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

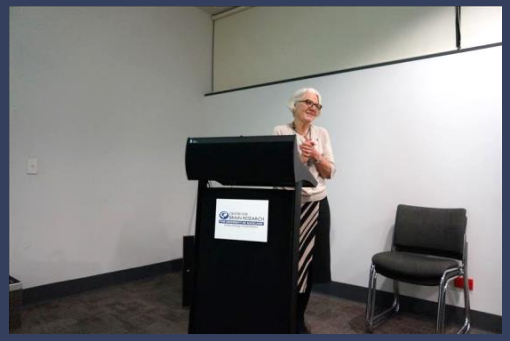
NEW ZEALAND MND REGISTRY

In the beginning…

- First conceived Nov 2016
- Launched 22 May 2017

Consenting Dr Claire Reilly
First Registry participant

Beth Watson
Former MND NZ President



Prof Paul Talman
Australian MND Registry

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The How

Registry is a research study

- allows collection of data
- ethics
- based at ADHB

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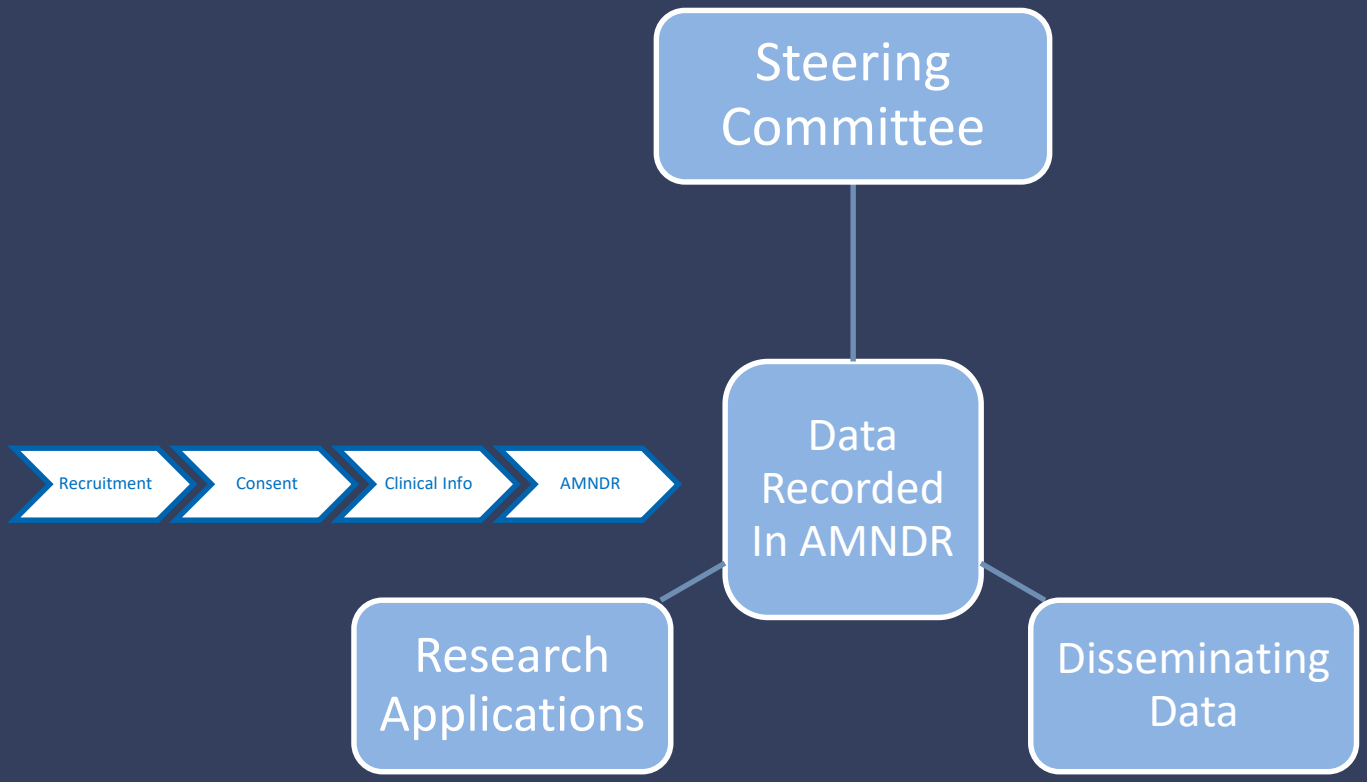
The How



