

WHY?

The purpose of this study is to learn more about what causes the muscle weakness and stiffness (myotonia) in myotonic dystrophy. This information is needed to help scientists design new treatments for myotonic dystrophy.

A second purpose of this study is to find the best way to measure whether myotonic dystrophy is getting better or worse, and determine how this condition changes over time. This information is needed to plan future studies to test treatments for myotonic dystrophy.

WHAT'S INVOLVED?

There are 3 visits to the University of Rochester for this study.

- Visit #1

This visit is a day and half long. You will stay over night with us at the University of Rochester.

- Visit #2

This visit takes place 12 months after your first visit and is a one day visit.

- Visit #3

This visit takes place 36 months after your first visit and is also a one day visit.

WHAT TESTS ARE DONE?

First Visit:

Day 1:

You will be asked to undergo:

- a physical examination;
- Electrocardiogram (EKG);
- Dual energy X-ray Absorptiometry (DEXA) – a scan to measure your bones and muscles; and
- Muscle strength and myotonia (delayed muscle relaxation) testing.

You will also provide urine and blood samples, and complete a set of questionnaires.

Day 2:

You will be asked to provide (fasting) blood samples and a urine sample. You will also undergo a needle muscle biopsy to obtain a small amount of muscle tissue (smaller than a pea).

Follow-up Visits:

At these visits, you will be asked to complete all the tests listed above, except the needle muscle biopsy.

WE NEED YOUR HELP:

Please consider helping us learn more about myotonic dystrophy.

Participants are compensated \$250 for each study visit and \$250 for the muscle biopsy (done at the baseline visit only).

A limited amount of travel money is available to pay for expenses to travel to the University of Rochester.



VOLUNTEERS:

We are looking for volunteers who have been diagnosed with myotonic dystrophy to help us learn more about this disease and how it affects your daily living.

Eligibility:

- A diagnosis of myotonic dystrophy
- You are 18-70 years old
- You have the ability to complete a 6 minute walk (the use of a cane or leg bracing is permitted)
- You are not currently pregnant



FOR MORE INFORMATION:

If you are interested in participating, please contact the study coordinator:

Jeanne Dekdebrun, M.S.
Neuromuscular Disease Center
University of Rochester Medical Center
601 Elmwood Avenue, BOX 673
Rochester, NY 14642
Phone: 585-276-4611
Jeanne_Dekdebrun@urmc.rochester.edu

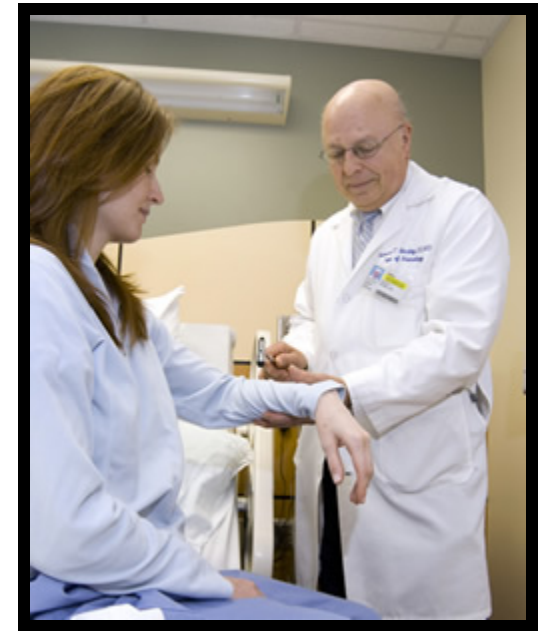
If you prefer to email Jeanne, please only include your name and phone number. To protect your privacy, please do not include any confidential medical information in this email.



The Senator Paul D. Wellstone Cooperative Research Center is funded by the National Institutes of Health.



Myotonic Dystrophy Research Study



“Pathogenesis and Progression in Myotonic Dystrophy”

Conducted by: Dr. Richard Moxley,
director of the Wellstone Muscular
Dystrophy Cooperative Research Center
located at the University of Rochester