

UK FSHD PATIENT REGISTRY



Research in the laboratory has led to greater understanding of the genetic causes of FSHD, moving researchers towards the development of new therapies. But FSHD is a rare disease and identifying enough people for clinical trials could delay the testing of potential new therapies. Registries allow people who may be interested in taking part in trials to be contacted quickly and easily.

Why should I register?

- Registering may open up opportunities to take part in clinical trials and other studies.
- Registries aim to speed up the development of new therapies for FSHD.
- You will have a link to the research community and receive newsletters containing information relevant to your condition, such as the latest research developments.
- Registries can be a source of information for doctors and scientist to gain more knowledge about the number of people affected by FSHD and how the condition progresses
- The information may be used to ensure that people across the UK have access to the same high quality care. -

How do I register?

Participants can register online. You can create an account which allows you to view and update your data at any time. If the participant is under 18, a parent or guardian must create an account on their behalf. If you cannot register online please contact us, our details are below.

Is my data safe?

All the data are stored in a secure server (protected in a similar way to online bank accounts) accessible to only specially appointed registry staff. Registration is voluntary and at all times the data remains your property and you have the right to withdraw your information at any time. The UK FSHD Patient Registry is independent from the NHS and is subject to different IT security assessments.

How does the registry work?

The registry comprises of a number of questionnaires. The majority of information is completed by you. The rest of the information is entered by the medical professional managing your FSHD. This could be for example a neurologist, pediatric neurologist or specialist nurse.

The information you will be asked to enter includes:

- Personal details, e.g. name, address, date of birth, gender.
- Details of your symptoms e.g. mobility, wheelchair use.
- Information about how your FSHD affects your levels pain and you quality of life.
- Details about the impact of Scapular fixation surgery

The information entered by a medical professional includes:

- Clinical diagnosis and results of genetic testing.

A medical professional can only enter your details after you have consented for them to do so. A curator is employed to maintain the data and make sure everything is up to date. You will be asked to update your details once a year.

If you have any questions please contact the registry curator: Ben Porter

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