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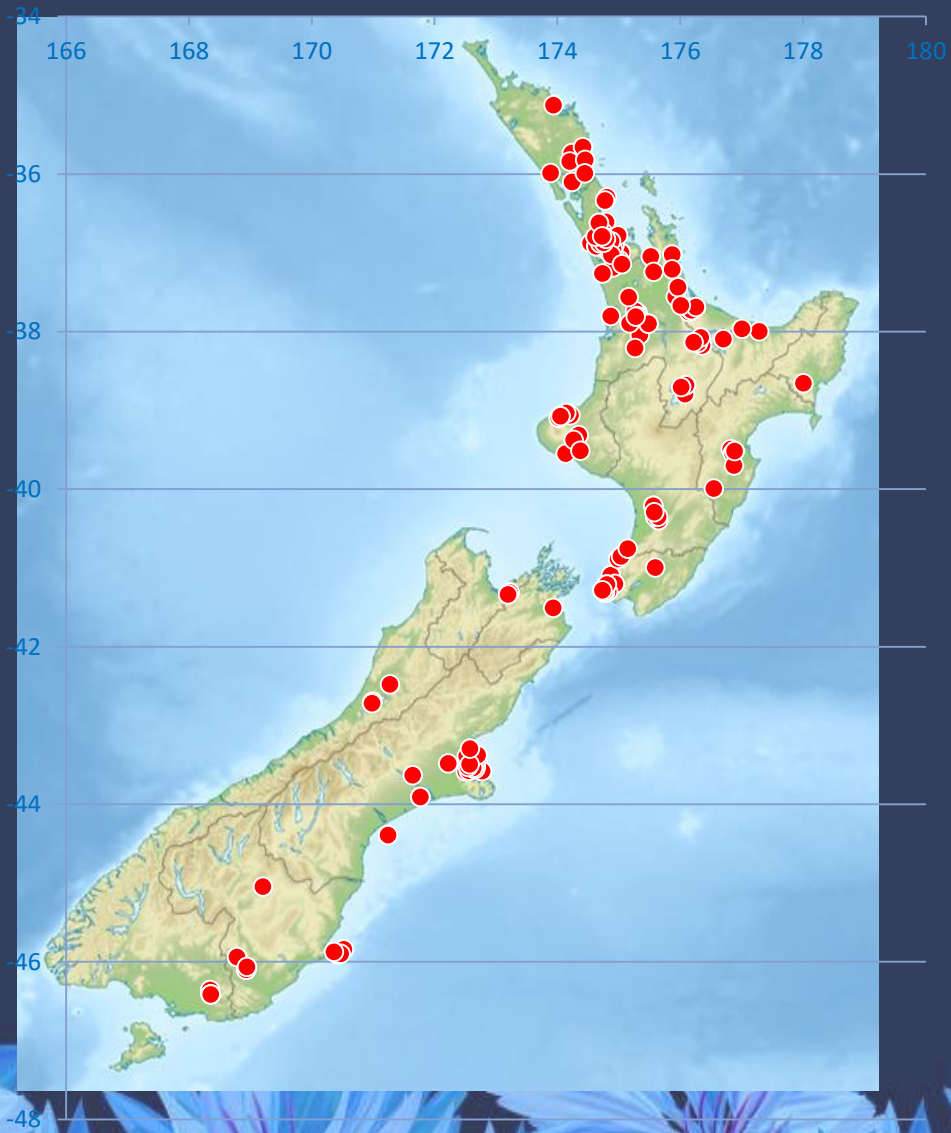
Registry Demographics

163 active participants



NEW ZEALAND MOND REGISTRY

Publications

Contents lists available at ScienceDirect

Journal of Clinical Neuroscience

journal homepage: www.elsevier.com/locate/jocn

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

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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

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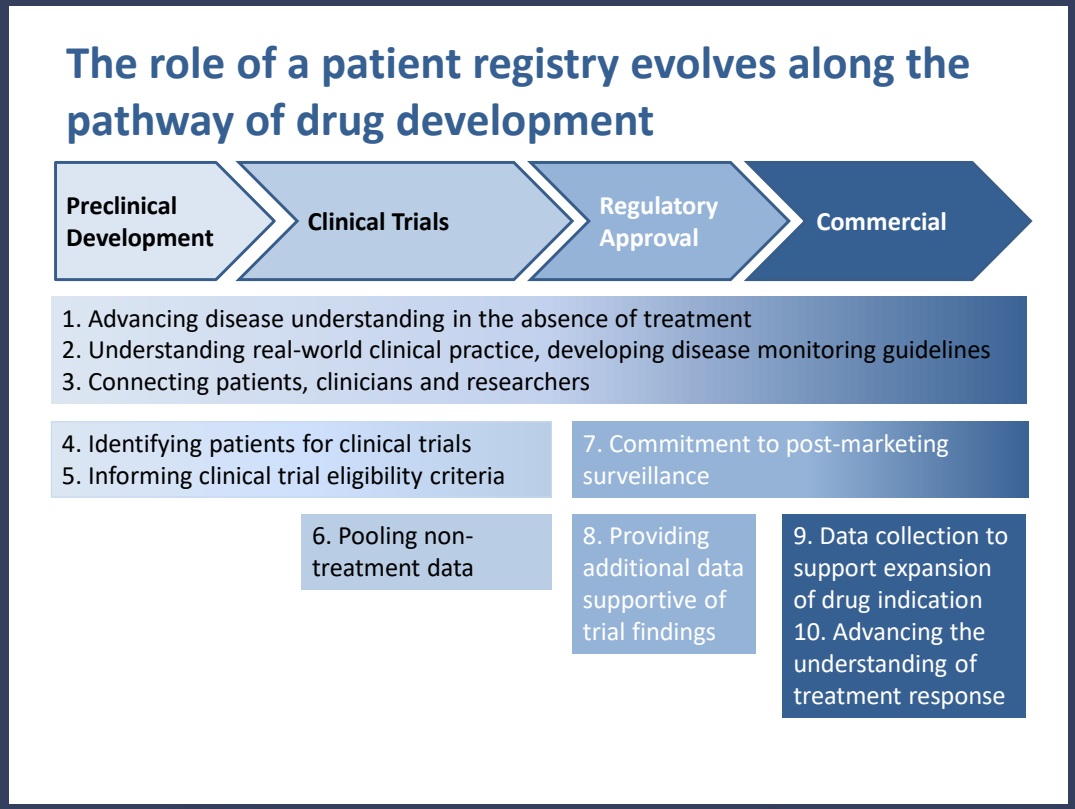
Registry Development



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

Rodrigues MJ et al. 2017

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Thank you

Please get in touch

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Visit: https://mnd.org.nz/registry/

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