

## Call for Proposal (CFP) – Submission Section A

(DUE: Thursday, April 1, 2021, at 5:00pm EST)

<b>Name of Hospital Foundation</b>	
Children's Health Foundation	
<b>PRIMARY submission contact</b>	
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<b>Name of the Initiative (could include program, project, seed funding, research, etc.) (max word count: 25)</b>	
Establishing a New Standard of Care for Paediatric Epilepsy Patients	
<b>Initiative URL (if applicable)</b>	
<a href="#">Establishing a New Standard of Care for Paediatric Epilepsy Patients   Children's Health Foundation (childhealth.ca)</a>	
<b>Please identify which of the following 6 pressing priorities within adolescent health the initiative will address:</b>	
1. Mental Health	<i>Yes, young people with epilepsy have a greater risk of mental illness than their healthy peers or even youth with other chronic disorders, such as diabetes. Rates of anxiety and depression are particularly high among this population. Additionally, suicide rates are five times higher than the average. Epilepsy patients struggle with the stigma associated with having seizures and experience fears about brain damage or death. This project will support improved care for the most severely impacted epilepsy patients, to help them live life fully. Patients who are part of the Comprehensive Epilepsy Clinic will have access to a clinical neuropsychologist who provides feedback to patients and their families, as well as to other members of the Epilepsy Team and consultation with schools may be provided. In addition, patients have access to specialized mindfulness training designed for young epilepsy patients.</i>

<p>2. Relationships with Food</p>	<p><i>Yes, young people with epilepsy have an increased risk of an eating disorder and poor-quality diet. Managing epilepsy also involves improving relationships with food. Children's Hospital has increased the capability of the Ketogenic Dietary services with currently over 30 children who have been part of the program in the last two years. The team will be creating educational videos for families to educate and explain the diet. Dr. Maryam Nouri and the dietician are also leading the Children's, LHSC site for the EpLink provincial research collaboration in the ketogenic diet group.</i></p>
<p>3. Sexual and Reproductive Health</p>	<p><i>Yes, epilepsy may influence sexual function and behavior and medications can impact hormones. Developmental delays, stigma and other factors play a part in developing healthy sexual and reproductive health. The social worker and epilepsy educator support young patients through these questions and families when seeking community support. Genetic testing and counselling are available through the epilepsy clinic.</i></p>
<p>4. Gender Identity</p>	
<p>5. Chronic Conditions</p>	<p><i>Yes, the World Health Organization (WHO) defines epilepsy as, "a chronic noncommunicable disease of the brain. It is characterized by recurrent seizures. Seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions. Seizures can also vary in frequency, from less than 1 per year to several per day." Epilepsy is one of the most common neurological conditions in the paediatric population, with an estimated 15,000 children in Ontario. Drug resistant epilepsy occurs when a child has failed at least two well-chosen and well tolerated antiepileptic drugs and may require nonpharmacological therapies. Thirty percent of epilepsy patients have drug resistant epilepsy. Young patients with epilepsy are more likely to have psychological problems, especially depression, anxiety and suicidal thoughts and</i></p>

	<p><i>behaviors. Problems may be a result of difficulties dealing with the condition itself as well as medication side effects.</i></p> <p><i>At Children's Hospital treating epilepsy has a range of approaches including psychosocial care. The clinical services available to young patients and families at Children's Hospital include: paediatric epilepsy monitoring unit; the comprehensive epilepsy clinic; genetic counselling; the shared decision making coach; the epilepsy surgery program; and the ketogenic diet and dietician. As well, the program is active with project ECHO, epilepsy across the life span.</i></p>
<p>6. Transition to Adult Care</p>	<p><i>Yes, adolescence is a crucial time with many changes, including critical thinking, cognitive skills, and autonomy (individual choice), all of which make for a complicated jump to adult life. An adolescent person with epilepsy may face additional challenges. The Transition Clinic is a process that prepares patients 16-18 years old and their families for 'adult' health care and assists in navigating the adult health care world. Children's Hospital's Paediatric Epilepsy program uses an evidence-based approach and has two types of transition clinics – one for patients who respond to medication and the second transition clinic is the Epilepsy Transition Clinic for youth who have been diagnosed with drug resistant epilepsy and are seen within the Comprehensive Epilepsy Clinic. They meet an Adult Epileptologist (Physician), Transition Specialist, and Paediatric Social Worker to discuss how treatment will look in the adult world and what extra supports are needed in the upcoming years to fully participate at home, in school and in the community.</i></p>
<p><b>Please provide a brief summary of the initiative. (max word count: 150)</b></p>	
<p>Epilepsy is a serious neurological chronic condition that negatively impact a young person's quality of life and development. Children's Hospital's Paediatric Epilepsy Program plans to expand its treatment for patients who have severe epilepsy and aims to establish a new surgical standard of care that has proven successful with patients aged 10-18 years.</p>	

New technology is available to guide treatment for children with drug resistant epilepsy. Children's Hospital is ready to bring robot-assisted stereo-electroencephalography (SEEG), a standard of care in the United States and Europe, to our Regional Epilepsy Surgery Centre of Excellence in Ontario.

The Paediatric Epilepsy Program has the exceptional leadership, multidisciplinary team, evidence and patient-family support program to expand its clinical capacity for this growing group of young epilepsy patients to have the chance to be cured of seizures. It will be a new standard of care with transformational health outcomes for young patients and families.

**What is the need or opportunity addressed by this initiative? How is this initiative going to address that need? (max word count: 350)**

Epilepsy is more common than we might think – one in 100 Canadians have the chronic condition. In Ontario, this equates to 95,000 people with epilepsy, with 15,000 under age 18. Epilepsy is concerning in young people because their brains are still developing and seizures can be damaging, resulting in behavioural problems, intellectual disabilities and a greatly reduced quality of life. Young people with epilepsy are also more likely to struggle with mental health issues than their peers. Some patients outgrow their seizures, others use medication to control the condition but 30% have drug resistant epilepsy.

Children's Hospital receives patient referrals from other hospitals, health centres and family doctor offices across Ontario. Drug resistant epilepsy occurs when a patient has failed at least two antiepileptic drugs. Ethan is an example of a patient with drug resistant epilepsy. His seizures escalated until he experienced three straight days of 15 to 20 second seizures, every couple of minutes. Surgery can be the best option for youth, like Ethan, providing favourable outcomes, long-term effectiveness and decreased health care use compared with ongoing medical management. Understandably, families often consider surgery a last resort because they overestimate the risks. Children's Hospital has made it a priority to establish a new surgical standard of care for drug resistant epilepsy patients. Children's Health Foundation is raising funds for the state-of-the-art "ROSA" SEEG robot and vital epilepsy patient and family supports estimated at \$930,000.

As one of two Regional Epilepsy Surgery Centres of Excellence in Ontario it is vital to offer the highest level of surgical care to ensure the best outcomes for patients and instill confidence when families are deciding whether their child should undergo brain surgery.

SEEG helps determine where seizures are originating from and if a patient is a good candidate for epilepsy surgery. Robot-assisted SEEG is minimally invasive, reduces the risk of complications and significantly decreases surgical time and the use of medical resources. Without robotics, an invasive procedure is required and involves opening the patient's skull. Children's Hospital will be the first paediatric centre in Ontario to have this technology available for epilepsy patients.