Who should register?

This registry is for patients living in the United Kingdom who are affected by Facioscapulohumeral muscular dystrophy (FSHD).

How do I register?

You can register online and create an account so that you can view and update your information at any time.

Register at **www.fshd-registry.org.uk**

What if I change my mind?

Participation is completely optional, and you can withdraw at any point. Please contact:

fshdregistry@newcastle.ac.uk

if you have any questions about participating.

WORLD FSHD DAY
Unite to find a cure

The registry participates in global awareness initiatives including World FSHD Day every June 20th.

For more information about the UK FSHD Patient Registry please visit **www.fshd-registry.org.uk**

SCAN ME
visit registry website

UK FSHD
PATIENT REGISTRY

UK FSHD Patient Registry
John Walton Muscular Dystrophy Research Centre
Translational and Clinical Research Institute
Faculty of Medical Sciences
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International Centre for Life
Newcastle upon Tyne, NE1 4EP

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Study Principal Investigator
Prof Chiara Marini Bettolo

Register at www.fshd-registry.org.uk

The John Walton Muscular Dystrophy Research Centre
The Newcastle upon Tyne Hospitals NHS Foundation Trust
Newcastle University
JWMDRC Patient Registries

UK FSHD
PATIENT REGISTRY

The UK FSHD Patient Registry

For patients living with FSHD in the United Kingdom

www.fshd-registry.org.uk

MUSCULAR DYSTROPHY UK OUR MUSCLES MATTER
Thanks and acknowledgement to our funder:

What is the UK FSHD Patient Registry?

Patient registries are databases containing information about individuals who are affected by a specific disease. The UK Facioscapulohumeral (FSHD) Patient Registry is a patient-initiated, clinically supported national platform, collecting data from FSHD patients. Established in 2013, the registry is run by the John Walton Muscular Dystrophy Research Centre at Newcastle University.

How will my data be used?

Healthcare professionals and pharmaceutical companies conducting clinical trials in the UK can seek assistance from the UK FSHD Patient Registry to identify individuals who may qualify for participation in a specific study. Additionally, the registry's data may be used to support scientific research aimed at enhancing understanding of FSHD. Personal identifiable information, however, will never be disclosed.

UKFSHD
PATIENT REGISTRY

Why should I join the registry?

Registering via our secure online website allows you to:

- Share information on your symptoms, trial preferences, access to care and support
- Answer questionnaires on our improved registries platform
- Nominate your neuromuscular consultant or other care providers to add important clinical data
- Receive information about clinical trials you might be able to participate in
- Provide essential information to support FSHD research

What information do we collect?

We collect personal information, including name, address, date of birth, NHS number, and the healthcare facility where you or your child receive treatment. Additionally, we gather details about genetic diagnosis, motor abilities, wheelchair usage, medications, and preferences regarding participation in research.

Is my data safe?

The details you provide about yourself or your child on the registry's online platform are securely stored on a GDPR-compliant server and kept strictly confidential. Access to this information is restricted to authorised members of the registry team.

Additionally, the registry operates under the oversight of an ethics committee and a Steering Committee, which includes researchers, healthcare professionals, and patient representatives. These committees ensure that all research collaborations adhere to strict ethical and regulatory standards.

Can I have more information about the registry?

Yes, please scan the QR code, or type in the address below to fill out a form and we'll send you more details:

SCAN ME

TO RECEIVE INFORMATION

bit.ly/ukfshdreginfo