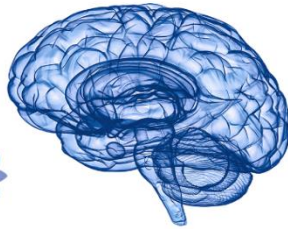


# Australian & New Zealand MND Symposium

28-30 APRIL 2022 | BRISBANE

## AUS & NZ MND Research Symposium

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The first Australian and New Zealand MND Research Symposium took place in Brisbane on Thursday 28th and Friday 29th April 2022 with an MND Connect - Research Live session on Saturday 30th April. The meeting was jointly hosted by MND Research Australia and FightMND. There was approx. 220 in-person registrants and another 40 online attendees.

The opening session had a strong focus on collaborative research programs with overviews of the MND Collective, the MiNDAUS Partnership, the MNDNZ Research Strategy, the MNDSA Clinical Pathway and Referral Network and the SALSA genetics database. Scientific sessions then followed focussed on the causes of MND, the role of TDP-43, treatment, development and biomarkers, clinical research and improving care. A “Rapid-Fire Research” session was on day 2 where presenters had 5 minutes to summarise their research findings. This format provided a stimulating fast-moving journey through the cutting-edge research being undertaken in Australia and New Zealand.

A small but strong cohort of New Zealand researchers attended in person and participated in many aspects of the event including chairing sessions, presenting their research, and networking with Australian counterparts to identify ways for collaboration between the two countries. Promising links were forged to work more closely in the future.

I spoke to Dr Claire Reilly, Dr Emma Scotter, Maize Cao, Miran Mrkela and Kyrah Thumbadoo about their experience attending the symposium and they kindly shared their thoughts below.

**Dr Claire Reilly** is the Community and Research Advisor for MND New Zealand and an advisor on the MND Registry Steering Committee. Claire is currently involved in many MND research studies in New Zealand. In addition to a wealth of research knowledge, Claire brings a unique experience to the team as she lives with MND. Claire presented on the first day giving an overview of the New Zealand MND Research Strategy.

**Dr Emma Scotter** is the head of the MND Research Lab based at the school of biological science, University of Auckland. Emma leads the MND Research Network, is an advisor on the MND Registry Steering Committee and PI for the New Zealand MND genetics study. Dr Scotter presented in the rapid-fire talks on the genetic of MND in New Zealand.

**Maize Cao** is completing a PhD entitled “Identifying TDP-43 loss of function markers in MND”. TDP-43 is the most important protein that is implicated in MND. Maize study is examining this in relation to loss of function in the disease. Her most recent [publication can be viewed here](#). Maize presented a poster at the symposium.

**Miran Mrkela** is completing a PhD entitled “Characterising the Genetic Heterogeneity of Motor Neuron Disease in New Zealand”. Miran’s research is focussed on understanding the genetics which underpin the development of Motor Neuron Disease in New Zealand. This is part to the genetic study under Dr Emma Scotter. Miran presented a poster at the symposium.



*New Zealand cohort attending the symposium. L-R – Maize Cao, Kyrah Thumbadoo, Miran Mrkela, Dr Molly Swanson, Dr Emma Scotter, Dr Alan Stanley and Dr Claire Reilly (front row).*

**Kyrah Thumbadoo** is doing a PhD under Dr Emma Scotter on “The Role of X-inactivation in the Phenotypic Expression of the X-linked Motor Neuron Disease gene UBQLN2”. Kyrah presented a poster at the symposium on her research.

## What did you enjoy about the symposium?

**Claire** - The face-to face (Kanohi ki te kanohi) interactions! Teleconferences are a useful tool but it’s so nice to finally exchange knowledge and ideas in person.

**Emma** - A wonderful chance to sure up existing collaborations and forge new relationships.

**Maize** - I agree with Claire, I think it was so nice being able to meet peers and have discussions with them.

**Miran** - I agree that the greatest part of the symposium was the face-to-face collaboration. There is something to be said for instant meetings over zoom BUT I don’t think they can replace that spontaneous face to face discussion.

**Kyrah** – The symposium was very well organised, with many different sessions, and lots of opportunity to interact and discuss research with those of different interests and focusses. I especially liked that the symposium was hybrid, with some presentations, as well as Q+A, seamlessly delivered virtually.

What presentation impressed you the most and why?

**Claire** - I really enjoyed the talk by Mel Syron who spoke about her father's MND journey as an Aboriginal man and the difficulties he experienced. It's a reminder of how we still have much to learn about how we approach pwMND from different backgrounds and cultures.

