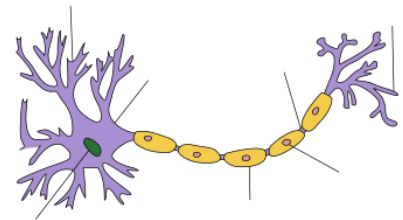


The New Zealand Motor Neuron Disease Registry was established in 2017 with the aim to help those people in New Zealand with MND to participate in national and international clinical trials and research about MND. The registry also aims to help researchers by assisting them to plan their research and helping to find people who may be interested in participating.

Because MND is not common, and New Zealand only has a small population, finding enough participants for a study about MND can be difficult. Without a registry to gather details in one place, finding enough patients for a meaningful study can take years, potentially delaying the testing of new treatments or the advancement of knowledge of MND. It is run by Assoc Prof Richard Roxburgh (Principal Investigator) and Dymrna Mulroy (Study Coordinator) with advice from the MND Registry Board who includes MND neurologists, MND scientists and MND Association reps. It is sponsored by MND New Zealand.



HOW ARE WE DOING!

**17 enquires  
made to  
research studies  
/ trials**

**10 research requests to the  
registry**

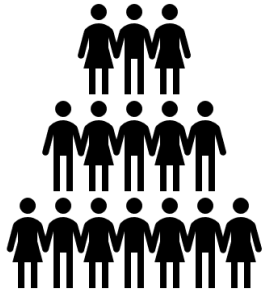
**Launched online  
consent form  
2020**

**71% enrolled  
online in 2020**

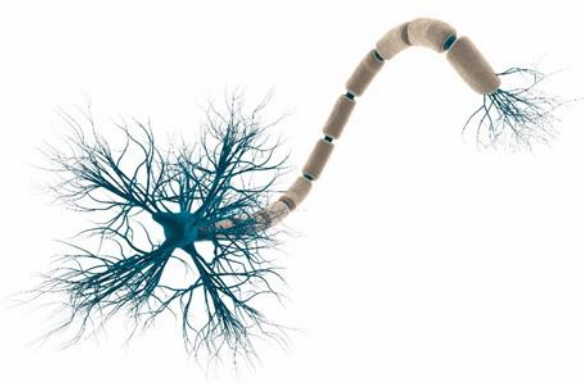
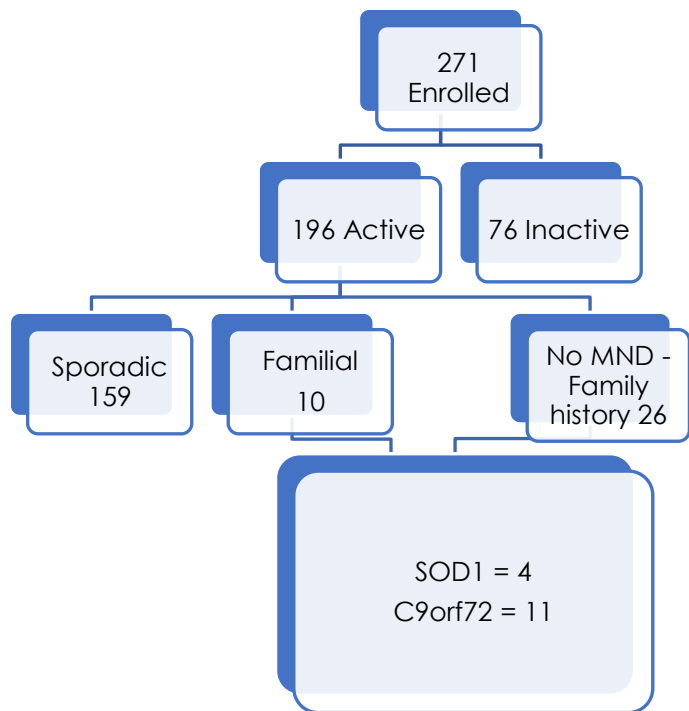
**271 People  
enrolled in  
Registry**

