
CONSENT FORM for Adults

UK Facioscapulohumeral Dystrophy Patient Registry

Name of Researcher:

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Please initial all boxes

1. I confirm that I have read and understand the information sheet dated February 2021 (version 1.7) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. By signing this document, I understand that I give consent for the storage of data on myself in the UK FSHD Patient Registry.
4. I understand that the storing of data will allow contact to be made with me if a suitable clinical trial becomes available.
5. However, I accept that allowing my data to be stored on this database does not mean I will automatically be entered into future clinical trials.
6. I understand that the data I provide may be used to inform future research outside of clinical trials and I am happy for it to do so.
7. I consent for my clinical and genetic data on the registry to be anonymously linked to samples that may be stored in the biobank.
8. I understand that the results from future research may not have any direct implications for myself or my family.
9. I confirm I am happy for specialists involved in my medical care to add relevant information to my database entry on my behalf.
10. I am happy to consent to be included in this registry.

Please sign below:

Name of Participant

Date