



# 2022 Pre-Budget Submission to the Government of Ontario

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epilepsy  
ontario

## Executive Summary

Ontario's Community Epilepsy Agencies are a key part of the healthcare continuum for the 100,000 people living with epilepsy in this province. Community Epilepsy Agencies begin where the doctor's office or hospital ends, with tailored patient education and mental health programs that focus on self-management and community-based care. These programs have a real impact on the quality of life and mental health of people living with epilepsy, and on Ontario's healthcare system as whole.

Epilepsy patient education programs have a direct effect on hospital capacity, reducing unnecessary Emergency Department visits and inpatient admissions. Given the 20,000 annual Emergency Department visits connected to epileptic seizures, maintaining and expanding the ability of Community Epilepsy Agencies to deliver these programs is an important investment towards reducing pressure on Ontario's hospitals as they grapple with the long-term procedure backlog brought on by COVID-19. Improving mental health through tailored epilepsy-specific programs similarly helps reduce usage at other points in the healthcare system.

However, the ability of Community Epilepsy Agencies to deliver these programs is precarious. Many parts of the province do not have a local agency directly serving them and many agencies have been unable to re-establish large fundraising events and activities, central to their budgets, that were impacted by COVID-19. Some agencies have had to lay-off staff just as many are reporting an increase in demand for services. Without provincial funding for their core programs, these services may be lost, with the effect felt at hospitals and physicians' offices.

**Multiple governments, going back years, have said 'NO' to requests to fund community-based epilepsy programs. The provincial government has understandably needed to focus its recent attention on the initial challenges associated with COVID-19, but as it continues to address the pandemic's longer-term impacts on our healthcare system our proposal could not be more relevant. Now is the time to say 'YES' to the 100,000 people living with epilepsy in this province by funding community-based programs that benefit them and their families.**

**The Ministry of Health must invest in education and support programs at Ontario's Community Epilepsy Agencies to both sustain and grow their capacity and reduce unnecessary healthcare system usage;**

- **Investing \$2.8 million per year, for four years, will save the province \$21 million for a net savings of \$9.7 million over that period;**
- **Savings will primarily be found through reduced hospital usage, reducing the number of visits by 16,000 over 4 years and shortening inpatient admissions;**
- **Funding can be deployed quickly through Ontario's Community Epilepsy Agencies and remotely delivered to areas without a local agency currently serving them, rapidly stabilizing and increasing the province's community-based epilepsy program capacity and quickly reducing pressure on hospitals.**

With this small but significant investment, the provincial government can take immediate action to improve hospital capacity by reducing unnecessary usage, create healthcare savings, and maintain and improve access to community-based services for thousands of people with epilepsy.

## **Background: The State of Epilepsy Community Care in Ontario**

Over 100,000 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 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 disease self-management education and support, outside of the clinical environment. Physicians do not have the capacity to deliver a 60- to 90-minute education session after diagnosis and the information is most appropriately delivered in the community. However, unlike other chronic diseases, community-based education and support programs have not been integrated into Ontario's healthcare 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 and group programs.

These agencies are in a constantly 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 and social impact of COVID-19 continues to constrain their capacity to fundraise. Many agencies have been forced to lay-off staff just as others report an increased demand for services. There is a very real risk that services could be lost in parts of the province.

## **Reducing Unnecessary Hospital Usage Through Patient Education**

Disease self-management 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 is 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

***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, is not a medical emergency unless other factors, such as being unusually long, injury, or complications such as pregnancy, diabetes, or water, are present.

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 epilepsy<sup>1</sup>; 64% had no medical intervention, including supplemental testing, after arriving at the ED; 73% had no other diagnosis; 20% resulted in hospital inpatient admission.<sup>2</sup>

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.<sup>3</sup>

This demonstrates the potential for reducing hospital usage and costs 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%.<sup>4</sup>

Epilepsy education programs can also shorten unplanned inpatient admissions from the ED. Researchers in the UK also found that patients who were admitted to an inpatient bed from the ED following a seizure visit 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 program.<sup>5</sup>

As the province grapples with the capacity issues caused by COVID-19 that will continue for years after the pandemic has ended, it is critical that resources are dedicated to reducing avoidable hospital usage. By funding education programs for people with epilepsy, the province can reduce both Emergency Department and inpatient admissions across Ontario for years to come.

