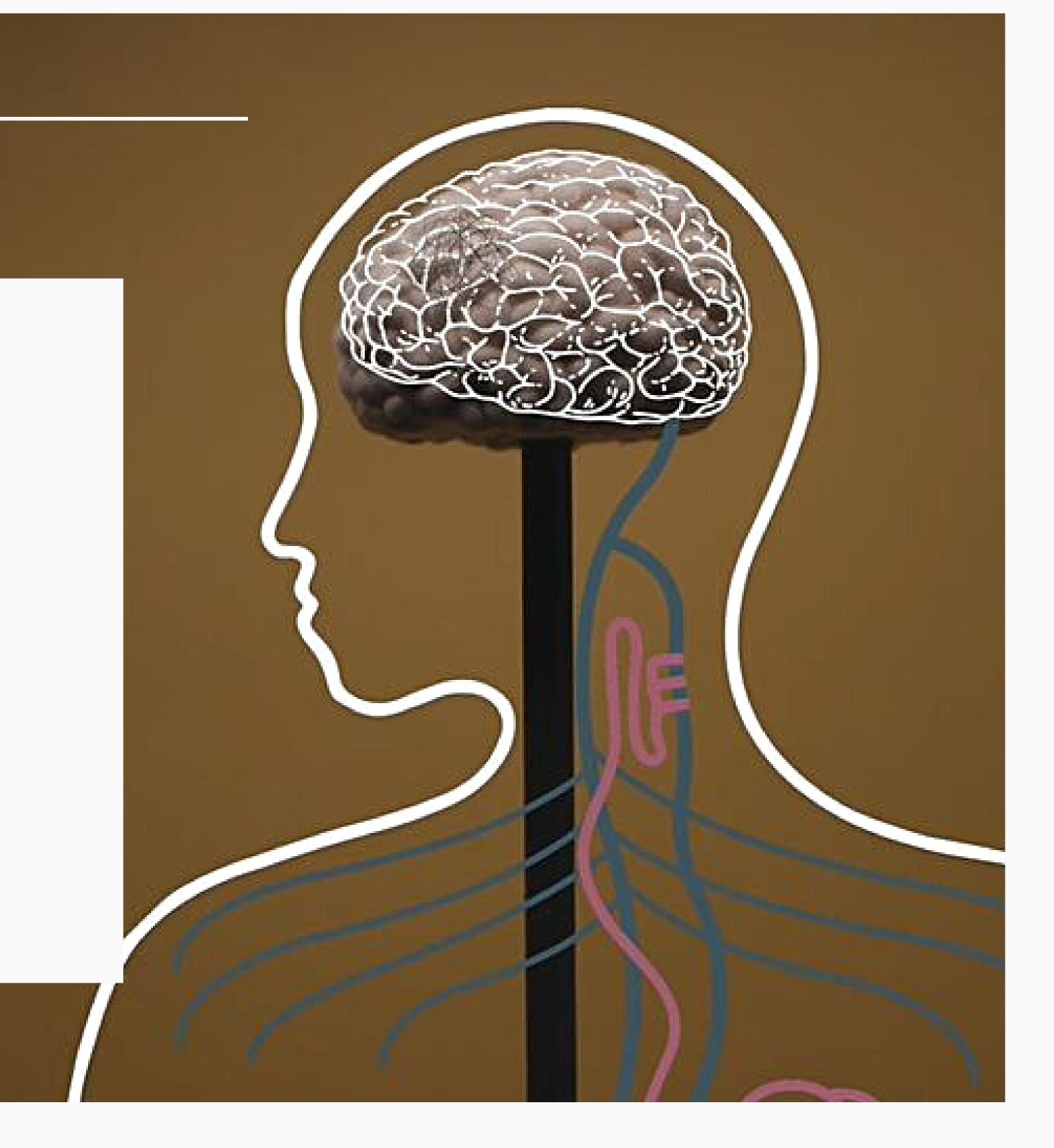
SEIZING HOPE

High Tech Journeys in Pediatric Epilepsy









FILM INFORMATION

Families with children suffering from pediatric drug resistant epilepsy (DRE) face complex realities. In a world guided by the promises of technology, the goal of Seizing Hope is to raise awareness about the options offered by different technologies specifically for the brain in complement or as an alternative to treatment with medication. As the directors and producers of this mini-documentary, we want to empower and improve decision-making by exploring values and priorities through the lens of the families and doctors who care for them. We compiled the stories of four families with children who have pediatric DRE to shed light on their hope, trust, and empowerment journey.

