



# Epilepsy Action Day at Queen's Park

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December 1, 2014

Educate. Engage. Empower.

# Who we are

- 15 epilepsy agencies across Ontario represent 78,000 people living with epilepsy and their families through a variety of supports and services
- People are patients for 20 minutes when in their doctor's office
- Agencies offer the community support necessary to enable people to live well with epilepsy
- People living with epilepsy learn how to manage their condition, enabling them to better fulfil the many roles they play in the community through information, education and support

- No direct operational government funding is received
- Agencies are funded through fundraised dollars including events, individual and corporate donations and grants



# Current Initiatives

- Epilepsy agencies are working on a number of initiatives across the province

**epilepsy @work**  
A toolkit for HR professionals

Designed for **HR professionals**, this toolkit will provide **training and information** on how to **support co-workers, clients and customers** with **epilepsy in the workplace**.

**Understanding Epilepsy in the Workplace**  
In 30 minutes you will be able to answer the question, "How can I help"? This is a course for employees and co-workers working in any workplace environment.  
[+ more info](#)

**Seizure Safety**  
These unique and original videos will teach the user how to recognize the most common seizure types and how to provide the most appropriate assistance, in various workplace settings.  
[+ more info](#)

**Helpful Resources**  
Here's the home of all of the just-in-time Helpful Resources for HR professional managers and supervisors, recruit occupational health and safety specialists.  
[browse](#)

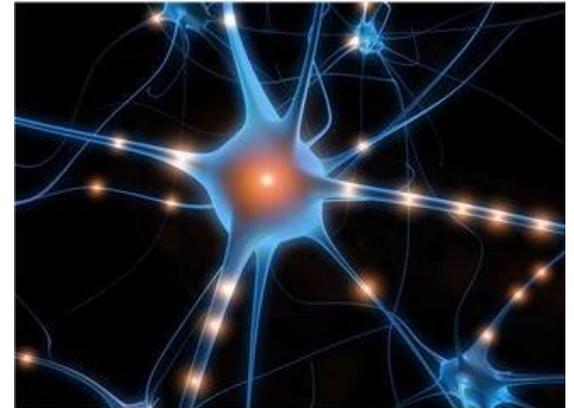


# Epilepsy 101

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## What is Epilepsy?

- A common brain disorder that is characterized by recurrent seizures
- Epilepsy has no age, racial, geographic or socio-economic boundaries



## What is a Seizure?

- A brief disruption in normal brain activity that interferes with brain function
- Type of seizure depends on which area of the brain is involved
- People may experience an alteration in behaviour, consciousness, movement, perception and/or sensation

# Treatment

## There is no cure...

- Up to 70% of people with epilepsy respond to drug treatment
- 30% of people with epilepsy still experience uncontrolled seizures
- Ontario must ensure access to all treatment options to help control seizures and improve quality of life

### Anti-seizure Drugs

- Main treatment for epilepsy
- For optimum seizure control, may be prescribed alone or in combination
- Seizures are eliminated in only about 60% of cases with the use of one drug



### Surgery

- Approximately 20% of patients are potential candidates but only 2% undergo surgery despite the fact that up to 80% of appropriately selected candidates can achieve seizure freedom with epilepsy surgery

### Other Treatments

- Medical Diet Therapies (only available to pediatric patients)
- Vagal Nerve Stimulation (VNS)

# Epilepsy in Canada – Mapping Connections

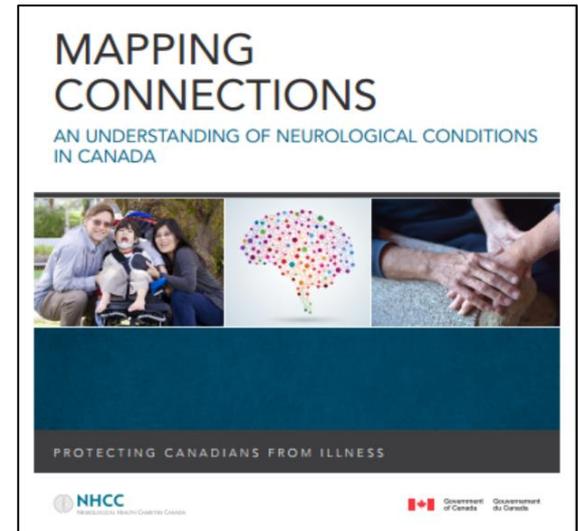
**\$3 billion**

Annual projected indirect economic costs for epilepsy due to working-age death and disability in the year 2031

**\$208,679,000**

Total direct health care costs for epilepsy in 2010-2011 in British Columbia

- Community-based epilepsy services provided by agencies help reduce costs to the health care system
- We provide information, education and support to people throughout their epilepsy journey
- We are working to quantify this through the Clinic to Community project and Epilepsy Support Centre is piloting a project to support this



