

Participate in Research

Canadian Neuromuscular Disease Registry



Principal Investigator:
Dr. Laura McAdam



What is this study about?

The Canadian Neuromuscular Disease Registry (CNDR) is a Canada-wide registry for people diagnosed with a neuromuscular disease. It collects medical and contact information from individuals across the country. CNDR will help improve our understanding of neuromuscular disease and generate appropriate clinical research.

Who can participate?

We are looking for Holland Bloorview clients to participate. We are looking for children/youth who:

- Are diagnosed with a neuromuscular condition
- Between the ages of 0 and 18 years old

What's involved?

Your medical chart will be reviewed by the research team and relevant information will be uploaded to the CNDR database. Personal information will be separated from your medical information to protect your identity and privacy. The following information will be collected:

- Name
- Contact details
- Diagnosis

If you choose to participate in this study, you will be expected to let us know if your address or email has/will change, to ensure it is up to date in the registry.

Potential Benefits?

This registry allows researchers to identify suitable study participants to be contacted quickly. CNDR helps researchers plan studies and answer questions about the diseases which could help other people who have neuromuscular diseases. For example, your information might help tell researchers how many people in Canada have neuromuscular diseases. Additionally, the CNDR publishes general information from the registry on the website (www.cndr.org). You may learn more about your disease here.

Potential Risks?

There are no risks or harms known for participating in the CNDR. No procedures or treatments are required to be part of the registry. There is a possible risk for a loss of privacy if a breakdown in the security system occurs. Everything possible will be done to prevent this risk.

CONTACT INFORMATION:

TO ASK QUESTIONS OR TO SIGN UP, CONTACT

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