



Pre-Budget Submission to the Government of Ontario

Submitted December 2018

epilepsy
ontario



Epilepsy And Seizures

Epilepsy is a neurological disease characterized by recurrent seizures. Seizures can take a variety of forms depending on what part, and how much, of the brain is causing the seizure to take place. Once an epilepsy diagnosis is made, anti-seizure medications are prescribed but may take months or longer to take effect. In some cases surgery may be an option; other treatments, with varying levels of effect at reducing the frequency of seizures, may also be used. In all approximately 70% of individuals with epilepsy have well controlled seizures, while 30% do not.

In Ontario, approximately 95,000 people live with epilepsy and 6000 new cases are diagnosed every year, meaning that at any given time there are tens-of-thousands of people who have been diagnosed with epilepsy but do not have, or have not yet achieved, seizure control.

A common and addressable impact on Ontario's healthcare system is unnecessary hospital visits, particularly to the Emergency Room, by people living with epilepsy. Most seizures, after someone has been diagnosed with epilepsy, are not medical emergencies. Seizures typically stop in less than five minutes, and unless they continue without stopping (Status Epilepticus) or are complicated by another factor such as injury, taking place in water, diabetes, or during pregnancy, there is no need for medical intervention.

Despite this, there are thousands of avoidable Ambulance calls and Emergency Room visits per year in Ontario. A study of people with epilepsy and their families conducted as part of Epilepsy Southwestern Ontario's Clinic To Community education program found that only 20% of people had gone to the Emergency Room unnecessarily because someone else (excluding family members and school officials) called the ambulance. Fear, needing reassurance, and lack of first aid training were identified as the most common reasons for Emergency Room trips. After taking part in the epilepsy education program, 86% of participants stated they felt more confident about when a seizure is, and is not, a medical emergency.¹

Delivering Epilepsy Education In The Community

Community Epilepsy Agencies throughout the province play a critical role in epilepsy care, creating an education and support system for people with epilepsy outside the hospital or clinic. Their expertise in providing epilepsy education programs means more thorough epilepsy information sessions than medical practitioners provide, and a more appropriate delivery model with more flexibility for support outside a clinical environment.

Community Epilepsy Agencies are vital for continuity of care for patients with epilepsy. More often than not, epilepsy has a significant adverse impact on the psychosocial life of patients, and their families. In order to address this co-morbid aspect of epilepsy care community-based education and support services as provided by the Community Epilepsy Agencies in the Province are an integral part of Ontario's Comprehensive Epilepsy Care system.

It is a tribute to the resilience and dedication of these Community Epilepsy Agencies that they have been able to provide these services without core funding to date. I am convinced that provision of sufficient resources from the Ministry of Health to the Community Agencies will enhance the support that they provide to those Ontarians, both adults and children, across the province.

Dr. O. Carter Snead III
Staff Neurologist
The Hospital for Sick Children

Epilepsy education works to better inform people living epilepsy, and their families, about how to effectively manage their condition, and includes the topics covered in the *Provincial Guidelines For the Management of Epilepsy in Adults and Children*. Key components include understanding treatment options and medications, epilepsy first aid, safety and lifestyle management (particularly to reduce seizure frequency), and psychosocial issues related to school, employment, family relationships, and mental health.

In-depth epilepsy education can have a significant impact, for patients, their families, and the healthcare system:

- Safety education and first aid training reduce injuries and unnecessary trips to the Emergency Room, easing pressure on hospitals.
- Medication information and seizure reduction plans help manage side-effects, improve medication adherence, and decrease the risk of seizures and the potential dangers of not following medication plans. Self-management education reduces seizure frequency and fear, and improves epilepsy knowledge.
- Social and mental health education helps identify strategies to minimize the impact of epilepsy on family, education, employment retention, and how to address the comorbidities common to living with seizures, particularly the markedly higher rate of mental health disorders in people with epilepsy.
- Epilepsy education programs also present the opportunity to identify and work with those patients who may benefit from on-going support through peer-group meetings, one-on-one counselling, and epilepsy education interventions in school or the workplace, where appropriate.

Ontario's Community Epilepsy Agencies provide these services through a variety of methods, ensuring that support and education is delivered effectively, in the community, and maximizing partnerships with hospitals, community health organizations, and the private-sector.

Southwestern Ontario, the GTHA, Niagara Region, Kingston, Ottawa, Timmins, North Bay, and Simcoe and Peterborough counties have agencies of varying service levels. Those agencies with the capacity, or who serve large geographic areas, use a hub and spoke model, maintaining a small central office space, while deploying staff to meet with clients directly in hospitals, clinics, or partner community locations, minimizing operational costs and reaching individuals where they live. Large portions of the province, particularly parts of Central and Northern Ontario, do not have a local agency with staff serving them.

