

Participate in Research

A longitudinal study of the relationship between impairment, activity limitation, participation and quality of life in persons with confirmed Duchenne muscular dystrophy (DMD)

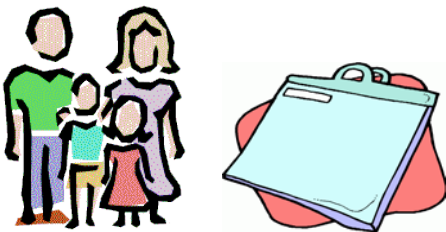


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Participate in a long-term research study looking at the relationship between activity limitation & quality of life in children with DMD

What is this study about:

The purpose of this study is to establish the largest long-term assessment of people with Duchenne muscular dystrophy (DMD). One of the first uses of this study will be to see how long-term steroid therapy affects the lives of children who use the drug. A second purpose of this study is to find out whether small differences in the genetic makeup of people with DMD (called Single Nucleotide Polymorphisms or "SNPs") affect how their disease progresses and how they respond to steroids.

Who can participate?

We are inviting **BOYS with DMD** and **AGE 4 to 7 years inclusive** to take part in our research study.

What's involved?

In this study, we will take a detailed look at children's physical abilities across medical problems they experience, and how they use healthcare services. We will also look at how families of children with DMD interact with their communities, and at their quality of life. For the family part of our study, we will ask parents questions about their quality of life, and about their attitudes towards their child's diagnosis, medical care and other support. There is also an optional genetic test for genes that have been found to be related to steroid response and muscle size and strength; to do this part, a small blood sample will be collected. Visits will take place during your child's neuromuscular clinic appointment.

Potential Benefits?

This study is not designed to benefit your child directly. However, knowledge gained through this study may provide future benefit to others who have a diagnosis of DMD or the scientific community.

Potential Risks?

It is possible that the testing will make your child tired. Blood drawing may cause soreness or bruising where the needle was inserted. In rare cases, a more serious injury happens, such as bleeding under skin. Questionnaires may make some people feel uncomfortable or upset.