

Natural history of disease progress in individuals with neuromuscular disorders
Investigator: Linda Lowes PT, PhD

Introduction – Why are we doing this research study?

Our team is collecting information about the strength and function of people with Limb Girdle Muscular Dystrophy. Our goal is understand the impact of this disease on your strength and function. We are looking for participants to come to Nationwide Children's Hospital (NCH) and let us test your strength, arm and reaching ability and walking (if able). You are welcome to do as much or as little as you are able and would like.

Participation is voluntary.

Your decision to participate or decline will not affect any care you might receive at NCH. If you agree to participate you can quit at any time if you wish.

What are possible Risks/Discomforts?

There are very little risks to being in this study. We will ask you to show us how well you complete everyday activities. There is always a risk that you might fall or be sore the next day if it is more activity than you are used to.

What are potential Benefits?

This is not a treatment trial. It may not benefit you directly but it will help us learn more about the disease.

How will my information be kept private?

Any information we collect will be kept confidential. We will store your information securely and will not report any identifying information when presenting our results.

Is there any payment/compensation for participation?

You will not be paid for participating in this research study

Who can I contact for additional information?

NMDtrialinfo@nationwidechildrens.org or 614 722-6881

If you have questions, concerns, or complaints about the research; if you have questions about your rights as a research volunteer; if you cannot reach the Principal Investigator; or if you want to call someone else - please call (614) 722-2708, Nationwide Children's Hospital Institutional Review Board (IRB). The IRB is the committee that reviews all research involving human subjects at Nationwide Children's Hospital.