



*Welcome to the Autumn 2015 edition of the BC Epilepsy Society newsletter. This issue includes updates about BC Epilepsy Society programs and services, breaking news about epilepsy research, gala fundraising event and community education. You will also find a great read from featured author 10-year-old Emily.*

## Old drugs and new tricks

**Repositioning drugs for use in epilepsy based on personalized, gene based medicine**

*By Alexander D. Smith, Ph.D. Epilepsy Canada Postdoctoral Research Fellow and Tara L. Klassen, Ph.D. Director Ion Channels in Excitability Disorders –Translational Laboratory, Faculty of Pharmaceutical Sciences, University of British Columbia, Vancouver*

Epilepsy affects 65 million people worldwide, and impacts ~1% of Canadians with 16,000 new diagnoses annually. Currently, over 70% of those with epilepsy do not know the cause of their disease. The unique and highly individualized nature of epilepsy makes it difficult to treat effectively – 20-40% of patients clinically diagnosed with epilepsy are not able to become seizure-free after being prescribed and taking two or more anti-epileptic drugs (AEDs)<sup>1-4</sup>. These patients are then classified as having “intractable”, “refractory”, “pharmacoresistant”, or simply “drug resistant” epilepsy. But these descriptors all fall drastically short of describing the life altering impact that irregular and unpredictable seizures can have, and that the ultimate goal of therapy is to become seizure-free.

### **What is personalized medicine?**

The term “personalized medicine” has become a common phrase spoken by celebrities, news anchors, families, and health care providers alike. Various definitions of personalized medicine exist, but at its heart, it is a medical disease management model in which

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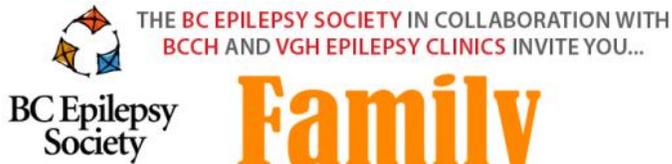
## Shakin' Not Cured Gala

Please consider joining us for our annual James Bond themed fundraiser for the BC Epilepsy Society. It will take place on Tuesday, November 10, 7:00pm at the Vancouver Aquarium. There will be live music, casino entertainment and a premier silent auction. For more information and ticket purchase, please click [here](#).

## Apple announces new ResearchKit

The EpiWatch app developed by Johns Hopkins, is the first study of its kind to be conducted with Apple Watch using ResearchKit. The study will test whether the wearable sensors included in Apple Watch can be used to detect the onset and duration of seizures. During the first phase of this study, researchers will use a custom application on the Apple Watch to provide patients with one-touch access to trigger the custom watch app to capture accelerometer and heart rate sensor data to capture the digital signature of their seizure and send an alert to a loved one. The app will keep a log of all seizures and the participant's responsiveness during the event. The app also helps participants manage their disorder by tracking their medication adherence and by screening for side effects, while allowing participants to compare their condition with others in the research study.

This new app, designed using ResearchKit, provides patients with interactive activities that help them manage their condition now, and opens the door to developing an app that can detect various seizure types and alert family and caregivers. Gregory Krauss, M.D., Professor of Neurology at the Johns Hopkins University School of Medicine says, "Now we have the opportunity to use technology to monitor seizures across the country and collect data in a totally new way."



# Family Education Day About Epilepsy

**SATURDAY NOVEMBER 21** REGISTRATION FROM 8:45-9:15 AM

**CHAN AUDITORIUM EDUCATION AND RESEARCH BUILDING**  
CHILDREN'S AND WOMEN'S HEALTH CENTRE OF BC 4480 OAK STREET, VANCOUVER, BC

TOPICS INCLUDE:

**Exciting Epilepsy Genetics Research**  
**Mental Health and Epilepsy**  
**Transition to Adult Healthcare Services**  
**Trust it or Trash it: Interpreting Health Information Online**  
**Personal Stories of Strength, Success, and Advocacy**  
**Learning, Memory Issues, and Coping Strategies**  
**Mindfulness and Living With Epilepsy**

**\$20 PER INDIVIDUAL/\$30 PER COUPLE** LUNCH IS INCLUDED

REGISTRATION REQUIRED | CONTACT [OUTREACH@BCEPILEPSY.COM](mailto:OUTREACH@BCEPILEPSY.COM) OR GO TO OUR WEBSITE [BCEPILEPSY.COM](http://BCEPILEPSY.COM) | CHILDREN UNDER 18 NO FEE

## Family Education Day About Epilepsy

Topics include:

- Mindfulness and Living with Epilepsy
- Exciting Epilepsy Genetics Research
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Please [click here](#) to Register.

