Institute of Child Health

Great Ormond Street Hospital for Children NHS Trust

Young Epilepsy

PARENTAL CONSENT FORM

Study Protocol Number: 11NR31

Patient Identification Number for this trial:

Title of project: Epilepsy in Infancy

Researchers: Professor J. Helen Cross, Dr Manju Kurian, Professor Rod Scott, Dr Michelle de Haan, Dr Finbar O'Callaghan, Dr Christin Eltze, Dr Elaine Hughes

(Please initial box

1. I confirm that I have read and understand the information sheet 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 participation of my child in the study is voluntary and that we are free to withdraw at any time without giving any reason, without his/her medical care or legal rights being affected. ☐

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 regulatory authorities or from the NHS Trust, 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. ☐

4. I agree to my child's GP, paediatrician and/or neurologist being informed of his/her participation in the study. ☐

5. I agree for my child's blood and DNA sample to be taken once at a routine clinic visit and stored for the purpose of this study. ☐

6. I understand it would be of additional benefit to obtain a further sample from parents. I agree for my DNA sample to be taken once and stored for the purpose of this study. ☐

7. I understand it would be of additional benefit to obtain a further sample from unaffected siblings. I agree for DNA sample(s) to be taken once from my unaffected child/children for the purpose of this study. ☐

8. I agree for the samples to be stored for twenty five years allowing future ethically approved research in this field, with the potential for advances in the treatment of childhood epilepsy. ☐

9. I understand a centralised registry will be used by local paediatricians, who will record and map management of my child from point of diagnosis. This will encompass information on clinical, neurodevelopmental, behavioural, and sleep assessments, as well as EEG, MRI and other investigations. Data will then be analysed by the central research team. ☐

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10. I understand that progress including seizure frequency, seizure types and any further investigations performed will be collected again at 12 months and 2 years. This will include further neurodevelopmental assessment. ☐

11. I understand that I may be contacted about further follow-up in future. ☐

12. I give consent for …… to take part in the above study. ☐

_____	_____	_____
Name of parent & relationship with the study subject	**Date**	**Signature**
_____	_____	_____
Name of person taking consent	**Date**	**Signature**

When completed, 1 copy for patient; 1 copy for researcher site file; 1 copy (original) to be kept in medical notes.