



**BC Epilepsy  
Society**

E-NEWS RELEASE

*Improving lives.  
Inspiring courage.*

December 6, 2016

## December 2016

### **A message from the Executive Director**

In my short time with the BC Epilepsy Society I have found one thing in common, passion. Each person I have met, from our professional staff, Board of Directors, Professional Advisory Committee, volunteers and the people we serve, adults and children, families, and caregivers, everyone is deeply committed to our Society. I have a heart-felt appreciation for the dedicated and hard working volunteers and staff. Having worked in the non-profit sector for over 25 years, I know that there is no greater reward than the opportunity to work with passionate people in an outstanding organization. I am truly inspired by so many, and thanks to our newest Board member, Katy Fairley for sharing her story.

It's been a busy and productive year. A few examples of accomplishments include:

Providing support, information and connection to other Society services through over 1,500 family meetings at BC Children's Hospital (BCCH) Neurology Clinic.

Providing ongoing support at our monthly in-person and on-line support groups..

Providing information through our information sheets at BCCH, Vancouver General Hospital Epilepsy Clinic and our website.

Responding to over 1,300 requests for information by email.

Responding to over 650 requests for information by phone.

Coordination of a Dravet Syndrome family education day, in collaboration with the BCCH Neurology Department.

Hosting and presenting a special Family Education event.

Hosting a special event with former Olympian Marion Clignet, who spoke about her life as an athlete and living with epilepsy.

I am very excited to join the BC Epilepsy Society at a time when we are planning for 2017. First, in the next week or so, we will launch a new and improved website to allow for easier navigation and to serve you better by sharing current information that has been vetted by our professional advisory committee – experts in the field of epilepsy treatment and research. More to come...

Best wishes during the Holiday Season

Lisa Westermark

Executive Director

## An Interview With Our Newest Board Member



As Vice-President, Business Development at Kinetic Construction, a Board Member, Vancouver Island Construction Association, Recipient of the "2014 Outstanding Woman in Construction", *Vancouver Regional Construction Association*, and a Past Board Member, Headway, Victoria Epilepsy and Parkinson's Centre, and newly appointed to the BC Epilepsy Society Board of Directors, Katy refuses to be defined by her epilepsy. We recently had a short interview with Katy and her experience living with epilepsy.

### **How were you diagnosed?**

I was diagnosed after a documented seizure the morning after my high school prom. I was 17. Documented just means it was seen by someone and I was lucky that my best friend was there and called an ambulance.

The ER doctor, to her credit, recognized immediately it was JME (juvenile myoclonic epilepsy) after talking with me, though more tests would be required. As she described the various symptoms of JME, I realized that I had been experiencing this form of epilepsy for years, probably since I was 14 years old.

I was leaving for university back east in 3 months. This was just one more thing I had to deal with and it was added to the laundry list of changes I was facing as I graduated. Looking back, it was a good distraction! My parents, somewhat surprisingly, let me work through it on my own. This was very helpful and I think allowed me to "grow up," feel like an adult, and deal with adult issues.

On the Internet, I found a message board dedicated to various neurological disorders and a board dedicated specifically to epilepsy. I posted a few times but did far more reading. Through that site, I learned how many types and forms of epilepsy there are.

### **Have you had challenges with medication?**

While I am no doctor, JME is a fairly benign and "easy to treat," meaning it responds well and can be controlled by medication. There are numerous types of AED (anti-epilepsy drugs) and I have taken 3 of them so far. For me, the most disruptive aspect of having epilepsy has been the side effects that come with the medication. The first drug I took caused me to gain a great deal of weight and my hair to thin (just what you want when you are 18!). I was put on a second drug to mitigate those side effects.

Thankfully, I've been on a drug with little to no side effects for nearly two years. I am very

grateful, not everyone who has epilepsy has that same experience with medication.

I have to be cognizant of my stress level and make sure I get the sleep I need. Both stress and lack of sleep are triggers for me.

### **Did you have concerns about telling your employer?**

I had a seizure in March of 2014, the first in 11 years. I had not told anyone at Kinetic that I had epilepsy. I couldn't drive for a few months – not until I was "cleared" by a neurologist. It was time to tell them. Kinetic was incredibly supportive and also gently curious; I was lucky in this regard. This gave me an opportunity to inform and educate, which is so crucial to changing people's perspectives on epilepsy.

