

Outcome Study Fact Sheet

Study Name: **The Relationship of Electrical Impedance Myography to Muscle Structure and Function in Facioscapulohumeral Muscular Dystrophy (FSHD).**

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Introduction and Purpose of the Study Recent genetic advances in the understanding of FSHD have identified potential future targets for therapy. Consequently, it is important that we have appropriate tools in place for use in FSHD clinical trials. We are conducting a study to evaluate a new measure of muscle structure, electrical impedance myography. This device is an excellent example of repurposing an existing technology – measurement of body composition using bio-impedance to the measurement of individual muscles. The ability to measure underlying changes in your muscle and understand how those changes relate to your strength or the underlying pathology in FSHD will be of vital importance in designing future FSHD therapeutic clinical trials.

How many people will participate? We are seeking twenty (20) volunteers to participate in this research study. Anyone with a diagnosis of FSHD who is able to walk independently and can travel to and from the University of Kansas Medical Center is eligible for this study.

If I am selected to come to KUMC, what will I do? You will meet with Dr. Statland and his neuromuscular colleagues one time. Your visit will last approximately 6 hours, and can be split over two days. During the visit, you will have a physical examination, answer questions on how FSHD affects you, perform strength testing and a functional

walking task, undergo magnetic resonance imaging of the muscles of your thighs and legs, DEXA imaging to determine your lean body mass, and undergo electrical impedance muscle measurements. We are also asking you to undergo a needle biopsy of one muscle in your thigh or leg and give a blood sample. The muscle tissue and blood sample will be used to evaluate how measurements made using electrical impedance myography relate to the underlying pathological changes in FSHD.

How much will this cost me?

There is no cost to participate in this study.

Can you help me with my travel expenses?

We have limited funds to help with the cost of travel to and from the medical center, for parking, and for overnight lodging if required.

Who can I call for more information?

For more information, please contact:

Melissa Currence
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THANK YOU FOR YOUR CONSIDERATION.