
CONSENT FORM FOR PARENTS

Title of Study:

UK Facioscapulothumeral Dystrophy Registry

Name of Researcher:

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

Please write your initials in the box

1. I confirm that I have read and understand the information sheet dated **January 2013 (version 1.0)** on behalf of my child 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 child's participation is voluntary and that I am free to withdraw at any time, without giving any reason, without his/her medical care or legal rights being affected.

3. By signing this document, I understand that I give consent for the storage of data on my child in the UK FSHD Patient Registry.

4. I understand that the storing of data will allow contact to be made with me/my child if a suitable clinical trial becomes available.

5. However, I accept that allowing my child's data to be stored on this database does not mean my child will automatically be entered into future clinical trials.

6. I understand that the results from future research may not have any direct implications for my child.

7. I confirm I am happy for the specialist in charge of my child's medical care to add relevant information to my child's database entry on his/her behalf

8. I am happy to consent on behalf of my child to be included in this registry

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature