

PRESS KIT

SEIZING HOPE

High Tech Journeys in
Pediatric Epilepsy





FILM INFORMATION

Film Title

Seizing Hope– High Tech Journeys in Pediatric Epilepsy

Logline

Can new technology bring hope to children who have drug-resistant epilepsy?

Technical Information

Running Time: 30 minutes

Genre: Mini-documentary

Subtitles: English, French, Spanish

Year of Production: 2021

Links: www.seizinghopefilm.com

Contact Information

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

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

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



SYNOPSIS

Short Synopsis

This mini-documentary is a story about hope for children and their families in mitigating and treating pediatric drug resistant epilepsy (DRE). It is a story about how families learn to trust their medical team, educate them, and help them consider neurotechnology options for their child. It is a story about empowerment as loved ones shed light on the ethical factors that led to their decisions. In doing so, they empower other families that face similar challenges to theirs.

It is a story of how children and families affected by DRE can seize hope in times of darkness for a better quality of life.

The film may be viewed in English with subtitles in French or Spanish.

Long Synopsis

More than 500,000 children in Canada and the USA have epilepsy. About a third of those children continue to have seizures despite taking anti-seizure medications, also known as pediatric drug resistant epilepsy (DRE).

Surgery may be one option for them, but what if there is another option that is less invasive or more effective?

Seizing Hope documents the stories of four Canadian families in their journey to learn, understand, and explore the ethical trade-offs and decision-making values around modern technology for the brain. They guide us through their journey towards hope, trust, and empowerment in times of darkness for a better quality of life for their children who have DRE. By addressing gaps in knowledge and considerations that involve values, priorities, and trust, we identify critical decision-making factors surrounding neurotechnologies and the pathway to their adoption for pediatric DRE.

EXECUTIVE PRODUCER STATEMENTS

I always had a fascination with how people behave and express themselves: how we speak, attract, value, and accept. I did my Ph.D. at Stanford University. I studied how electrical and blood flow signals from the brain can inform what researchers understand about human behaviour, and I worked on translating that knowledge into care for people with brain disorders and a better understanding of brain disorders by the public. In 1995, I co-founded what we then called the Stanford Center for Brain Research. I realized that while neuroscientists were paying attention to the technology, only a handful of people were thinking explicitly about the ethical implications of imaging and modulating the brain's many functions. I knew this was a new and exciting space for the Center and me professionally.

I aim to encourage accountability and communication in this neuroethics space that spans neuroscience and ethics. I hope that Seizing Hope is a starting point for neuroscientists, doctors, and patients to communicate and mutually understand one another's values, priorities, and needs.

- Dr. Judy Illes

As a trained neurosurgeon, I obtained my Master of Health Science at the Joint Centre for Bioethics, University of Toronto, in bioethics in 2004. I practiced in Manitoba as the only pediatric neurosurgeon at the Winnipeg Children's Hospital for 13 years. I then spent 5 years at BC Children's Hospital in Vancouver and as a professor at Neuroethics Canada at the University of British Columbia. In 2021, I returned to Winnipeg to lead the Division of Neurosurgery at the University of Manitoba. For 20 years, I have combined the practice of caring for children with neurological illnesses with interest in neuroethical issues that surround that care. It is crucial to consider the ethical implications of novel technologies, especially in vulnerable populations like children.

My hope for the documentary is to educate families with children who have epilepsy about the different neurotechnologies available, their benefits and risks, and how they can impact their child's life.

- Dr. Patrick McDonald

SCIENCE COMMUNICATOR STATEMENTS

I believe in bridging the gap between scientific research and ethics and finding creative methods to convey findings to the general public. When researchers communicate effectively with their peers, it brings awareness and understanding to their studies and encourages informed decision-making for everyone: researchers, governments, and individuals. That is the intention behind using a documentary format. I wanted to create a dialogue through an engaging, informative, and in-depth resource. By showcasing real people- real families- I hope that Seizing Hope can spark meaningful conversation around ethics, values, and research on the landscape of constantly evolving neurotechnologies.

- Dr. Johann Roduit

My partners and I at Cassiar Film Co. are always looking for opportunities to tell stories that have real-world impact. Before I start any project, I try to understand the viewer and how they will receive it. I want them to see and hear themselves in the story. That is why it was so important to really spend time with these four families and give them time and space to share their stories. I hope that any family who is going through a journey with epilepsy will watch this film and feel heard, and understood and that there are other families who have gone before them. Ultimately, though, our desire is that they find hope.

- Adam Wormald

BIOS: EXPERTS



Dr. Judy Illes

Dr. Judy Illes is a Professor of Neurology, Distinguished University Scholar, and UBC Distinguished Scholar in Neuroethics at the University of British Columbia (UBC). She is Director of Neuroethics Canada at UBC, and faculty in the Brain Research Centre and the Vancouver Coastal Health Research Institute. Illes' research focuses on the ethical, legal, social and policy challenges specifically at the intersection of the neurosciences and biomedical ethics. She has made groundbreaking contributions to neuroethical thinking for neuroscience discovery, clinical translation, and the commercialization of health care. In 2017, Illes was appointed to the Order of Canada, one of the country's highest recognitions of its citizens.



Dr. Patrick McDonald

Dr. McDonald is the Head of the Section of Neurosurgery at the University of Manitoba in Winnipeg and an Associate Professor in the Department of Surgery at both the U of M and the University of British Columbia. He was born, raised and trained in Toronto, obtaining his medical degree and pursuing neurosurgical training at the University of Toronto. After a fellowship as Chief Clinical Fellow in Neurosurgery at the Hospital for Sick Children, he obtained a Masters degree from the Joint Centre for Bioethics at U of T. In 2016, he relocated to Vancouver to be the Head of Neurosurgery at BC Children's Hospital and a faculty position at Neuroethics Canada. He has recently returned to Winnipeg as the Chair of the Section of Neurosurgery at the University of Manitoba and retains his association with Neuroethics Canada. His research focuses on ethical issues in the adoption of innovative neurosurgical procedures, especially neurotechnologies, and outcomes in pediatric epilepsy and hydrocephalus.

