
ASSENT FORM FOR CHILDREN

Title of Study:

UK Facioscapulohumeral Dystrophy Registry

Name of Researcher:

Prof H Lochmüller
Experimental Chair of Myology
Institute of Genetic Medicine
Newcastle University

Please write your initials in the box

1. I confirm that I have read/had read to me, and understand the information sheet dated January 2013, Version 1.0 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered in a way I understand.

2. I understand that I may ask for my details to be removed from this database 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 results from future research may not have any direct benefit to me.

7. I am happy for doctors in charge of my medical care to add relevant information to my database entry on my behalf.

8. I am happy to consent to be included in this registry.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature