

CONSENT FORM FOR PARENTS/ CARERS

Centre SAL/ MAN/ B'HAM/ CAM/ GOSH/ RF/ ICH

national collaborative study of lysosomal storage disorders

Title of Project: A study to investigate the natural history, effectiveness and cost effectiveness of current and emerging treatment options for people with lysosomal storage disorders

Name of Chief Investigator: Professor Stuart Logan Name of Principle Investigator: Please add in clinician

Study Number:

- I confirm that I have read and understand the information leaflet (dated xx/xx/xx) for the above study and have had the opportunity to ask questions.
- 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 my or my child's medical care or other legal rights being affected.
- 3. I understand that sections of any of my child's medical notes may be looked at by responsible individuals from the NCS-LSD Team, for the purpose of extracting material for incorporation in the proposed database, or from regulatory authorities. I give permission for these individuals to have access to my child's records.
- 4. I agree to my childs information being collected **<u>but do not wish</u>** to complete any additional questionnaires.
- 5. I give permission for my child's GP to be informed of their participation in this study.
- 6. I agree for my child to take part in this research.

Name of Child		
Name of Parent	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

3 copies: 1 for parent; 1 for researcher; 1 to be kept with hospital notes LSD_Con, Appendix 8B, Version 3: 15-11-08

Please initial box