Research participation opportunity

Research study title:
Biomarker development for muscular dystrophies

Participating investigators and research facilities:
Thurman Wheeler, MD, Massachusetts General Hospital (MGH) in Boston, MA
Basil Darras, MD, Boston Children's Hospital (BCH) in Boston, MA
Anthony Amato, MD, Brigham and Women's Hospital (BWH) in Boston, MA

Purpose of the research:
Current methods of measuring the response to new treatments for muscular dystrophies involve the examination of small pieces of muscle tissue called biopsies. We are interested in finding less invasive methods that reduce the need for muscle biopsies. The purpose of this research is to learn about the possibility of detecting and measuring the activity and severity of muscular dystrophies by examining a urine sample and a blood sample.

Eligibility criteria:
Males and females ages 5 years and older with myotonic dystrophy type 1 (DM1), myotonic dystrophy type 2 (DM2), Duchenne muscular dystrophy (DMD), Becker muscular dystrophy (BMD), or facioscapulohumeral muscular dystrophy (FSHD) confirmed by genetic testing or clinical history and examination are invited to participate.

In addition, male and female healthy volunteers ages 18 and older who are family members of an individual with muscular dystrophy also are invited to participate.

Research study activities:
We will ask eligible volunteers to provide a single urine sample and undergo a single blood draw.

Duration of participation in the research study:
We will ask you to come in for one visit to MGH, BCH, or BWH where it will take about 10 - 15 minutes for you to complete the study.

Benefits of participation:
You will have no direct benefit from participation in this research. However, others that have muscular dystrophy may benefit in the future from what we learn in this research study.

Payment for participation:
There is no payment for participation.

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Contact persons for more information:

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