### **How do you challenge stigma or stereotypes?**

I've had people comment upon learning I have it "but you are so well spoken!" This is always a bit of a head scratcher for me. Do they mean that people with epilepsy can't be well spoken or that every "normal" person is? It is important to talk about it because there is still a great deal of stigma surrounding epilepsy. It turned out others in my family had seizure disorders but it was not mentioned or talked about until after I ended up in the hospital. It was swept under the proverbial rug.

Additionally, I strongly and passionately dislike the term "epileptic." I am not an epileptic: I *have* epilepsy. It does not define me, no more than my blonde hair does. I'm not a blonde: I have blonde hair!

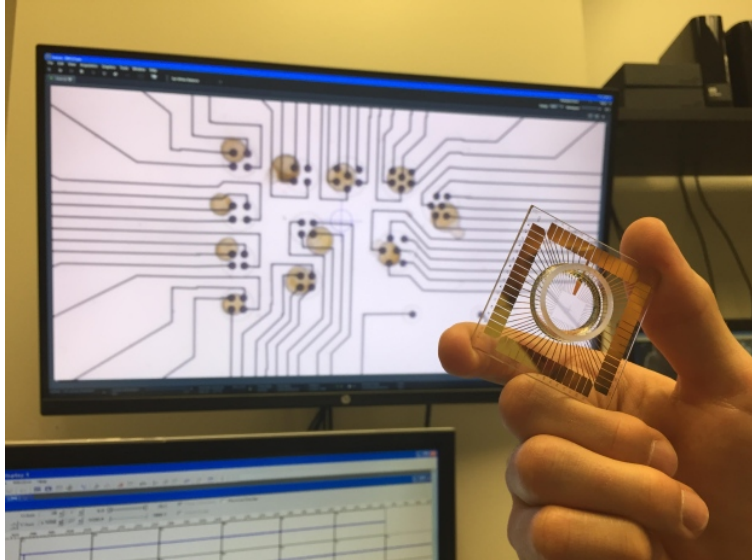
**Thank you Katy for sharing your story and inspiring others.**

## **Neuro Chip Could Help Scientists Identify Drugs That Work Best To Treat Epilepsy**

Scientists at the University of Calgary have developed a neuro chip that could one day be used in the treatment of Parkinson's, epilepsy and other neurological diseases.

The "bionic hybrid neuro chip" is able to record activity in animal brain cells for long periods of time, and in much greater detail than other existing technologies, according to lead researcher Pierre Wijdenes. That, he says, creates the opportunity to develop highly personalized medication in hard-to-treat epilepsy cases, for example.

"If you start to have seizures and you go your doctor ... the doctor will try different drug combinations on you. That will work for 50 to 60 per cent of patients, but for the other ones, this medication may not work," Wijdenes told [CBC News](#). In that case, one of the only options left for patients is surgery, in which the neurosurgeon would remove the part of the brain that is responsible for the seizures, he added. "We can take a sample of this tissue and do some drug testing ... right next to the O.R., and be able to test different drug compounds [and] find out the best medication that works [for this particular patient]," Wijdenes said. "So we're actually getting closer to personal medication in a sense." Wijdenes said the new chip is a "baby step" along the path to developing that kind of treatment, which could still be decades away.



Researchers place a sample of brain tissue in the chip, which can record the activity of neurons for weeks at a time in great detail. (photo, Jocelyn Boissonneault/CBC)

The chip works by mimicking the natural biological contact between brain cells, essentially tricking the brain cells into believing that they are connecting with other brain cells.

So far, the scientists have used the chip to take recordings from the neurons of a fresh water snail, *Lymnea stagnalis*, which provides structurally and functionally well-characterised neurons that are relatively large in size. They isolated individual neurons from the snails, cultured them in the laboratory and placed them on the chip inside an incubator. They then studied their electrophysiological activity over time. According to the researchers, whereas most setups can only record neuronal activity for a few minutes, the new neuro chip allows them to take continuous recordings for several weeks. This means that they can evaluate the effects of different drug compounds on neuronal activity over time.

