



2020 Pre-Budget Submission to the Government of Ontario

Revised and Re-Submitted
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epilepsy
ontario

Executive Summary

Over 95,000 people in Ontario live with epilepsy, with 6000 new cases diagnosed every year. Annually there are over 20,000 visits to Ontario's Emergency Departments by people with epilepsy following seizures, over 50% of which are likely unnecessary. As Ontario moves to prepare for potential future waves of the COVID-19 pandemic, now is the time to ensure that avoidable hospital visits are not straining capacity during a public health emergency.

Ontario's 14 Community Epilepsy Agencies provide education and support programs that improve quality of life for people living epilepsy and the families. A key component of these education programs is reducing unnecessary Emergency Department visits by training people with epilepsy, and those around them, on when a seizure is (and is not) a medical emergency. Epilepsy education programs have been shown to significantly reduce the number of Emergency Department visits, as well as the number and length of inpatient admissions from the ED, reducing healthcare costs.

Community Epilepsy Agencies also provide longer programs that support mental health for a population that is often already isolated and is 71% more likely to have a mental health issue in their lifetime. By addressing issues like depression, anxiety, and isolation, Community Epilepsy Agencies can improve client mental health and reduce usage and costs throughout the healthcare system.

COVID-19 has challenged Community Epilepsy Agencies to innovate in how they deliver programs. They have quickly adopted a remote delivery model and are increasingly networking their programs across agencies to maximize the impact with their strained resources. While their programs reduce healthcare usage and costs, these agencies continue to rely on charitable fundraising, leaving many programs and organizations at risk in the economic wake of COVID-19. Even under normal circumstance, agencies do not serve nearly as many people as they could if they had the proper resources, and parts of Ontario do not have a local epilepsy agency.

Epilepsy Ontario is cognizant of the province's financial situation, and has reduced this funding request by 5% from its previous submission, but the health and financial benefits for the province, as well as clients and local agencies, means this funding must still be considered a priority.

With adequate funding for epilepsy education and support programs, the province can achieve 4 priority objectives:

- **Reducing unnecessary hospital usage through patient education;**
- **Supporting the mental health of an at-risk population**
- **Reducing healthcare costs; and**
- **Innovating service delivery during COVID-19.**

An investment of \$2.8 million per year, for four years, to fund programs at Ontario's Community Epilepsy Agencies will not only pay for itself in reduced healthcare costs, it will contribute an additional \$9.7 million in net savings by 2024, while reducing hospital and other healthcare usage ahead of future COVID-19 waves, improving client mental health, and adapting epilepsy programs for remote delivery.

Background: The state of epilepsy community care in Ontario

Over 95,000 people in Ontario live with epilepsy, 30% of whom do not have effective seizure control. While recurrent seizures are the most obvious effect of uncontrolled epilepsy, epilepsy can impact all parts of a person's life, including their family, education, employment, and mental health. It is also often associated with other conditions, like autism, at a significantly higher rate than the general population.

Like many other chronic diseases, such as Alzheimer's or diabetes, an important component of epilepsy treatment is education and support, outside of the clinical environment. Physicians do not have the capacity to deliver a 60- to 90-minute education session and the information is most appropriately delivered in the community; however, unlike other diseases, community-based education and support programs are not yet part of Ontario's medical system.

Across Ontario, 14 Community Epilepsy Agencies do the same work as many health charities that receive government funding, providing this key information to patients, families, and the community about how to manage the disease, recognize when a situation is (and is not) an emergency, and how to respond appropriately. Larger agencies provide support groups and first-line mental health assistance through counselling programs. Yet, these agencies are in a consistently precarious financial situation, relying on charitable fundraising efforts and short-term grants. Even prior to the COVID-19 outbreak, agencies were chronically under-resourced, and many parts of the province do not have a local agency serving their community. The economic impact of COVID-19 has further strained their capacity to fundraise

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
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Objective I-Reducing unnecessary hospital usage through patient education

Education sessions at Community Epilepsy Agencies are typically delivered by qualified staff, such as social workers or health educators, and should be provided to every individual who has been diagnosed with epilepsy and, where appropriate, their family, co-workers, teachers, and classmates.

