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**ASSENT FORM FOR CHILDREN**

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**Committee:** NRES Committee North East- Newcastle and North Tyneside 1

**Title of Study:**

**UK Facioscapulohumeral Dystrophy Patient Registry**

**Name of Researcher:**

Dr Chiara Marini Bettolo  
Consultant Neurologist and  
Clinical Lead  
Translational and Clinical  
Research Institute 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 February 2019, (version 1.4) for those aged 6-10 years, or February 2021 (version 1.5) for those aged 11-15 years 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 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 benefit to me.
9. I am happy for doctors in charge of 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.



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Name of Patient

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Name of Parent

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Date