The New Zealand Motor Neurone Disease Registry

Kerry Walker, Registry Curator
The Why

• September 2015 – First Walk 2 D’Feet MND
  50% of funds raised → research

Patient Registries

• Collate all data in one place
• Attract research
• Access to participants
• Collaboration with international registries
In the beginning...

- First conceived Nov 2016
- Launched 22 May 2017

Beth Watson
Former MND NZ President

Prof Paul Talman
Australian MND Registry

Consenting Dr Claire Reilly
First Registry participant
The How

Registry is a research study
- allows collection of data
- ethics
- based at ADHB
The How

Steering Committee

Data Recorded In AMNDR

Research Applications

Disseminating Data
163 active participants
Clinical study

Establishment and 12-month progress of the New Zealand Motor Neurone Disease Registry

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ABSTRACT

There are only limited treatments currently available for Motor Neurone Disease, each with modest benefits. However, there is a large amount of research and drug discovery currently underway worldwide. The New Zealand Motor Neurone Disease Registry was established in 2017 to facilitate participation in research and clinical trials, and to aid researchers in planning and recruitment. The NZ MND Registry is an opt in patient registry which collects demographic, contact and clinical data for those who choose to enrol. We report anonymised aggregated data from the first year’s enrolment.

12th July 2018, there were 142 participants enrolled in the NZ MND Registry. Participant sex distribution reflects the demographics reported worldwide, but ethnicity is divergent from what is seen in New Zealand overall, with an over-representation of people who identify as New Zealand European. 85.5% of participants are diagnosed with sporadic MND and 6.1% with familial MND. The remainder were participants who have not been diagnosed but have a family history, or positive genetic test for a MND-causing
Research Studies

Enrolled
• Swallowing Skill Training
• Thought-assistive technology
• Stigma in MND
• Dr Scotter’s genetic research

Upcoming
• Blood-brain barrier using MRI
• Remote wheelchair assessment

“Thank you so much for helping us with finding our participants for this study, it wouldn't be possible without you :)

- Thought-Wired

Potential Studies
• Enquiries from pharmaceutical companies
Registry Development

The role of a patient registry evolves along the pathway of drug development

1. Advancing disease understanding in the absence of treatment
2. Understanding real-world clinical practice, developing disease monitoring guidelines
3. Connecting patients, clinicians and researchers
4. Identifying patients for clinical trials
5. Informing clinical trial eligibility criteria
6. Pooling non-treatment data
7. Commitment to post-marketing surveillance
8. Providing additional data supportive of trial findings
9. Data collection to support expansion of drug indication
10. Advancing the understanding of treatment response

The Bogard Model of the changing roles of a rare disease patient registry

Rodrigues MJ et al. 2017
Thank you

Please get in touch

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