Senior Author Dr Naweed Syed says "We don't know what goes wrong with conditions like epilepsy. This technology is proof of concept that we can integrate technology with the brain. We are hoping in the future we will be able to use these chips to regain lost brain function."

(source: CBC News , Jocelyn Boissonneault)

## 12 Tips For Managing The Holidays

The Holiday Season can be a hectic, exciting and stressful time for everyone and people with epilepsy are no exception. Being self-aware, avoiding your triggers, and planning ahead can help make the holidays happier.

### 1. Plan Ahead

Start early and plan ahead, last minute rushing around is the norm for many people but can be very stressful for someone with epilepsy.

Keep lists and focus on doing a certain amount each week, whatever is feasible.

Shopping online is increasingly popular and can help reduce the need to rush around the shops.

Set a budget and stick to it, you can share limits with friends and family so everyone has reasonable expectations and do not add financial stress.

Say "no". It's ok not to take on everything.

### 2. Transportation

Consider your energy levels and pace yourself.

Public transport can be in great demand at this busy time so try to avoid rush hour in order to get a seat.

Be realistic about what you can undertake and if someone offers to get something for you consider accepting the offer.

Shopping locally or online again can reduce the transport demands.

### 3. Eat Right

Do not skip meals: It might be tempting to pass by when you see long queues at restaurants when shopping but don't be tempted to skip meals.

During the holidays our patterns can alter so it's good to ensure you get to keep to a regular pattern of eating.

If you are on a Ketoenic diet, find options to incorporate into your holiday meals.

### 4. Take your medication

Take your medication as normal.

Ensure you have sufficient supplies of your prescription to last the holidays.

### 5. Get enough sleep

Regular sleep patterns are important for people with epilepsy.

If you are planning a late night try to ensure you are well rested prior to going out. If possible have some extra sleep the following day also. This will reduce your sleep debt (the amount of missed sleep you owe yourself).

### 6. Relax

Take a few minutes of quiet time each morning and evening to listen to a guided visualization, soothing music or do meditation – whatever method works for you to unwind and take a break from the cares of the day.

Breathe.

Get some exercise. Just going for a walk is great.

### 7. Limit or skip alcohol

Whether at parties or in the home everyone is potentially more exposed to alcohol over Christmas. Your doctor may have advised you on what is a safe limit for you. Stick to this advice, keep your intake moderate (typically 1-2 units) and avoid binge drinking. Don't be afraid to say no to another one.

Consider having Shandies instead or non-alcoholic beers and wines as options.

### 8. Avoid other stimulants and street drugs

Whether we are talking about high caffeine energy drinks or any kind of street drugs these are all associated with increasing seizures and must be avoided.

## 9. Christmas lights

While rare, flashing light is a trigger for a small number of people with photosensitive epilepsy the Christmas lights sold in stores here should all meet the required health and safety standards for flicker.

If it is not possible to avoid the lighting the simple measure of covering one eye with one hand should be sufficient to prevent a seizure on exposure to the flashing lights.

## 10. Excitement

Particularly for the children the anticipation of Christmas can cause huge excitement that, although it seems like fun, is felt by the body in a similar way to a stress reaction.

Keeping the atmosphere calm and routine stable can help prevent overexcitement and sleep problems.

## 11. Support (or lack of it)

Over the holidays, many people expect to spend more time than usual with family. A family that is supportive is a great bonus. If you lack a supportive family or network of friends this can leave you feeling isolated at an emotional time.

Consider in advance how you will obtain support to help you through the holidays whether through talking to your GP, joining a support group, getting referred to counseling, or calling a telephone helpline.

Don't be afraid to ask for the help you need to cope.

## 12. Manage your expectations

Keep your expectations for celebrations realistic. If you hope for perfection the likelihood is you will be disappointed at least some of that time.

Be flexible. The images we see in TV and advertising are idealized - the rest of us live in the real world. Sometimes "good enough" allows us to relax and enjoy more.

Enjoy the simple things.

(contribution source [Epilepsy Ireland](#) ).





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which provides education, advocacy, and support.*