**2 studies  
currently  
recruiting in NZ**

## NEW ZEALAND REGISTRY PARTICIPANTS



46 people enrolled  
in 2020



Genetic mutations  
recorded

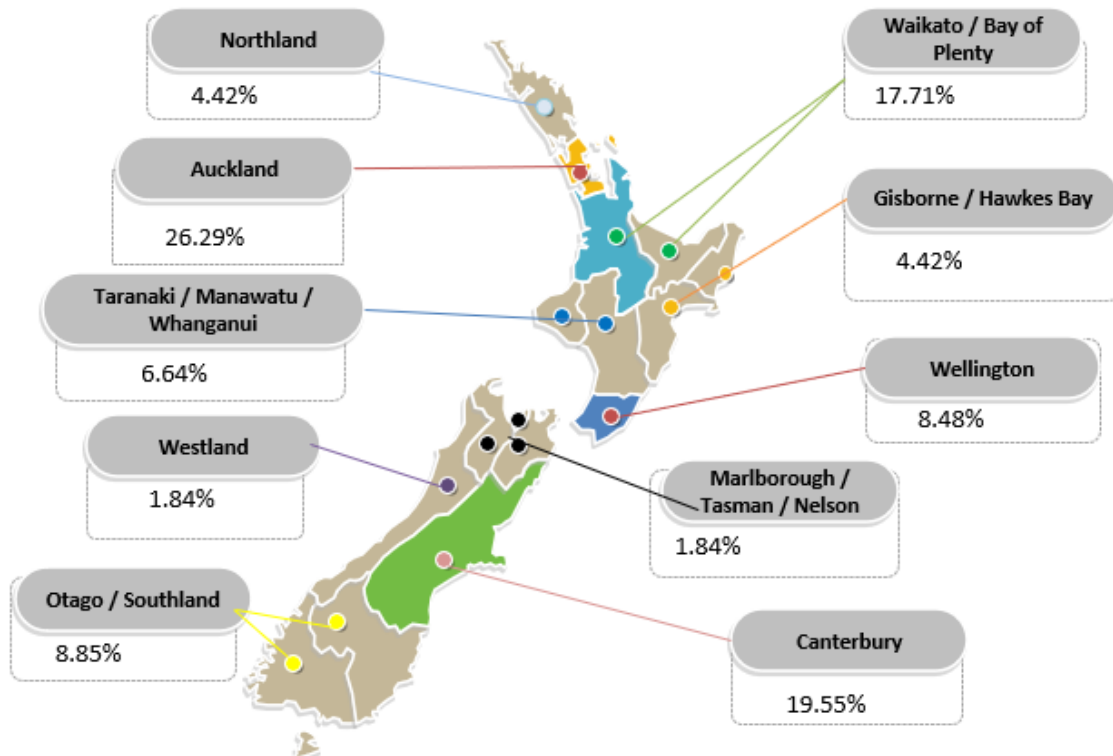
### Main source of referrals:

- MND Support Workers
- Neurologist/ Nurse specialist
- Genetic Screening study
- Self-Referral

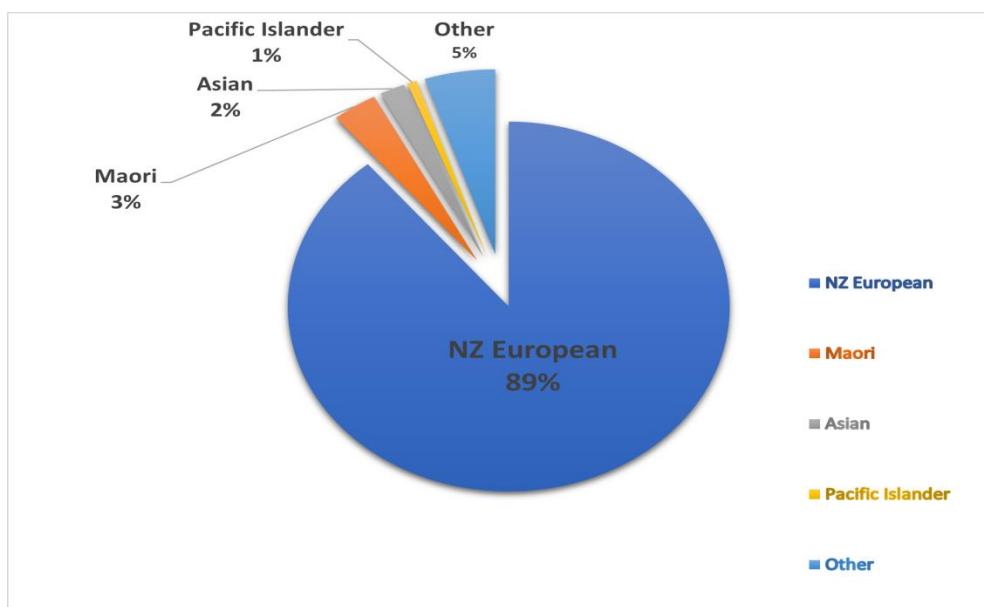
159 entered onto  
international MND  
registry