A key component of epilepsy education programs involves seizure first aid training and better knowledge of when a seizure might be considered a medical emergency. A typical seizure, once someone has been diagnosed with epilepsy, is not a medical emergency unless other factors, such as being unusually long, injury, or complications such as pregnancy, diabetes, or water, are present. Yet thousands of unnecessary Emergency Department visits following a seizure take place annually, contributing to hospital overcrowding.

Of the approximately 20,000 visits every year to Emergency Departments (ED) in Ontario where the main diagnosis is epilepsy¹, 64% had no medical intervention, including supplemental testing, after arriving at the ED, 73% had no other diagnosis, and only 20% resulted in hospital inpatient admission.²

This situation is especially startling given that a majority of ED visits for epilepsy are made by a minority of patients. Across the province, between 2015 and 2018, 33% of patients going to the ED for epilepsy accounted for 67% of visits. This top 33% made 4 times as many ED visits over almost twice as many years, when compared to the bottom 67%. The unscheduled inpatient admission rate by these high-usage patients was also 50% higher than the average for all unscheduled admissions.³

This demonstrates the potential for reducing hospital usage and cost through epilepsy education programs, especially by focusing a majority of program resources on those high-use patients most in need of education and support. By better educating people with uncontrolled epilepsy, and those around them most likely to call 911, about when a seizure is (and is not) a medical emergency, thousands of potentially unnecessary ED visits can be avoided. Studies from the UK found that similar epilepsy education programs reduced ED visits by 38%.⁴

Epilepsy education programs can also reduce and shorten unplanned inpatient admissions from the ED. UK studies have also found that patients who were admitted from the ED following a seizure visit did so less frequently and, if they were admitted, remained in hospital for less time if they had participated in the education program. The costs of their admission were 79% lower than if they had not taken part in the program⁵.

As the province prepares for future waves of the COVID-19 pandemic, it is critical that resources are dedicated to reducing avoidable hospital usage. By funding education programs for people with epilepsy, and those around them, about when a seizure is and is not a medical emergency requiring a hospital trip, Emergency and inpatient departments will see a reduction in avoidable use, effectively increasing capacity.

Objective 2-Supporting the mental health of an at-risk population

Community Epilepsy Agencies also provide on-going support programs, particularly to those clients who have complex needs and comorbidities. These supports include facilitated peer groups, advocacy and system navigation, intervention in schools and workplaces and, where the capacity exists, individual and group counselling for mental health issues.

These on-going support programs are especially critical for individuals and families impacted by multiple comorbidities, such as autism, or depression and other mental health issues.

Beyond the initial need for epilepsy education to better manage their condition, people with epilepsy face mental health challenges at a far higher rate than the general population. People with epilepsy are 71% more likely to have a mental health issue in their lifetime; 55% of people with uncontrolled seizures face depression; the rate of suicide by people with epilepsy is 10 times the general public.⁶ Females, seniors, visible-minorities, and those facing food insecurity have been found to have higher rates of both depression and epilepsy. Rates of social isolation are also above average.⁷

Fortunately, the effectiveness of mental health interventions for people with epilepsy is well documented.⁸

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.

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Group and individual counselling, with either Cognitive Behavioral Therapy or mindfulness-based therapies, have received the strong recommendation of the International League Against Epilepsy Psychology Task Force for treating depression and other psychological co-morbidities with epilepsy.⁹

With the current resources available, some agencies are able to provide mental health supports, but the service capacity of agencies varies significantly across the province, with large areas without any local mental health supports at the agency. Many agencies are beginning to integrate the use of a new remote group therapy program for people with epilepsy that has been developed by Eplink, the epilepsy research branch of the Ontario Brain Institute. This program has been trialed and shown to significantly reduce depression scores¹⁰, and its remote group delivery model will make it easily adaptable to the Community Epilepsy Agency model in Ontario, if there is sufficient funding to implement the program province-wide.

With funding, Epilepsy Ontario and the province's Community Epilepsy Agencies can sustain and increase their mental health support service levels. In the parts of Ontario without a community organization in place, Epilepsy Ontario will introduce local programs and staff or create networks for remote service delivery.

Objective 3-Reducing healthcare costs

As the province works to address the health and economic impacts of COVID-19, it is critical that programs include a financial lens as part of their rationale. The programs delivered by Ontario's Community Epilepsy Agencies can have a net positive impact on healthcare costs, producing savings in excess of the costs of delivering the programs.

Epilepsy education programs will be weighted heavily towards the thousands of people in Ontario with uncontrolled seizures who have disproportionately high healthcare usage, but who have never received the appropriate education, as well as those newly diagnosed individuals and families who are searching for initial assistance and information.

Using data obtained from studies of epilepsy education programs in Ontario and similar healthcare systems, and by targeting those clients with disproportionately high hospital usage, Ontario's epilepsy education programs can deliver net saving over four year, with savings continuing beyond the end of the funding period, by reducing avoidable hospital usage.

The on-going support programs delivered by Community Epilepsy Agencies will also help reduce healthcare usage, particularly related to mental health. Apart from the obvious impact mental health disorders can have on individual and family life, the financial impact of issues, like depression, on the broader healthcare system is well documented. People with epilepsy and mild-to-moderate depression make more than twice as many MD and psychiatric visits compared to people with epilepsy and no depression. This number continues to increase if the depression level goes from moderate to severe: the number of MD visits increases by another 59% and psychiatric visits goes up by 570%.¹¹ With even modest improvements in depression scores by people with epilepsy, such as moving depression scores from severe to mild-to-moderate, healthcare system costs can be reduced.

With the combination of Emergency Department, in-patient, and mental health cost saving, an investment of \$2.8 million per year for four years is projected to produce a total net-savings of \$9.7 million beyond the cost of the programs by 2024.

Objective 4-Innovating service delivery during COVID-19

As COVID-19 has disrupted many aspects of daily life, Ontario's Community Epilepsy moved the core of their service delivery into a remote model. This required innovation has revealed opportunities to change and improve how services are delivered, both within individual agencies and across the province.

Some agencies have taken this opportunity to begin integrating epilepsy education and mental health programs, researched and developed by Eplink, the epilepsy research branch of the Ontario Brain Institute and designed for remote delivery to groups of clients. Others have adapted their existing program content for online delivery. This has been combined with an increasing collaboration in online webinars and similar projects across agencies to replace traditional in-person group information sessions.

With this innovation framework, Epilepsy Ontario and the province's Community Epilepsy Agencies are moving forward with a more networked service delivery model. Epilepsy Ontario has received a one-time grant through the federal Emergency Community Support Fund to develop a cloud-based client database for all agencies to use and agencies have committed to staff-resource sharing and program co-ordination across traditional geographic boundaries.

If funded, program resources will be devoted to delivering direct services in three ways:

- Epilepsy Ontario directly hiring staff to serve those parts of the province without a local Community Epilepsy Agency, through a combination of local and remotely-based positions;
- Epilepsy Ontario hiring staff and coordinating remote programs with agencies serving catchment areas with small populations that may not warrant full-time local staff positions; and
- Community Epilepsy Agencies being funded for local staff, who will also contribute a portion of their workload to supporting an intra-provincial remote service network.

This approach will allow clients to access specialized supports at agencies outside their local community and to bring to together clients with similar needs from multiple communities in a virtual group setting to speed up and improve the service delivery process.

With an investment of funds from the provincial government, Epilepsy Ontario and Community Epilepsy Agencies across Ontario can better adapt their programs to the realities of COVID-19 while increasing the efficiency of service delivery.

