

REACH-DM-KIDS

DOES YOUR CHILD HAVE MYOTONIC DYSTROPHY?

A study your child can do from home!

PURPOSE

We are looking for children with myotonic dystrophy to participate in a remote study visit! The goal of our study is to determine what causes the disease variability seen in children with myotonic dystrophy type 1.

YOUR CHILD IS ELIGIBLE FOR THIS STUDY:

- If they have been diagnosed with congenital or childhood onset myotonic dystrophy type 1
- Are between 0-17 years old

WHAT WILL BE ASKED OF YOU AND YOUR CHILD:

- Participation in a remote study visit where we will ask questions about your child's myotonic dystrophy and evaluate your child's strength and more using special tools
- Answering questions about your child's mood, behavior, sleep, and more
- Blood collection

HOW DOES THE REMOTE STUDY VISIT WORK?

- A toolkit will be mailed to your home which contains everything you need to participate
- No need to travel! However, there will be options to participate in an in-person study visit or a repeat remote study visit

\$50 COMPENSATION WILL BE PROVIDED FOR COMPLETION OF THE REMOTE STUDY VISIT!

CONTACT US!

Myotonic Dystrophy Research Center
University of Rochester Medical Center
601 Elmwood Avenue, Box 645
Rochester, NY 14642

Phone: (585)-275-0420

Email: REACHDM@URMC.Rochester.edu

Erin Richardson, Study Coordinator
Jeanne Dekdebrun, Study Coordinator
Dr. Johanna Hamel, Co-Principal Investigator
Dr. Stella Deng, Co-Principal Investigator

