day 2 and Zoom Photo**
Terry Heiman-Patterson, MD Temple University, US
and MND Aus-GenieUs
- 9:40 AM **How to read a research paper**
Terry Heiman-Patterson, MD Temple University, US
- 10:00 AM **Small Group Exercise 2 - Critiquing a Clinical Research Paper**
Go through the questions with the folks in your breakout room
- 10:30 AM **Review of Exercise 2**
Terry Heiman-Patterson, MD Temple University, US
- 10:45 AM **Coffee Break in Breakout Rooms**
- 11:15 AM **Beyond clinical trials**
- MND Biology: What do we target?**
Catherine Blizzard, University of Tasmania
- Healthcare research**
Karen Hutchinson, Macquarie University
- 12.15 PM **Opportunities and Tips for MND Advocacy**
Moderator - David Ali, CEO, MND Australia
- MND Advocacy in Australia**
Carol Birks, ex-CEO, MND Australia
- What can you do as a Lived Experience Advocate?**
Peter Chambers
- Advocacy Discussion**
- 1:00 PM **Putting It All Together and Next Specific Steps**
Richard Bedlack, MD, PhD, *Duke University* and Allison Bulat, *ALS Research Ambassador and MND Aus/GeniUS*
- 1:20 PM **Adjourn**