Appendix I: Program delivery and cost/savings overview

		Year 1	Year 2	Year 3	Year 4	Total
	FTE Staff	Clients Seen				
High-Usage Clients (top 33%)	15.5	3108	3418	3760	3760	14046
New Diagnosis Clients	5	1000	1100	1210	1210	4518
On-going/Mental Health Support	13.5	2693	2962	3258	3258	12171
Annual Program Cost		\$2,796,044	\$2,822,119	\$2,848,455	\$2,875,054	
Program Cost to Date		\$2,796,044	\$5,618,163	\$8,466,617	\$11,341,671	\$11,341,671
ER Savings ¹²		\$955,258	\$2,046,162	\$3,289,644	\$4,582,046	
Inpatient Savings ¹³		\$1,749,580	\$1,924,538	\$2,116,991	\$2,116,991	
Mental Health Savings ¹⁴		\$517,209	\$568,930	\$625,823	\$625,823	
Year Gross Savings		\$3,222,046	\$4,539,629	\$6,032,457	\$7,324,860	
Gross Savings to Date		\$3,222,046	\$7,761,675	\$13,794,132	\$21,118,993	\$21,118,993
Net Savings to Date		\$426,002	\$2,143,512	\$5,327,515	\$9,777,321	\$9,777,321

Appendix 2: Program budget

	Year 1	Year 2	Year 3	Year 4	Total	%
Salary & Benefits						
Total Salary/ Benefits/MERC 34 FTE ¹⁵	\$2,248,658	\$2,271,145	\$2,293,856	\$2,316,795		
Central Coordinator ¹⁶	\$70,800	\$71,508	\$72,223	\$72,945		
UPLIFT Honoraria ¹⁷	\$136,000	\$136,000	\$136,000	\$136,000		
Salary & Benefits Total	\$2,455,458	\$2,478,653	\$2,502,079	\$2,525,740	\$9,961,930	87.8%
Infrastructure						
Communications	\$51,000	\$51,510	\$52,025	\$52,545		
Equipment	\$8,500	\$8,500	\$8,500	\$8,500		
Database	\$15,000	\$15,000	\$15,000	\$15,000		
Infrastructure Total	\$74,500	\$75,010	\$75,525	\$76,045	\$301,080	2.7%
Other						
Supplies	\$5,100	\$5,100	\$5,100	\$5,100		
Travel	\$6,800	\$6,800	\$6,800	\$6,800		
Other Total	\$11,900	\$11,900	\$11,900	\$11,900	\$47,600	0.4%
Administration	\$254,186	\$256,556	\$258,950	\$261,369	1031061	9.1%
TOTAL	\$2,796,044	\$2,822,119	\$2,848,455	\$2,875,054	\$11,341,671	