Community Epilepsy Agencies provide these services while receiving no core government funding for

As the Director of the Comprehensive Epilepsy Program at the Hospital for Sick Children I am keenly aware of the need for greater public education about epilepsy and its comorbidities...

People affected by epilepsy and their families require comprehensive epilepsy education to promote self-management allowing them to take control of their condition and manage day to day challenges. Accurate information about epilepsy treatment reduces ER visits and hospitalizations. Education about the potential comorbidities of epilepsy allows for faster identification and reduces severity.

Dr. Elizabeth J. Donner, MD
Director, Comprehensive Epilepsy Program
The Hospital for Sick Children

education and counselling, relying principally on grants, private partnerships, and fundraising efforts. There is a wide range of capacity levels between agencies in different communities. Nowhere do agencies currently have the resources to reach all people in their community living with uncontrolled seizures, or to keep pace with the annual growth of new epilepsy cases. This means that too many individuals and families who would benefit from epilepsy education programs are simply not being served, leading to an impact on other parts of Ontario's healthcare system.

How Epilepsy Impacts Ontario's Healthcare System

The problem of unnecessary Emergency Room visits in Ontario related to epilepsy is significant. In 2017, over 20,000 people made over 31,000 visits to the Emergency Room with a Main Diagnosis code of epilepsy or other unspecified seizures. This number excludes other related, potentially fatal, medical emergencies such as Status Epilepticus. Of people whose Main Diagnosis at the Emergency Room is epilepsy, 77% of visits arrive by ambulance, compared to 16% of all Emergency Room arrivals. The average time spent in the Emergency Room in 2017 for epilepsy and seizures visits was 6.7 hours, compared to 4.3 hours for all Emergency Room visits.²

There is also significant evidence to show that visits, particularly for visits coded specifically as epilepsy, are clinically unnecessary:

- Over 70% of Emergency Room visits for epilepsy had no other diagnosis noted during the visit.
- 57% of epilepsy cases had no medical intervention at the Emergency Room; an additional 14% had a CT scan as the only intervention.
- Less than 10% of cases for epilepsy were recorded as being the first time going to the Emergency Room for that reason.
- Patients who visited an Emergency Room for epilepsy had an average of 1.91 visits with a Main diagnosis of epilepsy or other unspecified seizure during the same year.

Using data from CIHI and the IntelliHealth database, Epilepsy Ontario believes that the estimated healthcare system cost of those Emergency Room visits with a Main Diagnosis code of epilepsy alone was over \$8,000,000 in 2016³; with the addition of visits by the same individuals who also had a visit with a Main Diagnosis code recorded as 'seizure' would increase that amount to over \$10,000,000.

In addition to Emergency Room visits there is anecdotal evidence, including from physicians, that many patients who have not had sufficient epilepsy education make unnecessary visits to specialists, for information and support around lifestyle and psychosocial issues, that may not require a neurologist. Many of these visits could be pre-empted by an epilepsy education program or addressed by a Community Epilepsy Agency.

In my experience, patients with epilepsy definitely benefit from Educational Programs concerning their condition. They tend to be more engaged and tend to have better seizure control. They are more likely not to interact with the medical system if they have seizures and would be less likely to go to an Emergency Department or to a physician's office if a seizure does occur.

Dr. Donald Borrett,
Neurology Specialty Clinic
Timmins and District Hospital

An Investment To Reduce Hallway Healthcare and Unnecessary Costs

Directing \$1.6 million in the first year and \$3.1 million per year in years 2-4, province-wide, for epilepsy education programs through Ontario's Community Epilepsy Agencies, would create 40 FTE epilepsy educator positions across the province, educating approximately 30,000 people with epilepsy and their families over 4 years. The focus of the education programs would be directed to those people with epilepsy most likely to make repeated use of Emergency Rooms: newly diagnosed individuals and those who do not have effective seizure control. Using the Emergency Room average of between 31 and 34% of people with epilepsy with uncontrolled seizures who visit the Emergency Department per year, with an average of 1.91 visits per person, and assuming a conservative 50% reduction in the number of visits for those who have completed the education program, the potential reduction in Emergency Room usage over 4 years would be over 22,000 visits.

Using the estimates on Emergency Room and Ambulance costs noted above, the \$11 million investment over four years would show a net savings of between \$2.4 and \$3.7 million beyond the cost of the program by the fourth year. The savings would continue beyond the funding period as those who took part in the program continue to have a reduced Emergency Department visit rate, increasing to between \$8.6- and \$10.5 million in savings by the following year.