**Emma** - I was very impressed by the work Fazel Shabanpoor is doing to improve the efficacy of antisense therapies for genetic MND.

**Maize** - I enjoyed listening to the project presented by Prof Danny Hatters on how the C9orf72 mutation in MND produces small proteins that stall ribosomes (which are important for production of new proteins). I thought the assays they did were very elegantly designed and clearly described. But I also thought Mel Syron's talk was heartfelt and thought-provoking. It was certainly a reminder of why we carry out the work we do.

**Miran** - Mel Syron's had a very memorable and personal talk regarding her father's experience. I'm sure this is only one story among many around the world in similar situations. From a scientific perspective I enjoyed Dr. Benjamin Trist's talk on SOD1 Maturation/dysfunction where he demonstrated that there is consistent SOD1 protein mislocalization in individuals who do not possess a mutation in the SOD1 gene (the first gene linked to the development of ALS) and that it is likely that multiple biochemical pathways converge to this protein aggregation. It was exciting to see a study leverage x-ray fluorescence microscopy to create elemental maps!

**Kyrah** -As a student researching protein functionality and aggregation, I was especially interested in Dr. Benjamin Trist's presentation on SOD1 dysfunction, and Dr. Marco Morsch's talk on TDP-43 protein modifications and subsequent condensate formation, together highlighting the importance of intracellular protein quality control and its role in MND. Professor Samar Auon's discussion on the experience of caregivers and families of patients with MND was also a salient reminder of the overarching impact of MND.

Were there any ideas or knowledge shared that could be considered in New Zealand?



**Claire** - I certainly think there are opportunities for collaboration, and we have made some valuable connections with our Australian colleagues. I was particularly interested in seeing how the Australian Registry is evolving into more of a patient-focused care platform (MiNDAUS) and it will be interesting to see how this develops.

**Emma**- The collaborative networking and administrative support that underpins Australian MND research gives much food for thought for us in New Zealand.

**Maize** - Several collaborations have been initiated between our New Zealand group with various Australian groups. Watch this space!

**Miran** - We have already seen a strengthening in the collaboration that exist between our group and others in Australia. It was also amazing to see 'Sporadic ALS in Australia' (SALSA) announce the start of a data browsing portal for their cohort and will undoubtedly be a great tool moving forwards!

**Kyrah** - Mel Syron's recount of her father's experience with MND from an indigenous experience served as a good reminder that the cause and experience of MND is heterogeneous and this means that patient care needs to be personalised to ensure maximum treatment outcomes. Steps that we can take as allies, particularly in New Zealand, is to advocate for our indigenous peoples.

After attending this symposium are you hopeful for the future of MND research?

**Claire**- I think the last few years have brought a lot of hope to people with MND and whānau particularly with our new understanding around the causes of MND & the emergence of genetic therapies and new DMDs. It was particularly encouraging to see the large number of early career researchers who are interested in MND and not just in the aetiology but also in the provision of care.

**Emma**- I feel very hopeful. There is incredible infrastructure and funding behind MND research in Australia and it shows in the numbers of attendees and the quality of the research. To see Australia, join Europe, the UK, Ireland, USA and Canada as a 'MND research superpower' is heartening and reflects increasing global awareness and resource.

**Maize** - I think there is a lot of talent in the field of MND research, and there have been several advancements in unlocking the genetics and molecular mechanisms of MND in the last few years. We were able to hear from scientists and clinicians who could communicate their ideas very well, so I believe the future of MND research is in capable hands.

**Miran** - I think that science at its core is a collaborative effort and that ultimately any big ideas and breakthroughs will be those born out of this collaborative spirit. So, it was especially heartening to see people leave the conference with new and exciting collaborations!

**Kyrah** – The most exciting takeaway I had from the symposium was the shared enthusiasm of all the researchers and presenters. This enthusiasm is the underlying driver of our work and seeing this from all researchers at all levels of their scientific career served to further encourage and re-energise research and collaboration.

What was your take home message from the symposium?

**Claire and Maize** - It's going to take a global collaborative effort to end this devastating illness, and everyone has a part to play and that also includes the people living with the disease. We need to make sure that people with living experience of MND can have their say in the future of research.

**Emma** - I agree with Claire and Maize and am increasingly seeing the value of great organisation to maximise the value of people's time and effort.

**Miran** - In a similar vein to what Claire said, scientific collaboration will be the path forward to important discoveries for MND.

**Kyrah** – Progress toward understanding mechanisms of disease has been made and this will only continue as collaborative efforts between New Zealand and Australia, further strengthen.

