

**CONSENT FORM for Patients**

**UK Facioscapulohumeral Dystrophy Registry**

**Name of Researcher:**

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

**Please initial all boxes**

1. I confirm that I have read 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 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 and plan future research.
7. I understand that the results from future research may not have any direct implications for myself or my family.
8. I confirm I am happy for specialists involved in my medical care to add relevant information to my database entry on my behalf.
9. I am happy to consent to be included in this registry.

**Please sign below:**

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent                      Date                      Signature