As a key component of the rationale for this type of program is ensuring that the spending continues to be an efficient method for reducing hospital over-crowding and hallway healthcare, a small portion of the program budget would be dedicated to central coordination and measurement of program outcomes. To effectively track the system impact, and demonstrate the success of the delivery model, a 4-year funding commitment would be recommended, with intermediate and final reports on the number of people with epilepsy, as well as family, schools, and co-workers receiving education, and tracking of reduced Emergency Room use and, if possible, other healthcare usage costs such as unnecessary specialist visits.

This funding would be distributed throughout the province, raising the service level of those communities with established Community Epilepsy Agencies, and allowing for the introduction of centrally managed epilepsy educators into communities without a standalone agency. Further, as Community Epilepsy Agencies are already established and providing this type of programming, the funding would focus on scaling up their capacities rather than creating new programs and methods in other locations, such as hospitals, making the investment as efficient as possible.

As a physician, primarily caring for epilepsy patients, it is clear to me that our clinic in an acute care hospital does not have the resources or time to devote to the critical processes of ongoing education and counselling...

These agencies save the province significant funding by reducing unnecessary visits by epilepsy patients to physician offices and emergency departments.

Dr. Peter L. Carlen, MD
Neurologist, Epilepsy Program, Division of
Neurology, University Health Network

Epilepsy Ontario is a registered charity in operation for over 60 years. As a past recipient of Trillium and other government funding, it is prepared to act as the primary project manager and distribute funds for these programs. Additionally, Epilepsy Ontario is in discussions with an existing Transfer Payment Recipient in the health sector that has indicated a willingness to act as the recipient of record for this project if it is funded.

Beyond The Emergency Room

Epilepsy has significant social and quality of life impacts, greater than in many other chronic conditions. It impacts education, employment, and mental health. People with epilepsy are 71% more likely to have a mental health disorder in their lifetime and the unemployment rate for people with epilepsy is 2-3 times the national average. Stigmatization and loss of independence are common, and this broader burden is particularly felt amongst individuals who do not have complete seizure control, with over 80% feeling a loss of independence.

Unlike many conditions, epilepsy extends to all aspects of a person's life. The constant fear of having a seizure, social stigmatization, uncertainty about how epilepsy can impact employment, school, relationships, and family can have a profound effect on those living with the condition. The burden placed on caregivers is also high.

The need for more comprehensive support for those most impacted by epilepsy is very real. However, as it can touch a person throughout their lifetime, it is harder to quantify short-term cost saving. Having the support necessary to achieve in school, minimize the financial impact of caring for children with epilepsy and other caregiver challenges, becoming and remaining a contributing member of the workforce, or receiving basic mental-health supports can have profound long-term impacts on the overall well-being of individuals with epilepsy and their lifetime healthcare and social system costs.

With an additional investment of \$1 million per year across the province, individuals living with epilepsy who require longer, more in-depth counselling and support will receive the assistance they need.

People living with epilepsy need access to services and supports within their community. Without this support, they disproportionately access Ontario's healthcare system and experience a lower quality of life. Supporting Ontarians living with epilepsy through our epilepsy agencies is a cost-effective way to improve the quality of life for people living with epilepsy, while reducing to burden to our healthcare system.

Dr. Kirk Nysten, PhD
Director, Knowledge Translation and
Outreach, Ontario Brain Institute

(Endnotes)

1 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.

2 Unless otherwise noted Emergency Room usage data is derived from Ontario Ministry of Health and Long-Term Care: IntelliHEALTH ONTARIO.

3 Emergency Room cost estimates are derived from a CIHI supplied 2016 reference cost of \$394.65 per Main Diagnosis of epilepsy visit, plus estimates of OHIP physician and ambulance billing based on IntelliHealth data and OHIP benefits schedule. Population estimates are based Statscan, Government of Ontario data. Prevalence rates are derived from *Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data*, July 2015, published by OBI & ICES. Cost projections have been adjusted for inflation.

For a more detailed analysis of figures, see Appendix 2.

