



Study Number:

Patient Identification Number for this trial:

CONSENT FORM FOR ADULTS

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 sheet **dated 20.09.13**
Version 4 or **12.1.15** 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 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. 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 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 taking part in this
research. I give permission for these individuals to have access to my records, and for my
anonymised data to be stored securely in line with standard data protection procedures as
registered for this project.

☐

4. I agree for my 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 GP being informed of my participation in the study.

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☐

6. I agree to take part in the above study.

7. I agree that *anonymised* genetic information about me 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 Participant

Date

Signature

Name of Person
taking consent

Date

Signature

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