BIOS: COLLABORATING EXPERTS



Dr. George Ibrahim

Dr. George Ibrahim is a pediatric neurosurgeon at The Hospital for Sick Children (SickKids) and an Associate Professor in Biomedical Engineering at the Institute of Medical Sciences, and the Department of Surgery at the University of Toronto. His clinical and research interests include the surgical treatment of medically intractable epilepsy, spasticity and functional disorders in children.



Dr. Robert Naftel

Dr. Robert Naftel is an Assistant Professor of Neurological Surgery at Vanderbilt University. His clinical and research interests include pediatric epilepsy hydrocephalus, brain tumours, and pediatric vascular disorders. His work also focuses on patient satisfaction, patient education, and the use of technology and social media for patient outreach.



Dr. Mary Connolly

Dr. Mary Connolly is Director of the Epilepsy Surgery Program, BC Children's Hospital Division Head, Division of Neurology, Department of Pediatrics at the University of British Columbia. Her research centers on pediatric neurology with a primary focus on epilepsy.



Dr. Winston Chiong

Dr. Winston Chiong is an Associate Professor of Neurology and Interim Director of the University of California, San Francisco (UCSF) Bioethics. He studies the ethical, policy and health equity implications of alterations to brain function informed by the experiences of patients with brain diseases and those undergoing new brain-based therapies. He serves on the Neuroethics Working Group of the National Institutes of Health (NIH) BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Working Group.

BIOS: SCIENCE COMMUNICATORS



Johann Roduit- Producer

Dr. Johann Roduit is a founding partner of Conexkt, a Certified B Corp innovation studio. Through his work, he fulfills his commitment to integrating ethics into the heart of technology, innovation, and design. Johann holds a Ph.D. in Biomedical Ethics and Law from the University of Zurich, and has previously worked in the University's Institute for Biomedical Ethics. He uses his expertise in ethics, science communication, and innovation to help clients positively impact their community.



Adam Wormald- Director

Adam Wormald is a filmmaker who believes that nothing cuts to the core of human emotions like a well-told story. His company, Cassiar Film Co, helps businesses and organizations harness the power of video to inspire, educate, and entertain. He loves the challenge of taking complex ideas and making them accessible to a wide audience.

BIOS: CAST

The Bagg Family

The Bagg family is located in northern British Columbia, Canada. Since birth, Kallysta Bagg has had epilepsy stemming from hypoxia, with low amounts of oxygen in the body tissues. At 15 months old, she had her first seizure, and her second seizure came a few months later. Medication like Keppra, widely used for epilepsy, provided Kallysta and her family with no relief as her attacks began to occur every day, never stopping on their own.

The Bagg family looked towards another option, vagus nerve stimulation (VNS), a “pacemaker for the brain.” In 2020, they proceeded with the VNS surgery. Kallysta is now five years old, and her seizures happen once a month.

Kallysta Bagg and her family partook in Seizing Hope to encourage other families to do their research and communicate to others to trust their doctors, to empower them in their decision-making.



BIOS: CAST



The Chartrand Family

On April 5th, 2014, life for 8-year-old Callie Chartrand and her family changed. Callie was sick with flu-like symptoms and was taken to the hospital after her first seizure. The family learned that the Herpes Simplex Virus Type 1 attacked her brain. Medications did not work. After several considerations, the family flew to Calgary for surgery that was enabled by a robotic procedure to stop the seizures.

Callie Chartrand's mother Lorie, wants Seizing Hope to become a starting point for people to learn to advocate for their children, start a conversation on the treatments of epilepsy and, most importantly, show love, support, and kindness.

BIOS: CAST

The Thompson Family

Kaydance Thompson was 3.5 when she suffered her first seizure. From then on, she would experience 30 grand mal seizures a day. She would not recognize her mom, and could not talk or walk. Medication did not improve her seizures. Kaydance underwent various treatments for her seizures.

Kaydance, and her mother and aunt, share their story on Seizing Hope with the hope of helping and inspiring other families that face similar situations and challenges. They aim to encourage conversation about choice, trust, and neurotechnology available to patients with pediatric DRE.



BIOS: CAST



The Cowin Family

Eight years into her life, Sophie Cowin experienced her first seizure. Unlike the convulsing most seizure patients experience, Sophie has complex febrile seizures. This condition is especially threatening as it causes a person's body temperature to sink very low. Treatment solely with medication was not an option for Sophie; she opted in for neurotechnology available only at a few centers worldwide.

Sophie and her family walk us through hardships and hopes for drug resistant epilepsy.

CREDITS

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

Producer: Dr. Johann Roduit

Director: Adam Wormald

Film Production: Cassiar Film Co

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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 (xʷməθkʷəy̓əm) Nation in the University of British Columbia Vancouver, the Musqueam(xʷməθkʷəy̓əm), Squamish (Sḵwxwú7mesh), and Tsleil-Waututh (Seíí/witulh) Nations in the City of Vancouver, Očhéthi Šakówiŋ, Michif Piyii (Métis), and Anishinabewaki Nations in Winnipeg, the Očhéthi Šakówiŋ, Michif Piyii (Métis), Cree, and Anishinabewaki Nations in Kleefeld, and the Anishinabewaki, Mississauga, Haudenosaunee (Ho-de-no-sau-nee-ga), and the Wendake-Nionwentsio Nations in Oshawa and the City of Toronto.