

13. Parent/Guardian Consent

Study Title: Genetic Basis of Epilepsy

I have been invited to provide permission for _____ to participate in the above study, which is being conducted under the direction of Professor Ingrid Scheffer and Professor Sam Berkovic. I understand that while the study will be under their supervision, other relevant and appropriate persons may assist or act on their behalf.

I have read, or have had read to me in a language that I understand, this document and I understand the purposes, procedures and risks of this research project as described within it.

I give permission for _____'s doctors, other health professionals, hospitals or laboratories outside this hospital to release information to the Epilepsy Research Centre, University of Melbourne, concerning their disease and treatment that is needed for this project. I understand that such information will remain confidential.

I consent to the publishing of results from this study provided my child's personal identifying information is not included. I understand that their family tree and detailed medical information may be included and in rare circumstances, it may be possible for someone to identify them.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I give my permission for _____ to participate in this research project according to the conditions as outlined in this document.

I understand that I will be given a signed copy of this document to keep.

Optional consent:

- I agree to the collection and storage of _____'s DNA sample and to the use of this DNA sample for genetic testing as outlined in this document.
- I agree to some of _____'s blood sample being used to grow a cell culture.
- I agree to _____'s deidentified genetic information being released to researchers who are working independently from the Epilepsy Research Centre as described in section 4.

Participant's name (printed): _____

Name of person giving consent (printed): _____

Relationship to participant: _____

Signature: _____ Date: _____

Name of witness to parent/guardian's signature (printed): _____

Signature (Witness): _____ Date: _____

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's name (printed): _____

Signature: _____ Date: _____

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the consent section must date their own signature.