

Paul and Sheila Wellstone Muscular Dystrophy Center

Academic Health Center



Research study for FSHD

(Facioscapulohumeral Muscular Dystrophy)

conducted by Dr. Michael Kyba and Dr. Peter Karachunski

Your participation is essential to advancing research on FSHD

Participants are sought for a University of Minnesota study on muscle stem cells in FSHD.

What is involved?

Study participants (FSHD and control individuals) will choose to provide any one or all of the following tissue samples:

- a small muscle biopsy taken with a needle from a muscle in the leg
- skin biopsy
- blood and/or urine sample

What are we trying to find out?

What causes FSHD is not well understood. Researchers know that DUX4 dysfunction causes symptoms of FSHD, however they do not know how or why only certain muscles are affected. Researchers have developed a way to study this by looking at muscle in affected and unaffected individuals. We are hopeful that by learning more about what causes FSHD we will be able to develop effective treatments for FSHD.

Will I benefit directly?

There is no direct clinical benefit to study participants. This study is aimed at understanding why and how muscle is lost in FSHD. This knowledge is essential to developing a therapy.

How can I participate?

This study involves a collection of one or all of the above listed tissue samples from you and a control. For every FSHD participant, we need a corresponding control (unaffected) participant. You can help – if you have a sibling, spouse, loved one, friend, or colleague who would be willing to participate and serve as your control, please do let us know.

Thank you for your support!

Isolating and studying cells from controls and individuals with FSHD is critical for advancing our understanding and future treatment of this disease.

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