



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

CONSENT FORM FOR PARENTS

Title of Study:

UK Facioscapulohumeral Dystrophy Patient Registry

Name of Researcher:

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Please write your initials in the box

- 1. I confirm that I have read and understand the information sheet dated February 2021 (version 1.7) 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 data I provide about my child may be used to inform future research outside of clinical trials and I am happy for it do so.
- 7. I consent for my child's 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 my child.
- 9. 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.
- 10. I am happy to consent on behalf of my child to be included in this registry.

Name of Patient

Name of Parent

Date