## NEWZEALAND REGISTRY PARTICIPANTS

### GEOGRAPHICAL LOCATION



### ETHNICITY



## RESEARCH STUDIES

### PREVIOUSLY RECRUITED TO FOLLOWING STUDIES:

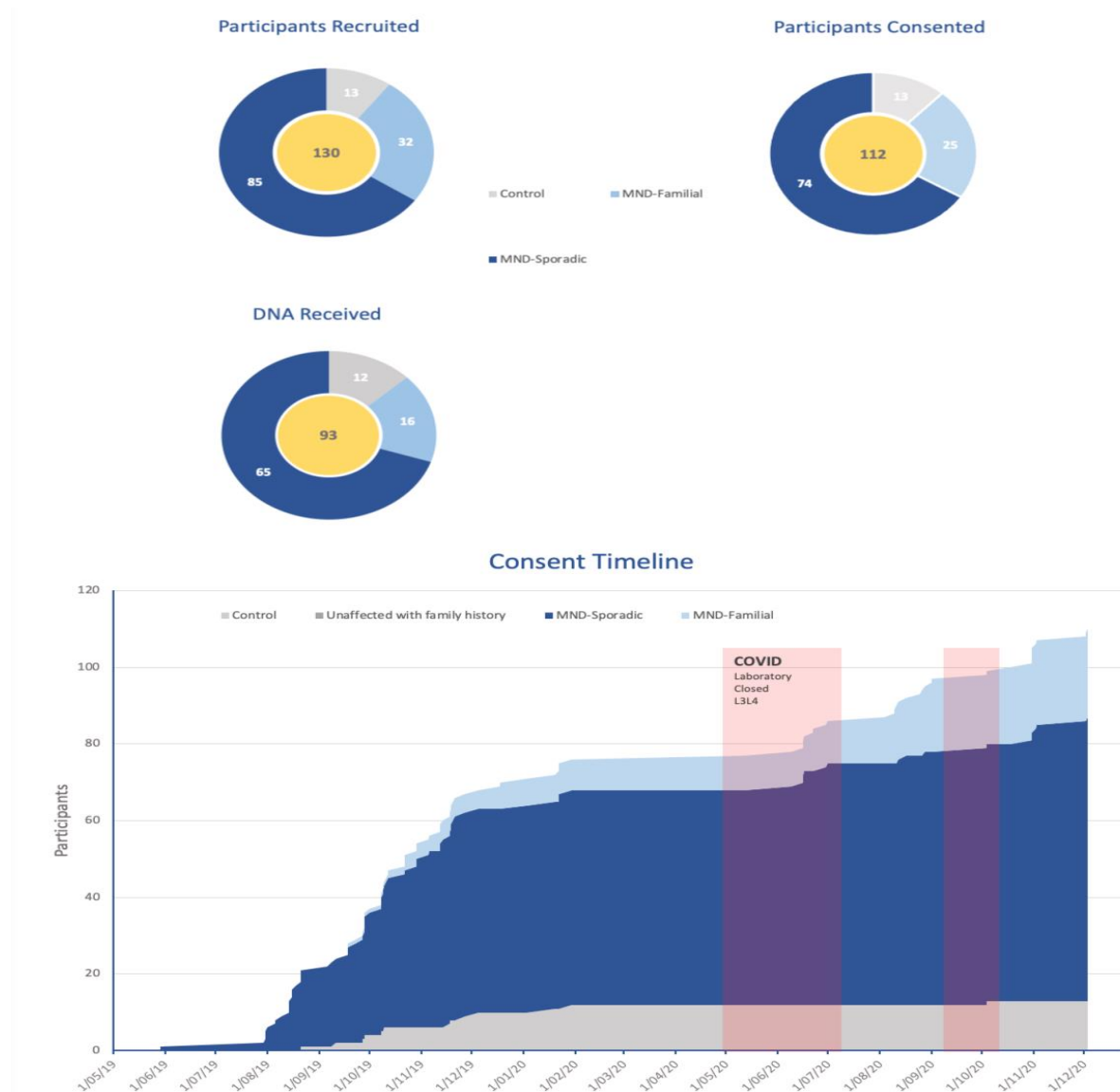
- Swallowing Skill Training
- Thought-assistive technology
- Stigma in MND
- Remote wheelchair assessment
- ALS Quest

### CURRENT COLLABORATIONS:

- Genetic Screening in Motor Neuron Disease
- Using MRI to investigate blood-brain barrier leakage in Motor Neuron Disease

If you are interested in finding out more about these current collaborations, please contact the registry.

## GENETIC SCREENING IN MND PROGRESS REPORT DECEMBER 2020



## PLANS FOR 2021

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### RESEARCH

- Continue recruitment to Genetic Screening in MND and MRI Blood-brain barrier study
- Further outreach to international clinical trials to try and entice a research site in New Zealand
- Promotion of the registry amongst the MND Research Network

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### COMMUNICATION

- Bi-yearly update to stakeholders on the registry
- Publishing communication on research and news from the registry on MND NZ website

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### GOALS

- Increase registration enrolment by 25% from 2020 to 2021
- Collaborate with international researchers
- Refine data in registry to ensure everyone with a positive genetic test result is recorded

## CONTACT DETAILS

If you would like any information about the registry, please don't hesitate to contact us.

Email: [MNDRegistry@adhb.govt.nz](mailto:MNDRegistry@adhb.govt.nz)

Phone: 0800 MND REGISTRY or 027 561 7332

Website: <https://mnd.org.nz/registry/>

Post: Dympna Mulroy  
NZ MND Registry  
Neurology Department  
Auckland City Hospital  
Private Bag 92024  
Auckland 1142

