**Survey Request: Informing Choice for Neurotechnological Innovation in**

**Pediatric Epilepsy Surgery**

You are invited to participate in this survey about how parents and caregivers of children with drug resistant epilepsy (DRE) make choices about treatments that involve neurotechnologies. Neurotechnologies are interventions that use energy to stimulate the brain or monitor from it. Some are described [in this video](https://www.youtube.com/watch?v=bxe3u0D_k0Y).

The questions in this survey were developed from discussions we had with parents and caregivers of children with DRE from Canada and the USA in focus groups and interviews.

This survey has received ethics approval (H18-02783). Full study details are below and in the survey. Participation in our survey is voluntary and completely confidential, and will take 20-30 minutes. Click [here](https://dcida2.cheos.ubc.ca/#/decision_aid/DRE2_caregiver) to take the survey.

[**Take the Survey Now**](https://dcida2.cheos.ubc.ca/#/decision_aid/DRE2_caregiver)

Best regards,

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Study details

**Who is conducting the study?**

Neuroethics Canada at the University of British Columbia (UBC) along with researchers across Canada and the USA.

**Who can participate in this study?**

You are invited to participate because you are a parent or caregiver of a child with epilepsy that has not responded to medication - we call this drug resistant epilepsy or DRE.

**Why is this survey being carried out?**  
The results of the survey will help us to understand what is most important to parents and caregivers when making decisions about using neurotechnologies to treat epilepsy in children with DRE. We will also be using the results to develop resources to support parent and caregiver decision making.

**What does participation in the survey involve?**  
The survey should take between 20-30 minutes to complete. It includes questions about yourself and your child, and then asks you to make some choices between different treatment options for pediatric drug-related epilepsy. You will be asked to choose the option you prefer.

**Are there any potential risks to taking part?**  
We do not anticipate any risks to you.

**Are there any potential benefits to taking part?**

There are no direct benefits to you, but you will be giving valuable information to the researchers and contributing to epilepsy treatment research.

**Will my taking part be kept confidential?**  
All information collected about you during the course of the research will be kept **strictly confidential.**  The data will be stored on secure network servers and will remain in Canada at all times. The information you give will not be used in any way that could identify you. When results of the survey are published, you will not be identified in any way.

**What will happen to the results of the research project?**  
The results of this study will be published in academic journals and professional meetings, and will be summarized on websites associated with UBC and its collaborators.

**Who can I contact if I have questions or concerns about the study?**  
If you have any questions or need additional information about the study, please contact Dr. Judy Illes at (604) 822- 0746. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

**Consent to Participate**

I understand that my participation in answering this survey is voluntary and that I am free to withdraw at any time by exiting the survey without having to give a reason and without penalty.

I understand that data I provide will be treated securely and kept confidential. My responses will be anonymized before analysis. Only the project team will have access to my responses.

By clicking "Next" and completing the survey, you are giving consent.