Appendix 1: Proposed Budgets

Education Program 4 Year Proposed Budget

	Year 1	Year 2	Year 3	Year 4	% of Budget
Salary & Benefits¹					
Community Epilepsy Educators Year 1:20, Year 2-4:40 FTE	\$1,322,740	\$2,698,390	\$2,752,357	\$2,807,405	
Central Coordinator ²	\$70,800	\$72,216	\$73,660	\$75,134	
Data & Information Management Support	\$14,750	\$15,045	\$15,346	\$15,653	
Salary & Benefits Total	\$1,408,290	\$2,785,651	\$2,841,364	\$2,898,191	90%
Infrastructure					
Office & Telecom	\$47,250	\$92,250	\$94,000	\$96,000	
Equipment	\$21,000	\$24,200	\$8,200	\$6,150	
Infrastructure Total	\$68,250	\$116,450	\$102,200	\$102,150	3.5%
Other					
Supplies	\$10,080	\$19,680	\$20,100	\$15,350	
Travel	\$21,000	\$42,000	\$24,600	\$12,300	
Administration	\$79,131	\$155,000	\$155,000	\$155,000	
Other Total	\$110,211	\$216,680	\$199,700	\$182,650	6.4%
TOTAL	\$1,586,751	\$3,118,781	\$3,143,264	\$3,182,991	\$11,031,786

**Counselling and Support Program
4 Year Proposed Budget**

	Year 1	Year 2	Year 3	Year 4	% of Budget
Salary & Benefits¹					
Counselling Staff	\$849,132	\$866,115	\$883,437	\$901,106	
Salary & Benefits Total	\$849,132	\$866,115	\$883,437	\$901,106	90.5%
Infrastructure					
Office & Telecom	\$27,000	\$27,000	\$27,540	\$28,090	
Equipment	\$10,000	\$2,400	\$2,400	\$1,000	
Infrastructure Total	\$37,000	\$29,400	\$29,940	\$29,090	3.2%
Other					
Supplies	\$5,760	\$5,875	\$5,990	\$4,584	
Travel	\$5,000	\$5,100	\$5,200	\$3,500	
Administration	\$50,000	\$50,000	\$50,000	\$50,000	
Other Total	\$60,760	\$60,975	\$61,190	\$58,084	6.2%
TOTAL	\$946,892	\$956,490	\$974,567	\$988,280	\$3,866,228

1-Includes MERC and benefits at 18% of salary.

2-Includes responsibilities for training, evaluation, and related functions.

Appendix 2: Data Tables

EMERGENCY ROOM USAGE HISTORY VIA INTELLIHEALTH DATABASE

	2013	2014	2015	2016	2017	Average
VISITS						
Main Diagnosis Code G40 (Epilepsy)	11,228	12,062	12,731	13,482	13,495	
Increase rate from previous year		1.05%	1.06%	1.06%	1.00%	1.04%
Main Diagnosis Code R568 (Seizure not otherwise specified) visits by patients also with G40 visit in same year	3,776	3846	3790	3981	4194	
Ratio of R568 to G40 visits	33.6%	32.0%	31.9%	30.0%	31.1%	31.7%
Combined Total Visits	15,004	15,918	16,521	17,463	17,689	
Increase rate from previous year		1.06%	1.04%	1.06%	1.01%	1.04%
PATIENTS with G40 visit	7,828	8,304	8,864	9,091	9,176	
Average visits per patient	1.91	1.92	1.86	1.92	1.93	1.91

	2013	2014	2015	2016	2017	Average
VISITS						
Main Reason Code G40	11,228	12,062	12,731	13,482	13,495	
Number with G40 as only diagnosis recorded	8,025	8,614	9,060	9,695	9,473	
Percent G40 only diagnosis	71.5%	71.4%	71.2%	71.9%	70.2%	71.2%
Number Recorded as First Visit	1,002	1,040	1,191	1,353	1,211	
Percent First Visit	8.9%	8.6%	9.4%	10.0%	9.0%	9.2%
Number with No Intervention and not First Visit	6,543	7,011	7,231	7,698	7,622	
Percent with No Intervention and not First Visit	58.3%	58.1%	56.8%	57.1%	56.5%	57.4%
Number CT Scan Only Intervention and not First Visit			1,805	1,936	1,993	
Percent CT Scan Only Intervention and not First Visit			14.2%	14.4%	14.7%	14.4%

USAGE PROJECTIONS

	2018	2019	2020	2021	2022	2023
Average annual rate of increase in visits of previous 4 years, applied to projection years	1.04%					
Projected G series visits using 1.04 per year increase	14035	14596	15180	15787	16419	17075
Average increase rate applied to above to account for R568 coded visits	1.317%					
Projected Total Visits	18484	19223	19992	20792	21623	22488
Average number of visits per patient	1.91					
Projected number of patients (visits/1.91)	9677	10064	10467	10886	11321	11774

	2017	2018	2019	2020	2021	2022	2023	
Projected Uncontrolled Epilepsy Population (2017 estimate, 28955, increased by 1.8% per year).	28955	29476	30007	30547	31097	31656	32226	
Projected Epilepsy patients visiting ER	9,176	9677	10064	10467	10886	11321	11774	
Percentage of uncontrolled population visiting ER	31%	33%	34%	34%	35%	36%	37%	34%



