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Speaker Night Series Launches with Presentation on Epilepsy Surgery Wednesday October 9, 2013

Whether you are an individual living with epilepsy, care for someone with epilepsy, or are a member of the community who wants to know more, our 2013/2014 series of Speaker Nights, offered in partnership with the Queen's Epilepsy Society, will offer you great information from the experts on epilepsy and seizures.

The Epilepsy Resource Centre is proud to present a special speaker's night event this Fall with guest speaker Dr. Taufik A. Valiante, a neurosurgeon from Toronto Western Hospital, who is co-director of their Epilepsy Program. Dr. Valiante will be presenting an interesting talk about epilepsy surgery, including when epilepsy surgery is used, who is a candidate for surgery, and details about the surgery itself.

Everyone is welcome to join us on Wednesday, October 9 at 7pm. To RSVP to this event, please contact our office at (613) 542-6222 or by email at: admin@epilepsyresource.org.

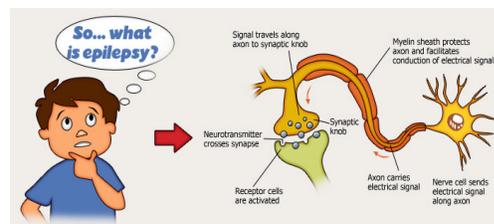
Speaker Night Series 2013/2014

Kingston Speaker Nights

- Dr. Taufik A. Valiante, Neurosurgeon from Toronto Western Hospital
Topic: Epilepsy Surgery
Date: Wednesday October 9, 2013
Time: 7pm
Location: Botterell Hall, 18 Stuart Street, Queens University, Kingston ON, Room: B139
- Dr. Allison Spiller from Kingston General Hospital
Topic: Women and Epilepsy
- Dr. Athen MacDonald from Hotel Dieu Hospital
Topic: Youth and Epilepsy

Brockville Speaker Nights

- Dr. Athen MacDonald from Hotel Dieu Hospital
Topic: Youth and Epilepsy



For more details about our upcoming speaker nights (dates and locations) please contact our office or visit www.epilepsyresource.org. Everyone is welcome to attend and we look forward to seeing you there.



Epilepsy Surgery

Most people who have epilepsy take medication to control their seizures, and approximately 70% achieve seizure freedom. However, for the remaining 30% for whom medication isn't working, epilepsy surgery may be considered as a possible treatment.



Epilepsy surgery is a procedure that either removes or isolates the area of the brain where seizures originate. The surgery works best for people who have seizures that always originate in the same place in their brains. While the idea of brain surgery can be intimidating, in patients with an identified focal seizure focus, the success rate of surgery is up to 80%. This is the number of patients that will be seizure free for 5 years after surgery with some patients experiencing occasional auras and some still taking anticonvulsant medication

Who is a good candidate?

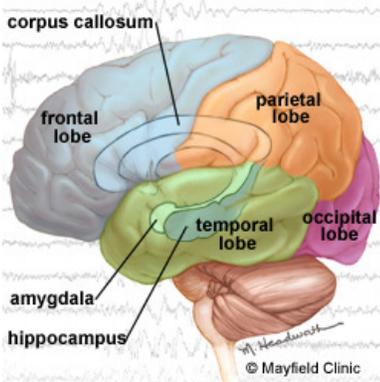
There are many factors that neurosurgeons consider when it comes to performing brain surgery on an individual. To be considered for epilepsy surgery, typically you must have tried at least two anti-seizure drugs without success. Your physicians must ensure that the correct seizure diagnosis has been made and that the correct drugs have been used in the appropriate amounts. Even then, however, there is no clear definition of when to move to surgery. Among the factors to consider are seizure type, frequency and severity, the length of time since the diagnosis and the impact of the epilepsy on the patient's quality of life. There are also other reasons to consider surgical therapy. For instance, repeated seizures may lead to neurological deterioration and certain patients may have intolerable side effects from anticonvulsant medications.

It is important to stress that not all patients with medically refractory epilepsy can be helped with surgery. The best surgical candidates have seizures arising from a single location and from an area of the brain that is relatively silent meaning that the seizure focus can be safely and completely removed.

Lengthy testing and evaluation by a team of health professionals is required to determine who is a good candidate for surgery. Typically, the assessment process involves an in-patient assessment of seizures, including video-monitoring and 24 hour EEG recordings, along with a thorough neurological and physical exam, brain imaging, and a neuropsychological assessment.

