

How Do I Find Studies?

- Search “FSHD” at clinicaltrials.gov and navigate to contacts and locations to find the site closest to you.
- Join the National FSHD Registry at dystrophyregistry.org. You will complete surveys annually to update your information so you can receive information about studies for which you may be eligible.
- Go to fshsociety.org. Click on “Get Involved” → “Volunteer for Research”

What if I am Not Eligible or Cannot Participate?

That is ok! Many studies have specific criteria that are designed to make sure it is safe for you to participate. Your safety is the first and most important concern in any study. If you are not eligible for one study, it does not mean you may not be eligible for another. If you cannot participate at this time due to time constraints, travel, etc., then you can encourage others, such as family, to participate. You can also ask the research site to contact you about future studies.

As a general guideline, you should see a neuromuscular specialist or neurologist on a regularly (semi-annually or annually). They can keep track of how you are doing and how you are progressing. Plus, it is a great way to stay “in the know.” They can let you know if you may be eligible for a new study and give you more details about the study. They can also let you know if there are any newly approved treatments or guidelines for FSHD patients.

FSHD Research Sites

Kennedy Krieger Institute, Baltimore, MD
Kansas University Medical Center, Kansas City, MO
Stanford University, Stanford, CA
The Ohio State University, Columbus, OH
University of California Los Angeles, Los Angeles, CA
University of Colorado, Denver, CO
University of Florida, Gainesville, FL
University of Massachusetts, Worcester, MA
University of Rochester Medr, Rochester, NY
University of Texas Southwestern, Dallas, TX
University of Washington, Seattle, WA
University of Utah, Salt Lake City, UT
Virginia Commonwealth University, Richmond, VA

European Sites:

Nice University Hospital, Nice, France
Niguarda Ca’ Granda Hospital, Milan, Italy
Radboud University, Nijmegen, the Netherlands



How to Get Involved in FSHD Research

Kiley Higgs, FSHD Project Manager
Ksims2@kumc.edu
913.945.9922

Leann Lewis, FSHD Study Coordinator
Leann_lewis@urmc.rochester.edu
585.275.7680



Why Should I Participate?

The main reason most people participate in research is to help find answers and solutions for FSHD. Many people are concerned that their children and grandchildren may inherit FSHD and would like to see them have access to treatment in their lifetime. The quicker we can recruit individuals for research studies, the quicker we can find answers and develop treatments.

When you are involved in research, it is a great way to stay in the know. You are working with top researchers in the FSHD field who know what new and upcoming studies are out there. Also, if you are currently participating in a research study (or were recently in one), we have a better idea if you qualify for new upcoming studies, and we may be able to screen you at one of your current study visits for a new study, if allowed by the sponsor.

What is the Typical Timeframe of a Research Study?

This varies study to study. Some studies are a one-time visit, or one-time survey. Others, usually clinical trials that involve study drugs, may last for a year or longer and require multiple visits. Contact your local research site to find out what studies are currently ongoing and ask what the expected time commitment is for each to see if it works for your schedule.

What is Needed/Criteria for Participation?

Each study has its own specific criteria for eligibility. Each criterion is to ensure research volunteers can safely participate in the study procedures. Generally, most studies will expect that:

- You have genetically confirmed FSHD, or have symptoms of FSHD and have at least one immediate family member who is affected. It is helpful to have a copy of your results for your own records, and to provide to researchers. Some studies will genetically test you for FSHD before enrolling you in the study.
- You are not wheelchair-dependent full time: Many studies perform muscle testing and functional assessments, which require some walking.
- You do not have a major medical problem that potentially makes it unsafe for you to participate, such as cancer, or major heart, kidney or breathing issues.
- You are not pregnant or planning to become pregnant. The study procedures may pose risks to the fetus.

What to Expect at a Research Visit?

Each study and institution is a little different in how they run their research studies. What you can expect from each one is an appreciation for your time in volunteering. **We cannot do this without you!** You can also expect confidentiality of your information and your participation. All studies need to be approved under strict research guidelines explaining how data will remain anonymous and secured.

Generally, you are expected to travel to the institution to participate in person. Most studies require that participants remain anonymous, so you will be seen alone at your visit and not pooled with other participants. Some studies involve surveys that can be done at home, or blood draws that can be done at your doctor's office or local blood draw laboratory.

You will never be persuaded to enroll in a study that you are not comfortable with. You also have the right to drop out of a study.

Contacting an institution about a study to learn more information does not obligate you in any way and is the best way for the researchers to give you more details and answer all of your questions.