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*I might have Epilepsy,  
but Epilepsy doesn't  
have me!*

decisions and practices are customized to an individual, using knowledge of that person's genes, proteins, and environment (e.g. lifestyle and diet) to prevent, diagnose, treat, and effectively manage the patient's lifelong health<sup>5</sup>.

### **Personalized medicine in epilepsy**

In epilepsy, personalized medicine is making huge strides in clinical practice due to the increasing demand for molecular diagnoses, the broader availability of more comprehensive genetic tests, and their decreasing costs. Currently, a variety of gene tests are used for preemptive screening of known risk genes, to characterize family and population genetic profiles, and for molecular autopsy following Sudden Unexpected Death in Epilepsy (SUDEP). Next generation sequencing has also greatly advanced the pace of gene discovery in epilepsy, especially amongst those with rare monogenic syndromes and children with severe early onset epilepsies<sup>6</sup>.

The identification of new molecular causes of epilepsy will drastically increase in the near future with the launch of the Epilepsy Genetics Initiative (<http://www.cureepilepsy.org/egi/>). This confidential database will allow patients and their families to authorize the submission of their personal exome data (the information on all the protein coding genes in their bodies) by certified diagnostic labs. This information, when combined with de-identified personal health information, will be analyzed regularly for potential causes of the patient's epilepsy. While this has great promise in identifying new epilepsy genes, it also adds an additional layer of complexity for personalized medicine. Specifically, the selection of the correct drug therapy to target the underlying molecular cause becomes more difficult, particularly because this mechanism may not have been previously targeted by AED therapies. *Read the full article at the following link.*

[http://www.bcepilepsy.com/\\_pvw938F74FF/research/old\\_drugs\\_new\\_tricks.aspx](http://www.bcepilepsy.com/_pvw938F74FF/research/old_drugs_new_tricks.aspx)



BC Epilepsy Society is in its fourth year of partnering with Kids Up Front Vancouver, a charitable organization that provides access to arts, culture, recreation, and sports events for kids who otherwise would not have these opportunities.

The following are just some of the opportunities our families have been able to enjoy: Vancouver Canucks, Vancouver Giants, Vancouver Whitecaps, BC Lions, Vancouver Canadians, BC Ballet, Vancouver Symphony, Vancouver Art Gallery, Children's Festival, Vancouver Fringe Festival, and tickets to Play land.

Anyone can donate tickets to Kids Up Front, which in turn distributes them to partner agencies such as the BC Epilepsy Society to encourage mentoring and family bonding.

Childhood and adolescence are important periods from many developmental perspectives: physical, psychological, emotional, and cognitive. It's during this time that kids establish their value systems, learn to engage with others, and develop self-esteem.

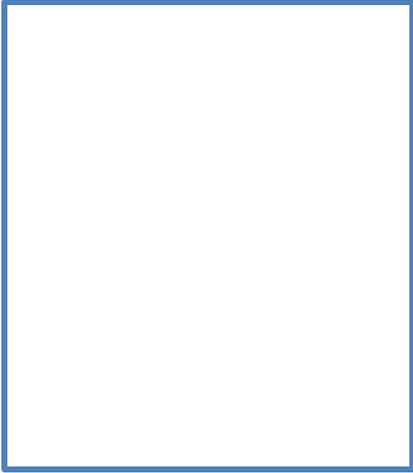
By supporting children who normally don't have access to leisure activities and family outings, Kids Up Front make these events possible.

Tickets are available throughout the year! If you are interested, please contact Marlyn Chow at the BC Epilepsy Society office.

Phone: 604-875-6704

*Having epilepsy does not mean you have to expect and cope with depression. Don't be afraid to reach out if you need to.*

## Exercise your right to good health



Having epilepsy increases your risk of developing high blood pressure and prediabetes, but with regular exercise, you can help manage those health problems. Staying active also eases depression, which is common in individuals with epilepsy. It combats bone loss—a side effect of certain anti-seizure medications, and it may even reduce the frequency of seizures, based on preliminary research. Try these exercises to get on track toward better overall health.

