STANFORD UNIVERSITY Research Information Sheet

Protocol Director: Brenda E. Porter

IRB Use Only
Approval Date: ***
Expiration Date: ***

Protocol Title: Pediatric Epilepsy Surgery: Decision-Making Survey

DESCRIPTION: You are invited to participate in a research study on pediatric epilepsy surgery decision-making. We would like to understand which factors are most important to families when deciding whether their child will undergo epilepsy surgery. You do NOT have to participate in this current project. We will use this information to help physicians more effectively assist caregivers with making surgical decisions for their children and aid in the development of useful informational tools for parents. You will be asked to take a survey about your experience with epilepsy surgery. If your child had previously participated in a Tuberous Sclerosis study on neurodevelopmental outcomes your responses may be compared to the neurodevelopmental outcome your child had in the study. You still can participate even if your child has never been in any prior research studies.

TIME INVOLVEMENT: Your participation will take approximately 15 minutes.

RISKS AND BENEFITS: There are no foreseeable risks associated with this study. The benefits that may reasonably be expected to result from this study are a more effective parent-physician conversation and/or better informational aids that help parents more fully understand the process of epilepsy surgery. We cannot and do not guarantee or promise that you will receive any benefits from this study. Your decision whether or not to participate in this study will not affect your medical care.

PAYMENTS: You will receive no payment for your participation.

SUBJECT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The alternative is not to participate. You have the right to refuse to answer particular questions. Your individual privacy will be maintained in all published and written data resulting from the study.

CONTACT INFORMATION:
Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the Protocol Director, Brenda E. Porter, at (650) 724-4179.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the Stanford Institutional Review Board (IRB) to speak to someone independent of the research team at (650)-723-2480 or toll free at 1-866-680-2906. You can also write to the Stanford IRB, Stanford University, 3000 El Camino Real, Five Palo Alto Square, 4th Floor, Palo Alto, CA 94306.

Please print a copy of this page for your records.

If you agree to participate in this research, please complete the following survey.