UCL INSTITUTE OF CHILD HEALTH

Great Ormond Street Hospital for Children NHS Foundation Trust

Study Number:

Patient Identification Number for this trial:

CONSENT FORM FOR PARENTS/GUARDIANS

Participant consent form for*: Molecular genetics of human birth defects*

Name of Researcher: Prof Peter Scambler and Prof Philip Beales

Please initial box

1. I confirm that I have read and understand the information sheets **dated 20.09.13** Version 4 or **12.01.15** Version 5 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 them at any time without giving any reason, without my/my child's medical care or legal rights being affected. I understand that the results of the study and any extracted DNA or cell lines already made prior to withdrawal of consent, will be kept and shared with other researchers around the world. ☐

3. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from UCL Institute of Child Health, Great Ormond Street Hospital NHS Foundation Trust, or from regulatory authorities where it is relevant to my child's taking part in this research. I give permission for these individuals to have access to my child's records, and for my child's anonymised data to be stored securely in line with standard data protection procedures as registered for this project. ☐

4. I agree for my child's DNA, cell lines and other samples relevant to the study to be stored at UCL Institute of Child Health. I understand that DNA and cell lines will be shared with other researchers around the world as detailed in the information sheet. ☐

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5. I agree to my child's GP being informed of my child's participation in the study. ☐

6. I agree for my child ……to take part in the above study. ☐

7. I agree that *anonymised* genetic information about my child may be included in research into future drug development or for the delivery of personalised medicine (e.g. response to medication based on an individual's genetic code). ☐

8. I consent for the following samples to be taken (please tick box):

☐ Blood sample ☐ Nasal brushing ☐ Urine sample ☐ Other (please specify)…….

☐ Skin Biopsy ☐ Saliva sample ☐ Hair follicle extraction

I also understand that the research project might discover incidental genetic errors in other genes not related to the condition/birth disorder being studied.

I therefore: –

DO / DO NOT (delete as appropriate) wish to be informed of significant additional genetic errors in genes not related to the condition/birth disorder being studied that may have the potential to affect my/the future health of my family.

_____	_____	_____
Name of Parent /Guardian	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

When completed: one copy for parent/guardian; one copy for research site file; one (original) to be kept in medical notes.

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