What happens during surgery?

Surgery for epilepsy is a delicate and complicated operation. It must be performed by a skilled, experienced neurosurgeon and surgical team, and so it is usually performed at special medical centers that treat patients with epilepsy rather than at local hospitals. In our area, individuals are typically referred to Toronto, London, or Montreal for epilepsy surgery.



Although epilepsy surgery is complex, the treating team of neurologists and neurosurgeons follow a straightforward set of principles. The strategy is to identify the area of abnormally discharging neurons (the "seizure focus") and to remove it when possible.

Credit to: www.epilepsymatters.com/english/tresurgery.html

Epilepsy Surgery Cont'd

Making an Informed Decision

As with any operation, there are risks to surgery for epilepsy. The risks depend on the area being operated upon and may include producing a disturbance in motor strength, in sensation, in vision or speech. There have also been rare cases of surgical mortality. Fortunately, with continuing refinement in neurosurgery, the chances of long lasting complications are small at approximately 2%.

When deciding if surgery is right for you, it can be helpful to obtain as much information as possible from experts in the field of epilepsy and to speak with individuals who have had epilepsy surgery. If you would like to speak with others who have had the surgery, please contact our office.

Learn more at our Speaker Night!

For more information on epilepsy and epilepsy surgery we recommend attending our epilepsy surgery speaker night on October 9, 2013, presented by Dr. Valiante from Toronto Western Hospital. For more information, please visit our website at www.epilepsyresource.org.

Jessica's Surgery Success Story

Hello, my name is Jessica and over 20 years ago, at the age of 13, I was diagnosed with epilepsy. My epilepsy consisted of complex-partial seizures where I would blank-out for 1 to 2 minutes with lip-smacking. When a seizure was over, it took me about 5 minutes to come around and then a further half-hour to truly feel myself again. After being diagnosed, my seizures became well-controlled with medication. I was able to complete high school, go to university and start working.

Unfortunately, at the end of 2009 I started having complex-partial seizures again. I was started on new medications but they did not help the situation anymore. I was having 5 to 10 seizures a month. I was unable to work or drive and aspects of daily living were becoming limited.

In 2011, my Epileptologist asked if I would consider being assessed for Epilepsy Surgery. I was a bit nervous ,but I agreed. I was referred to Toronto Western Hospital where I underwent a number of medical tests to determine if I was an appropriate candidate for surgery. To begin with, I had to spend 6 nights in the Epilepsy Monitoring Unit where I was connected to 24- hour EEG monitoring and slowly taken off my antiepileptic medication to determine the area of my brain where the seizures were coming from when a seizure did occur. This testing worked very well.

I also had neuropsychological testing and a WADA test completed to make sure that the surgery in the specific area of my brain that did need to be removed to help stop the seizures would not complicate how other areas of the brain work. These tests also helped to confirm the area of my brain that would take over for the small piece of brain that did need to be removed to stop the seizures.

On December 17, 2012 I had a Left Anterior Temporal Lobectomy, performed by epilepsy neurosurgeon Dr. Taufik Valiante, at Toronto Western Hospital. I only had to stay in the hospital for 3 nights after the surgery was done and since the day of surgery I have been completely seizure-free! I am a firm believer now that people need to start learning more about epilepsy surgery and I am happy to say it is starting to gain much needed public awareness. This surgery can be of great benefit to people with some forms of epilepsy.

If you have any further questions about what I feel has been a truly positive experience with epilepsy surgery, please get in touch with The Epilepsy and Seizure Disorder Resource Centre of Southeastern Ontario & we can talk!

2013 United Way Campaign

The 2013 campaigns for the Kingston, Frontenac, Lennox & Addington United Way and Leeds & Grenville United Way kicked off this September. Every Fall our communities come together in support of the United Way, raising critical funds for more than 100 local community programs and organizations. The Epilepsy Resource Centre is a proud member agency of both United Ways. We would not exist without their support.

In support of the 2013 United Way campaigns, the Epilepsy Resource Centre will be hosting two bake sales for each of the United Way Campaigns that we support. Come out and enjoy some homemade treats while supporting your local United Way!

