

Inviting you or your child to take part in the New Zealand Neuromuscular Disease Registry



If you or your child has a neuromuscular disease we will be inviting you to take part in this registry. The registry has received ethics approval. The registry will accelerate and facilitate clinical trials by locating potential research participants quickly and efficiently

What are the Benefits?

There are good reasons for you to register here:

- You may be offered the opportunity to participate in international clinical trials
- You will be regularly updated about research results, as well as about TREAT-NMD activities.
- You will receive feedback on new research developments
 - This means that you will be informed about new treatments and about what specialists think are the best ways of caring for people with neuromuscular conditions
- You will be assisting the neuromuscular community with the development of recommendations and standards of care for specific conditions
 - The standards of care are guidelines for the treatment of patients that have been compiled by international experts.
- You will help researchers gain more knowledge about the prevalence and natural history of neuromuscular conditions within New Zealand and about the way you are being cared for.
- Allow clinical trials in New Zealand to be more easily planned
- There is the sense of “belonging” to a broader community
- Feel as if you are not being left behind as clinical trials develop
- Have a link to the research community

There are also many benefits to the Research Industry

- Easy access to patient community
- Clear concept of target market
- Feasibility and planning of clinical trials
- Recruitment of patients into clinical trials