- Going for regular, brisk walks helps protect your heart and lungs and control your weight.
  - Bike riding is a great way to boost your health and fitness.
  - Swimming laps and doing water aerobics are wonderful ways to get fit. Just use caution, because a seizure in the water could be dangerous.
  - Active contact sports—such as basketball, soccer and ice hockey—can be a good workout for your heart and lungs.
  - Volleyball and tennis are great for your bone health and overall fitness. Plus, the risk of sustaining a concussion is lower than in contact sports.
  - Yoga doesn't just increase strength and flexibility. It also reduces stress.
  - Strengthening exercises should be a regular part of everyone's fitness routine. (*source: CNN*)
- 

## Tell your Story

“I want people with epilepsy to know that there are ways in which they can play a role in their own recovery. It’s all in how they approach what is happening and how they can use that as a catalyst for their own growth. If there’s one thing that I’ve learned, it’s that people are willing to embrace you if you share your story.” Danny Glover

## Hi, I'm Emily.....

*The contributor of this feature article is Emily, a 10-year-old girl with epilepsy. She is also a BCES Youth Ambassador. If you would like to reach out to Emily and her family please contact us at [services@bcepilepsy.com](mailto:services@bcepilepsy.com)" Below is a letter she wrote to share her experience with the Ketogenic Diet.*

Hi, I'm Emily.

I'm now 10 years old and would like to share my story, because I want children to know that if they have health issues they shouldn't care that they're not like everyone else.

I was six years old and on summer break when my family noticed I had seizures. I was washing my hands and all of a sudden hahahahaha I was laughing hysterically. My parents didn't know what was happening to my eyes. They were doing weird things and they rolled back into my head. I didn't know what had happened I just remember being confused and my mom shaking me yelling my name because I wasn't responding. My parents rushed me to the hospital and that is where the doctor in emergency thought I was having absence seizures.



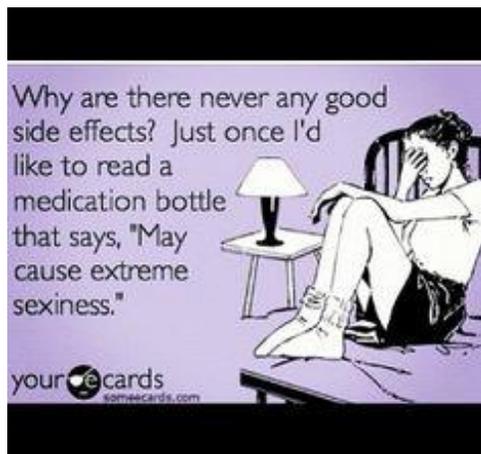
*He made us go to Children's Hospital a few days later. My parents researched about it and found out that I had epilepsy. The doctors at Children's hospital made me take an EEG exam. The doctors then confirmed that I had Epilepsy. The doctors told my parents to give me some medicine but unfortunately it didn't work. Then they gave me different medicine and I was still having lots of seizures. My parents tell me I was having over 300 per day. After being on different types of medication my seizures got worse. It seemed that no matter what the doctors did, my seizures didn't want to go away. This all happened in the first month of grade one. My parents and I were scared and we didn't know what we could expect. It was all very confusing and scary. The doctors at the hospital were all very nice and they even helped us have the BC Epilepsy Society come to my class and tell all the kids about epilepsy.....*

*Continue reading [here](#)*



## Did you know?

- Approximately 0.6% of the Canadian population has epilepsy. This includes those who take anticonvulsant drugs or who had a seizure within the past 5 years.
- Each day in Canada, an average of 42 people learn that they have epilepsy.
- Each year an average of 15,500 people learn they have epilepsy; 44% are diagnosed before the age of 5, 55% before the age of 10, 75-85% before age 18 and 1% of children will have recurrent seizures before age 14. Additionally, 1.3% are over the age of 60. This means that about 60% of new patients are young children and senior citizens. (source: Stats Canada)



## Know your triggers

There are many triggers that affect those living with epilepsy. Recognising them can help determine what may cause a seizure.

- \*Lack of sleep/change in sleep habits
- \*Flickering/flashing lights
- \*Stress
- \*Alcohol
- \*Missed medication

The BC Epilepsy Society was incorporated as a registered charity on August 17, 1959, under the leadership of pediatric neurologist Dr. Norman Auckland. Dr. Auckland believed that an increased understanding of epilepsy, among those living with the disorder and their families, could help those living with epilepsy to help themselves. The Society's programs and services today remain true to Dr. Auckland's original vision of support and education.

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