



## **FSHD European Patient Survey online**

There is a growing interest from several pharma companies to run clinical trials in FSHD. FSHD Europe is working with the Pharmaceutical Industry to ensure that when trials are developed, they are designed and organized in a way to maximize patient involvement and participation.

**In order to achieve this, we are conducting a large-scale survey of patients across Europe to find out what they want from a clinical trial and what would encourage them to participate.**

FSHD Europe are providing funding to the John Walton Muscular Dystrophy Research Centre (JWMDRC) at Newcastle University to develop, manage and analyse this survey. The survey will include questions about the patient's condition and how they currently manage it. It will also include some questions to gain insight into the FSHD community's thoughts and opinions on clinical trials.

**We are looking for FSHD patients and caregivers to complete this survey. There are no right or wrong answers, we are looking for your thoughts and opinions.**

We hope you will consider participating, but participating is your choice. You may not directly benefit from this research; however, we hope that your participation in the study may help guide future clinical trials.

The survey will take around 45 minutes to complete and answers are anonymous. You will not be paid for completing the survey. It will be open to complete **until the 9<sup>th</sup> of May**.

**Please follow [this link](#) to complete the survey.**

We are committed to sharing the information we learn from the survey with the FSHD community. If you have questions or would like further information, please contact Megan McNiff at JWMDRC: [megan.mcniff@newcastle.ac.uk](mailto:megan.mcniff@newcastle.ac.uk)