KFL&A United Way Bake Sale

Date: **Friday October 4, 2013**

Time: **10am to 1pm**

Location: Epilepsy Resource Centre Office: 100 Stuart Street, Kingston

Leeds & Grenville United Way Bake Sale

Date: **Saturday October 5, 2013**

Time: **11am to 3pm**

Location: Baldrees No Frills, 706 King Street East, Gananoque

For more information on the two United Way campaigns and how to offer your support, please visit their websites at:

- United Way KFL&A - www.unitedwaykfla.ca
- United Way L&G - www.uwleedsgrenville.org



Call For Volunteers - Purple Day Committee

The Epilepsy Resource Centre is looking for energetic and eager volunteers to assist with our upcoming 2014 Purple Day campaign, which occurs annually in March. Our committee volunteers will assist in planning and preparing our Purple Day campaign and events. This is a great opportunity to assist with bringing awareness and information to the community about epilepsy and seizures.

Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness. Each year dozens of people participate in the worldwide day in multiply countries.

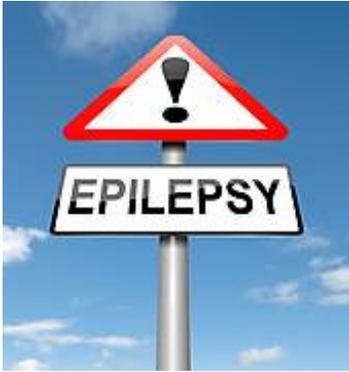
If you are interested in becoming a Purple Day volunteer, please contact Hanna Kitchingman at our office, (613) 542-6222 or by email at hannakitchingman@epilepsyresource.org. We look forward to hosting some new and exciting events this year!

If you would like to learn more about Purple Day, please visit their website at www.purpleday.org or visit their facebook page at Purple Day for Epilepsy.



Epilepsy Presentation and Displays

Interested in learning more about epilepsy and seizures?



Fall is here again, and with it comes back to school for elementary, secondary and post secondary students. Here are 2 questions to consider:

1. Do you have a student in your class or school who has epilepsy?
2. Are you and/or your school interested in learning valuable information about epilepsy and seizure disorders?

If you answered yes, the Epilepsy Resource Centre would be happy to come to your school and offer a presentation for students, teachers, and staff.

The Epilepsy and Seizure Disorder Resource Centre is committed to offering free information presentations to all schools, students, teachers and staff on the topic of epilepsy, seizures, and seizure first aid. We want to bring epilepsy out of the shadows and into the community through epilepsy education. We want individuals to know and understand what epilepsy is, the different types of seizures and what to do if someone has a seizure.

If you would like to learn more about our education presentations, or you would like us to come speak to your school, classroom or organization, please contact our office at (613) 542-6222 or email us at admin@epilepsyresource.org.

OBI-EpLink Update - August 2013

EpLink is the Epilepsy Research Program of the Ontario Brain Institute. It is one of the largest epilepsy research programs in Canada, with more than 30 researchers. The EpLink Non-Profit Advisory Committee is pleased to provide highlights from some of the research projects involved in this important program.

Dr. Berge Minassian – Curing the Worst of the Worst Epilepsies

Genetics is one of the hottest fields in epilepsy research, and it is the specialty of Dr. Berge Minassian of the Hospital for Sick Children in Toronto. Dr. Minassian has two major lines of research. One of them is a very large project, supported by Genome Canada, which involves sequencing the whole genome of people with epilepsy. The goal is to find some of the genes which contribute to epilepsy, most of which are still unknown.

The other project, which is supported by EpLink, relates to a rare, but very terrible, disease called “Lafora disease”. In Lafora disease, children develop normally until their early teens, at which time they start to have uncontrolled seizures and dementia. The disease leads to death in about 10 years. Fortunately, Lafora disease only occurs in less than 1 in 200,000 people, but it is devastating when it occurs.

Dr. Minassian has been studying this terrible disease for some years, and has been able to find two of the different mutated genes that cause it. What appears to go wrong in Lafora disease is that the mutated genes produce in an abnormal form of glycogen, which is starch-like, and which the neurons of the brain can’t break down. The abnormal glycogen slowly builds up in the neurons until it eventually kills them – causing the seizures and dementia.

Now that he has found the mutated genes, Dr. Minassian is working on drugs that will stop the abnormal starch from being formed, or will break it down if it does occur. His work is progressing well, and he hopes to have his drugs in clinical trials within the next half decade.

For more information on EpLink please visit their website at <http://eplink.ca/>.