**Working status for people with epilepsy:**

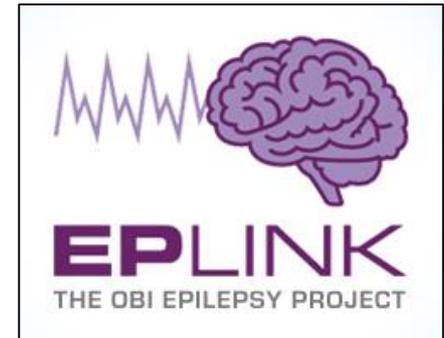
**50%** reported they were working

**32%**  
unable to  
find work

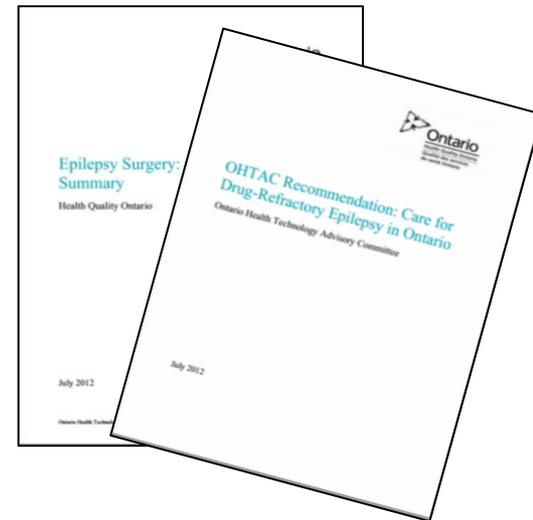
**18%**  
unable to  
work

# Provincial Epilepsy Strategy

- Importance of epilepsy has been well recognized by Ontario government through a number of initiatives
- Status of Provincial Epilepsy Strategy:
  - Two of the five guidelines have already been completed
  - Two epilepsy patient representatives in place (London/Toronto)
- Next steps:
  - Implementation of Community Epilepsy Liaisons (CEL) - a key role on the care team at the Epilepsy Monitoring Unit (EMU) that provides a link between hospital and community
  - For initial phase, Epilepsy Ontario will submit an application for funding for five CEL's to fulfil this role
  - After the initial phase, Epilepsy Ontario would like to see community-based services and Community Epilepsy Liaisons expand further into communities across Ontario



**\$1.5 million**  
Funding for EpLink  
Research through Ontario  
Brian Institute (OBI)



# Epilepsy in Schools: Rescue Medications

- Children and youth with epilepsy who have an increased risk of status epilepticus may be prescribed an emergency medication (rescue medication)
- Prompt treatment can mean the difference between life and death during a prolonged seizure or seizure cluster
- Despite written doctor orders and parental wishes, some staff refuse to provide rescue medication for students
- Status:
  - Epilepsy Ontario and our partners have been advocating for legislation that enforces appropriate policies and procedures to ensure that students are protected at school
- Next Steps:
  - Ministry of Education is completing a review of how medical conditions are handled in schools – expected Jan 2015

**Status Epilepticus:**  
Prolonged seizures or seizures that repeat without recovery in between can indicate a life-threatening situation

## Recommendation:

Amend existing legislation in *Sabrina's Law* or bring forward new legislation to protect and keep children safe at schools including education on seizures awareness, first aid training, and administration of rescue medications

## Partner Organizations:



Anaphylaxis Canada



# Epilepsy in Schools: Neurological Conditions

- Children with neurological conditions are in every classroom across Ontario
- Evidence-based interventions and educational supports are required to ensure they reach their full potential and become contributing, productive citizens
- Status:
  - Neurological Health Charities Canada (NHCC) – Ontario Working Group (OWG) submitted an action plan to better engage children and youth with neurological diseases, disorders and injuries in Ontario’s education system
  - It is understood there is an ongoing review of the Categories of Exceptionalities
- Next Steps:
  - Epilepsy Ontario supports the NHCC-OWG recommendations and would like to see them adopted
  - Epilepsy Ontario would like to work collaboratively with the Ministry of Education and our education partners to ensure that students with brain conditions have the opportunity to be part of Ontario’s education success story

## Recommendation:

Advocate to the Minister of Education to ensure neurological conditions are considered during the review of the Categories of Exceptionalities that is currently underway

# What Can You Do?

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People living with Epilepsy still need your continued help and action. Please help us advocate for the following:

- Ensure community-based services and Community Epilepsy Liaisons expand further into communities across Ontario
- Amend existing legislation in *Sabrina's Law* or bring forward new legislation that incorporates all conditions to protect and keep children safe at schools including education on seizures awareness, first aid training, and administration of rescue medications
- Advocate to the Minister of Education to ensure neurological conditions are considered during the review of the Categories of Exceptionalities that is currently underway

**THANK YOU FOR YOUR CONTINUED SUPPORT**

Thank you!

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