AVERAGE COST CALCULATION

CIHI generated average ER cost for patients with epilepsy G40 (2016); excludes physician billing	\$394.65
PHYSICIAN ASSESSMENT BILLING AVG, assuming a partial assessment and adjusted for date and time using 2016 as reference year.	\$20.71
CONSULTATION BILLING AVG, based on average of billing costs for 1st consultations for all G series, using 2016 as a reference year.	\$28.03
AMBULANCE (\$195 per ambulance call, adjusted to reflect 77.3% of G-series ER visits by ambulance)	\$150.74
Average Cost per Visit (2016)	\$594.13

PREVALENCE & POPULATION CALCULATIONS

Prevalence calculation: OBI/ICES Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data July 2015	6.8/1000
Population of Ontario, 2017: https://www150.statcan.gc.ca/n1/pub/12-581-x/2018000/pop-eng.htm	14,193,384
Projected Ontario Population growth rate: https://www.fin.gov.on.ca/en/economy/demographics/projections/#s2	1.8% per year
Uncontrolled epilepsy as percentage of epilepsy population	30%
Estimated Uncontrolled epilepsy population, 2017	28955
Epilepsy patients visiting ER, 2017	9,961
Percentage of Uncontrolled patients visiting ER, 2017	31%

PROGRAM OUTCOME ESTIMATES

If percentage of uncontrolled epilepsy population visiting ER is 34%.

	2019	2020	2021	2022	2023
Average minimum patients served per FTE per week (assuming .75 patient increase in years 2-3)	3.5	4.25	5	5	
Patients served per year (assuming 20 FTE positions year 1, 40 FTE years 2-4)	3500	8500	10000	10000	
Patients served to date	3500	12000	22000	32000	30500
Clients Served to date likely to be ER patients (based on 34% visit probability)	1190	4080	7480	10880	10370
Estimated number of visits at 1.91 visits per patient served to date	2273	7793	14287	20781	19807
Average 2016 visit cost adjusted for inflation (1.88% 2016-2018, 2% 2019->)	\$629.01	\$641.59	\$654.42	\$667.51	\$680.86
Total cost	\$1,429,683	\$4,999,807	\$9,349,639	\$13,871,464	\$13,485,664
Estimated number of reduced ER visits based on 50% reduction after program	1136	3896	7143	10390	9903
Total cost savings for reduced visits based on 50% reduction	\$714,842	\$2,499,903	\$4,674,819	\$6,935,732	\$6,742,832
Program cost	\$1,586,751	\$3,118,781	\$3,143,264	\$3,182,991	
ER Visit cost savings to date	\$714,842	\$3,214,745	\$7,889,565	\$14,825,297	\$21,568,129
Program cost to date	\$1,586,751	\$4,705,532	\$7,848,795	\$11,031,786	\$11,031,786
System Savings to date	-\$871,909	-\$1,490,786	\$40,769	\$3,793,511	\$10,536,343

If percentage of uncontrolled epilepsy population visiting ER is 31%.

	2019	2020	2021	2022	2023
Average minimum patients served per FTE per week (assuming .75 patient increase in years 2-3)	3.5	4.25	5	5	
Patients served per year (assuming 20 FTE positions year 1, 40 FTE years 2-4)	3500	8500	10000	10000	
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Program cost	\$1,586,751	\$3,118,781	\$3,143,264	\$3,182,991	
ER Visit cost savings to date	\$651,767	\$2,931,091	\$7,193,426	\$13,517,182	\$19,665,058
Program cost to date	\$1,586,751	\$4,705,532	\$7,848,795	\$11,031,786	\$11,031,786
System Savings to date	-\$934,984	-\$1,774,440	-\$655,369	\$2,485,396	\$8,633,272



Epilepsy Ontario is the voice of epilepsy in the province. Since 1956, we have been serving the province as a registered health charity incorporated under the statutes of Ontario as a non-profit and non-governmental organization. We aim to raise public awareness and improve education through publications, conferences, outreach initiatives and our website.

Epilepsy Ontario works in partnership with Ontario's Community Epilepsy Agencies:

Epilepsy Durham Region

Epilepsy Niagara

Epilepsy North Bay

Epilepsy Ottawa

Epilepsy Peterborough & Area

Epilepsy Sault Ste Marie

Epilepsy Simcoe County

Epilepsy South Central Ontario

Epilepsy South Eastern Ontario

Epilepsy Southwestern Ontario

Epilepsy Toronto

Epilepsy York Region

Seizure & Brain Injury Centre (Cochrane-Timiskaming)

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