Reference: centre/reference no.

Consent form: Research Study: Imprinting disorders, finding out why?

Please initial boxes where applicable.

- 1. I confirm that I have read and understood the information sheet (leaflet version....., please complete) 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 my child from the study at any time, without giving any reason, without my medical care or legal rights being affected.
- 3. I am willing for my General Practitioner to be informed of any relevant medical information obtained about my child as part of the study
- 4. I agree to the use of a stored sample of blood/ saliva/ skin sample from my child in this research project, or to the use of a new blood/ saliva/ skin sample obtained from my child for the purpose of this research project
- 5. I agree that part of the same DNA sample may be sent to collaborators including those working **in other parts of the United Kingdom and abroad** provided that no clinical or identfying information are sent
- 6. I understand that genetic information <u>relating to imprinting disorders</u> about my child may become available from this research.
 - (a) I would like to be notified of these results
 - (b) I would <u>not</u> like to be notified of these results
- 7. In the event that a new imprinting problem is found, I agree for further studies on the sample to define the precise extent and significance of the change
- 8. I give permission for publication of results of genetic analysis and brief medical information (<u>not</u> photographs or details that would allow identification) about my child in a medical journal
- 9. I give permission for my childs medical notes to be seen by the study researchers
- 10. I agree that my child may participate in the study

Name of child

Name of parent/guardian

Date

Signature

Name of clinician obtaining consent

Date

Signature

PTO

Future and Further Research

Please initial boxes where applicable

Part B Consent for Related Genetic Research

I am willing for my child's DNA sample to be used for further related research provided that it has been approved by a research ethics committee. This may include genetic research. This will be linked to the clinical information but will be anonymised. I understand that this will mean that I cannot be contacted with any results.

Part C Further unrelated research on the DNA sample

I am willing for my child's DNA sample to be used anonymously for any research project provided that it has been approved by a research ethics committee. This will be unlinked to clinical information and will be anonymous. I understand that this will mean that I cannot be contacted with any results

Part D Future research projects

I am happy to be contacted about future Wessex Genetics research projects

Name of child	Date of birth of child	
Name of parent/guardian	Date	Signature
Name of clinician obtaining consent	Date	Signature
Research ethics number07/H0502	/85	

3 copies required: top copy for researcher; one copy for participant and one copy for medical notes