## **Supporting Mental Health**

Community Epilepsy Agencies also provide longer-term support programs, particularly to those clients who have complex needs and comorbidities. These programs 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 support programs are especially critical for individuals and families impacted by multiple comorbidities, such as autism, depression, or 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.<sup>6</sup> 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.<sup>7</sup>

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 epilepsy-specific local mental health supports. Many agencies are implementing a Cognitive Behavioral Therapy training program, tailored to the needs of people with epilepsy, that has been researched by EpLink, the epilepsy research branch of the Ontario Brain Institute. This program has been trialed and shown to significantly reduce depression scores<sup>10</sup>, and its remote group delivery model makes 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 programs with a combination of local staff and networks for remote service delivery.

These mental health support programs delivered by Community Epilepsy Agencies can also help reduce healthcare usage. Apart from the obvious impact mental health disorders can have on individual and family life, the financial costs of issues, like depression, has on the 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%.<sup>8</sup>

Fortunately, the effectiveness of mental health interventions for people with epilepsy is well documented.<sup>9</sup> 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.<sup>10 11</sup>

## **An Investment to Reduce Healthcare Costs and Hospital Pressure**

As the province works to address the health and economic impacts of COVID-19, it remains important that programs include budgetary and healthcare system considerations 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, primarily through reduced hospital usage.

Using data obtained from studies of epilepsy education programs in similar healthcare systems, CIHI costing, and the Intellihealth database, and by targeting those clients with disproportionately high healthcare usage, Ontario's epilepsy education and support programs can deliver significant net saving over four years by reducing avoidable healthcare usage.

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 self-management education, as well as those newly diagnosed individuals and families who are searching for initial assistance and information. Even small usage and cost reductions by these groups of patients, at rates more modest than those found in studies in other jurisdictions, will produce net savings in cost and usage. Additionally, even moderate improvements in depression scores by people with epilepsy reduces usage throughout the healthcare system and contributes to reductions in costs.

With the combination of Emergency Department, in-patient, and mental health cost savings, 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 funding the programs, by the fourth year.<sup>12 13 14</sup>

Epilepsy Ontario and the province's Community Epilepsy Agencies have established an increasingly networked service delivery model which can be used to quickly deploy resources to frontline services and remotely deliver programs across traditional geographic boundaries. If funded, program resources will be primarily devoted to funding direct service staff through a combination of local Community Epilepsy Agencies and Epilepsy Ontario directly hiring staff to serve those parts of the province without a local Community Epilepsy Agency or where agencies serve catchment areas with small populations that may not warrant full-time local staff.

This approach will allow clients to access programs even when not available in their local community and, where appropriate, to bring together clients with similar needs from multiple communities in a virtual group setting to speed up and improve the service delivery process.

This investment by the government of Ontario will support people with epilepsy, stabilize and expand programs that contribute to Ontario's COVID-19 strategy by reducing unnecessary pressure on hospitals as they address the pandemic-related procedure backlog and future waves, and achieve cost savings for the province.

## 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%)	20	4400	4840	4840	5000	19080
New Diagnosis Clients	5.5	1210	1331	1331	1375	5247
On-going/Mental Health Support	8.5	1870	2057	2057	2125	8109
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 <sup>12</sup>		\$809,252	\$1,733,418	\$2,694,227	\$3,724,003	
Inpatient Savings <sup>13</sup>		\$2,445,575	\$2,690,132	\$2,690,132	\$2,779,062	
Mental Health Savings <sup>14</sup>		\$359,173	\$395,090	\$395,090	\$408,151	
Year Gross Savings		\$3,614,000	\$4,818,640	\$5,779,449	\$6,911,216	
Gross Savings to Date		\$3,614,000	\$8,432,640	\$14,212,089	\$21,123,306	\$21,123,306
<b>Net Savings to Date</b>		<b>\$817,956</b>	<b>\$2,814,477</b>	<b>\$5,745,472</b>	<b>\$9,781,635</b>	<b>\$9,781,635</b>

## Appendix 2: Program Budget

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



## 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
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 80% of education program clients will be in the high-usage client category, with an average reduction in ED visits per patient per year of 20%, and that 20% 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.
- 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.



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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