Endnotes

1. Here epilepsy INCLUDES a visit with a Main Diagnosis code of Epilepsy (G40), or a visit with a Main Diagnosis code of Seizure NOS (R568) IF the patient also had a Main Diagnosis of G40 during the same review period. It EXCLUDES visits with a Main Diagnosis code of Status Epilepticus (G41).
2. Per Intellihealth Database
3. Ibid
4. Noble AJ, Snape D, Nevitt S, et al. Seizure First Aid Training For people with Epilepsy (SAFE) frequently attending emergency departments and their significant others: results of a UK multi-centre randomised controlled pilot trial. *BMJ Open* 2020;10:e035516. doi:10.1136/bmjopen-2019-035516
5. Noble AJ, McCrone P, Seed PT, Goldstein LH, Ridsdale L (2014) Clinical- and Cost-Effectiveness of a Nurse Led Self-Management Intervention to Reduce Emergency Visits by People with Epilepsy. *PLoS ONE* 9(3): e90789. doi:10.1371/journal.pone.0090789
6. Jones JE, Hermann BP, Barry JJ, Gilliam FG, Kanner AM, Meador KJ. Rates and risk factors for suicide, suicidal ideation, and suicide attempts in chronic epilepsy. *Epilepsy Behav.* 2003;4 Suppl 3:S31-S38. doi:10.1016/j.yebeh.2003.08.019
7. The association between depression and epilepsy in a nationally representative sample. Fuller-Thomson E, Brennenstuhl S. *Epilepsia.* 2009;50(5):1051-1058. doi:10.1111/j.1528-1167.2008.01803.x
8. R, Tang V, Wagner JL, Modi AC, LaFrance Jr WC, Goldstein LH, Lundgren T, Reuber M. Psychological treatments for people with epilepsy. *Cochrane Database of Systematic Reviews* 2017, Issue 10. Art. No.: CD012081. DOI: 10.1002/14651858.CD012081.pub2.
9. Michaelis R, Tang V, Goldstein LH, et al. Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. *Epilepsia.* 2018;59:1282–1302.
10. Do distance-delivery group interventions improve depression in people with epilepsy? Hum, Kathryn M. et al. *Epilepsy & Behavior*, Volume 98 (2019): 153 – 160
11. The impact of comorbid depression on health resource utilization in a community sample of people with epilepsy. Cramer, Joyce A. et al. *Epilepsy & Behavior*, Volume 5, Issue 3, 337 – 342
- 15 Includes MERC and benefits at 18% of salary.
- 16 Includes responsibilities for training, evaluation, and related functions.
- 17 The UPLIFT program is a remotely delivered group-based intervention to reduce depression amongst people with epilepsy. The program is delivered by 2 facilitators, one of whom is a lay facilitator. This budget line is provide the lay co-facilitator with a small hourly honorarium for participation in the program.
12. The Intellihealth Database reports an average of 1.32 ED visits per year for the top 33% most frequent (high-usage) patients between 2015 and 2018 and an average of 0.659 annual visits for the bottom 67% (low-usage) patients. Cost/visit reductions use an average cost of Emergency Department visits for epilepsy of \$594.13 per visit in 2016 dollars (and adjusted for inflation for future years). The reduced visit number assumes that 75% of education program clients will be in the high-usage client category, with an average reduction in ED visits per patient per year of 33%, and that 25% of clients will be newly diagnosed, with 30% assumed to be in high-usage client category and 70% in the low-usage category (based on the average rates for uncontrolled and controlled epilepsy). The ED visit reduction is calculated by multiplying the number of clients in the high- or low-usage category by the annual average visit and multiplying the result by 33%. The calculation assumes that the reduction will continue in subsequent years. Cost estimates are derived from a CIHI supplied 2016 reference cost per Main Diagnosis of epilepsy visit, plus estimates of OHIP physician and ambulance billing based on IntelliHealth data and OHIP benefits schedule. CIHI generated average ED 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. Total (2016): \$594.13. Inflation adjusted costs- 2020-21-\$641.59, 2021-22-\$654.42, 2022-23-\$667.51, 2023-24-\$680.86
- 13 Inpatient cost calculation are based on an average of 0.172 discharges from unplanned admissions per ED visit, per year amongst the high-usage cohort (2172 discharges per 12601 visits), with a median Resource Intensity Weight of 1.461 per discharge (based on IntelliHealth inpatient data) and multiplied against the Cost of a Standard Hospital Stay (2017/18) of \$5,460 . While the UK study notes a cost reduction rate of 79% after participation in an education program, the study also notes a higher ratio of Inpatient admissions to ED visits than Intellihealth notes for Ontario hospitals. The cost reduction calculation has been adjusted to reflect this lower ratio, with an effective cost reduction of 20%. Per Noble AJ, McCrone P, Seed PT, Goldstein LH, Ridsdale L (2014) Clinical- and Cost-Effectiveness of a Nurse Led Self-Management Intervention to Reduce Emergency Visits by People with Epilepsy. *PLoS ONE* 9(3): e90789. doi:10.1371/journal.pone.0090789
- 14 Based on a cost of \$77.20 and \$20.10 for MD and Psychological visits respectively, per The Schedule of Benefits: Physician Services is a schedule under Regulation 552 of the Health Insurance Act and a reduction in depression severity from Severe to Mild/Moderate Depression, corresponding with a reduction in visits rates from 12.3 to 7.7 per person per year for MD visits and from 4.4 to 0.77 visits for psychological treatments, with a NNT of 5 amongst participating patients and assuming a 1-year only reduction. Assumes 50% of client-load take part in a multi-week group-based CBT or mindfulness therapy program or equivalent. Per Noble AJ, Reilly J, Temple J, et al Cognitive-behavioural therapy does not meaningfully reduce depression in most people with epilepsy: a systematic review of clinically reliable improvement *Journal of Neurology, Neurosurgery & Psychiatry* 2018;89:1129-1137.



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 Sudbury

Epilepsy Toronto

Epilepsy York Region

Seizure & Brain Injury Centre (Cochrane-Timiskaming)

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