Recent Events: Summer 2013



Epilepsy Resource Centre Fire Truck Pull Wrap Up

On July 21st, 2013, the Epilepsy Resource Centre hosted the first annual Fire Truck Pull, *Pull Together for Epilepsy!* The event was a huge success and a fun day for the entire community! Nine teams of eight participants came out to compete in four different competitions. Our category winners included:

Crème Glacee in "The Fastest Pull"

The Gananoque Fire Department in "The Most Funds Raised"

Girl's Inc. Women in "The Most Spirited Team"

The Kingston Fire Dragons from Kingston Fire and Rescue in "The Overall Event Winner" (Pull time plus funds raised)

The event was emceed by Big Kris of K-ROCK 105.7. An honorary team, which included members of the community living with epilepsy, Ted Hsu, John Gerretsen, and media representatives, mustered up their strength to perform the first pull, and started the day off on a strong note!

We are extremely grateful of the many wonderful people who took the time to be a part of this event, including the Kingston Fire and Rescue, the many teams that pulled together, our amazing volunteers, and the crowd of spectators who participated by supporting the event and the participants involved. It is hard to convey how much we truly appreciate the many dedicated people involved in this fundraiser, and the success of the event. But most importantly, we are extremely happy to see the step we have taken in bringing epilepsy out of the shadows.

As we wrap up the summer, we are already looking towards the second annual Fire Truck Pull with excitement! Now is a great time for you to start thinking about how you can be involved in *Pull Together for Epilepsy!* Whether it is through giving your feedback on this year's event, volunteering at the event or with the planning process, or putting a team into the competition, do not hesitate! There is a way for everyone to be involved! For more information about how you can be involved in the 2014 Fire Truck Pull, contact the Epilepsy Resource Centre at 613 542 6222.

Prepare to pull epilepsy out of the shadows in 2014!



Girls Inc. Women Pulling Together

Recent Events: Summer 2013

Pull Together for Epilepsy

Thank you to our Sponsors!

The Epilepsy Resource Centre would like to extend a warm and heartfelt thank you to all our wonderful sponsors who assisted in making the first annual Pull Together For Epilepsy: Fire Truck Pull a success.

We would like to thank the following:



Government of Canada



Centennial Engravers and Trophies



SUDEP Cycle for Olly Friday July 26th, 2013



SUDEP Aware is a not-for-profit organization dedicated to raising awareness and understanding of Sudden Unexpected Death in Epilepsy (SUDEP), with the ultimate goal of finding its cause(s) and prevention. From July 22 to July 28, 2013 four individuals cycled together across Ontario to raise awareness for SUDEP.

On Friday July 26th, 2013 these cyclists came to Kingston and stopped off at the Epilepsy Resource Centre office to get a much deserved send off and to receive a donation from DuPont and Avanta Spa on behalf of Chelsea Tobin family and friends.

To read about their amazing journey, please visit their SUDEP Aware blog at www.sudepaware.org/cycle2013/blog/.



2013 SUDEP Aware Cyclists, Susan Harrison (Executive Director), and the Tobin family

Did You Know?



More than 50 million people across the world have epilepsy, and of that large number, 300 000 are Canadians. This is approximately 1% of the population. Epilepsy strikes all ages - children, adults, and seniors. However, not everyone with epilepsy is considered a candidate for epilepsy surgery.

- Epilepsy surgery is only used when the injured brain tissue causing the seizure can be identified and safely removed without damaging other parts of the brain or any major body functions.
- Epilepsy surgery is an under-used treatment option for epilepsy. Approximately 20% of people with epilepsy are potential candidates, but only 2% undergo surgery
- There are 2 main types of Epilepsy Surgery:
 1. Removal of a specific area of the brain that produces the seizure
 2. Interruption of the nerve pathways along which seizure impulses are spread.

THE EPILEPSY AND SEIZURE DISORDER RESOURCE CENTRE

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Donations

Please send this information form along with your cheque or cash donation to:
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100 Stuart Street
Kingston, Ontario, K7L 2V6
Phone: (613) 542-6222 ~ Fax: (613) 548-4162

Payment Method: Cheque Cash
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Full Name: _____

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You can also donate to the Epilepsy and Seizure Disorder Resource Centre online using a credit card. Please visit our website, www.epilepsyresource.org and click on the CanadaHelps.org logo.

**Tax Receipts are provided for all donations*

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Please make all cheques payable to the **Epilepsy & Seizure Disorder Resource Centre*