The views and research presented in this documentary represent a multi-year neuroethics project funded by the National Institute of Mental Health of the USA National Institutes of Health, BRAIN Initiative.

Contact Information

Judy Illes, CM, PhD
Director, Neuroethics Canada
jilles@mail.ubc.ca
+1 604 822 0746

Johann Roduit, PhD Conexkt Ltd. johann@conexkt.world +1 604 721 6544

Marianne Bacani, CMP Events and Operations Director, Neuroethics Canada bacanim@mail.ubc.ca +1 604 822 7920

Technical Information

Running Time: 30 minutes Genre: Mini-documentary

Subtitles: English, French, Spanish

Year of Production: 2021 Links: <u>seizinghopefilm.com</u>

VIEWING THE FILM WITH STUDENTS

The following three sections offer you a range of activities that can be completed before, during, and after the film. You will also find follow-up questions based on the themes of the film, and links to resources for further research or discussion.

Pre Viewing Activities

- Show students the trailer and posters on the website for the film.
- Separate students into small groups to discuss themes and ideas.

Viewing Activities

• Have the students take note of the film for discussion or questions

Post Viewing Activities

Have students write a note that communicates something they have learned, felt, or decided from watching this film. Consider these prompts:

- Something they have learned.
- Something they are still wondering about.
- How did they feel before and after watching the film?
- Did their ideas about epilepsy or technology for the brain in the film change after watching it?
- What did they think the main ideas of the film were before watching it? What were they after? Did they change?

DISCUSSION TOPICS

Online Resources

- Neuroethics Canada Resources on Neuroethics and Pediatric Epilepsy
- Novel Epilepsy Treatments: Factors That Matter the Most to Parents and Doctors
- The BRAIN Initiative 2.0: From Cells to Circuits, Toward Cures

Discussion Points (Highschool)

- What is pediatric DRE? What are seizures?
- What are the different types of treatments for pediatric DRE?
- What are some of the possible side effects of medication that treat epilepsy?
- What factors do parents consider when thinking about brain technology?
- How can doctors gain the trust of parents with kids suffering from DRE?
- Why is bringing awareness to DRE and its treatment options important?

Discussion Points (Post-secondary)

- What are some of the common seizure types? What are its effects and how might they affect a child growing up?
- What is the process of diagnosing children with DRE?
- What are the different types of treatments for pediatric DRE?
- What are the factors families and doctors need to consider to determine which treatment option for a child?
- What are the ethical and legal implications of neurotechnology?
- How can doctors gain and preserve trust when presenting the treatment options to parents with kids suffering from DRE?

CREDITS

Executive Producers: Dr. Judy Illes, Dr. Patrick McDonald

Producer: Dr. Johann Roduit

Director: Adam Wormald

Film Production: Cassiar Film Co

This film was made possible by a grant from the National Institutes of Health/National Institute on Mental Health, #RF1 MH11780501, a special initiative on ethical, social, and legal considerations for advanced technologies for the brain.

We also gratefully acknowledge ongoing support for neuroethics research, education, and outreach from the Vancouver Coastal Health Research Institute, the Canadian Institutes of Health, the New Frontiers in Research Fund, the North Family Foundation, the Dana Foundation, and the UBC President's Office and other internal University of British Columbia Programs.

Dr. Illes held the Canada Research Chair in Neuroethics during the project. Dr. McDonald held the Alcan Chair in Neuroscience at UBC (2016-2021) and was the Head of Pediatric Neurosurgery at BC Children's Hospital during this project.

Many thanks to the team at Neuroethics Canada, Advisory Board members, collaborators and colleagues, and patients and families who work tirelessly on our initiatives with us.

COI Statement

The faculty experts describe the use of neurotechnology throughout the film. None have a financial interest in any of the devices discussed.

Special thanks to

Kallysta and the Bagg Family
Sophie and the Cowin Family
Callie and Lorrie Chartrand
Kaydance Thompson and Heather Carnie

COVID Safety Statement

All filming was done in compliance with public health and safety guidance for COVID-19.

Seizing Hope was filmed on the traditional, ancestral, and unceded lands of the Musqueam (x\sim \theta \theta \cdot \theta \thet