



BC Epilepsy  
Society

E-NEWS RELEASE

Improving lives.  
Inspiring courage.

April 18, 2016

## April 2016

### A message from the Executive Director

Hello BC Epilepsy Community,

Spring is flying by and we have been working hard on new initiatives to better serve our community. As our services evolve we really want to hear from you. Please help us design and improve programs that meet your needs and make sure your voice is counted by completing a short five-question survey. The survey will help us better understand your experience living with epilepsy and BC Epilepsy Society. [SURVEY](#). We hope to check in with you regularly with short surveys posted on our social media so check-in frequently.

We are also excited to preview our upcoming event with the incredible professional athlete, Marion Clignet. Marion is coming this summer from France to give a public talk about her life, athletic career and how she thrives while living with epilepsy. Please see her bio below.

BC Epilepsy Society is pleased to welcome Megan Gelmon from Sana Counseling as a partnering volunteer. Megan brings both professional and personal expertise to our organization and we are looking forward to all she has to offer.

We would like to express on behalf of our staff and volunteers, a heartfelt thank you to you, our community, for your generous support. If it is within your heart and means, please consider becoming one of our [100 Champions](#). We look forward to hearing from you.

Have a wonderful and healthy month.

Regards,

Lori Eisenhaur

Executive Director

### In Recognition

In recognition of National Volunteer Week and we would like to take this opportunity to extend our gratefulness for our volunteers at BCES. We salute you!

## Monthly Volunteer Opportunity

BC Epilepsy Society is seeking to find a new partner for our print services. If you or anyone you know is interested in donating or offering a great non-profit discount on printing, please contact our office at [info@bcepilepsy.com](mailto:info@bcepilepsy.com)

## Introducing Megan Gelmon

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Hello everyone!

Nice to meet you! My name is Megan Gelmon. I have had epilepsy since I was 10 years old and I know that our beautiful city lacks resources for people like myself, and my family and perhaps you feel similarly. So, I'm very excited to be working alongside the BC Epilepsy Society.

I will be contributing to the BC Epilepsy Society in a few ways! Bi-weekly blogs on mental health and related topics will be posted to the website. I will also be putting on webinars that are free for our community and be sure to find me at monthly meetings!

I would love to help you and the society in any way possible! I suppose I should add that I am a Professional Registered Therapeutic Counsellor. If you would like some support on your journey with epilepsy, Sana Counselling is the name of my private practice and you or your family members are welcome, as our demographic is one of my specializations!

I am so glad to meet you! I look forward to getting to know you better. Stay tuned for more...



## Thriving with Epilepsy- Marion Clignet

**Coming August 14th, 2016, BC Epilepsy will be hosting Marion Clignet for an inspirational talk about thriving with epilepsy including an optional 5 km hike. Check back soon on our website and social media for registration. Please continue reading to learn more about Marion's accomplishments.**



Hi there.

My Name is Marion Clignet. At the age of 22, I discovered I had epilepsy, I was told I wouldn't be allowed to drive for a year. Why? We had to find the right treatment if possible that would allow me to live seizure free. A tad frustrated by this change, and frustrated by the way the doctors told me I had to be secretive around my epilepsy, because it was very taboo.

I decided to do just the opposite. I secured a job as a strength and conditioning coach 30kms from my house, and bought a bike to get me there and back. One thing led to another. I battled with neurologists to find the right medications with the least amount of side effects, and I fought hard to push myself forward and not get caught up feeling sorry for myself because of this sudden change.

I fought so hard, that I rode myself to win the following titles:

- • US National team time trial Champion
- • US National Road Silver Medalist
- • Qualified for the World Championships to represent the USA in 1990 (they then told me they wouldn't take me to worlds because I had epilepsy and was a risk to the team) We'll just say that I am never one to bow down to 'authority' and born of French parents, I finished that 1990 season in France and from there turned another chapter in my cycling career.
- • 10 x FRENCH NATIONAL Road, track and time trial Champion
- • 6 x WORLD PURSUIT, TEAM TIME TRIAL, and POINTS RACE CHAMPION
- • 2 x OLYMPIC SILVER MEDALIST (Atlanta and Sydney)
- • World record holder from 1996-2000 (3000m pursuit)
- • Over 250 victories including stage wins in the Tour de France and Giro Feminin
- • French Long Distance duathlon champion

- Sub 3hour Marathon (2'58 Paris 2013)
- Trail and mountain running races

I stopped racing bikes in 2003 and began coaching. My desire to share my knowledge, has taken me from coaching regional men to a Tour de France men's team as well as elite women. To nourish my addiction to endorphin producing sports, (don't worry they're legal!) I took up running and after a few years of pounding, injuring myself, trying to get paces right, trying all sorts of shoes, I'm at long last moving ahead! I have tried just about everything. I ran 10km, cross country and marathons. I'm now running trail and mountain races. 2016 has started with a bang and at present I've raced 5 races from 18km to 55km with loads of climbing and descending. Why do I continue? I THINK I'M ADDICTED!! And this is a good way for me to share with YOU that I may have epilepsy but epilepsy doesn't have me!

Look forward to meeting you all August 14th!

## **Even controlled, epilepsy may still cause problems for kids.**

### **Study finds social and educational issues may be a concern as children get older**

Even when their seizures are well-controlled, children with epilepsy can still have learning and behavioral disorders that lead to social and educational problems when they're young adults, a new study finds.

"Frequency and intensity of seizures remain important predictors of how well a child does into adulthood. But, somewhat to our surprise we also found seizures are by no means the sole influences of social and educational outcomes among adults with childhood epilepsy," said study lead author Anne Berg. Berg is a scientist with the Ann and Robert H. Lurie Children's Hospital of Chicago, and professor of pediatrics and neurology at Northwestern University Feinberg School of Medicine.

To read the full article, please click on this [LINK](#)

## **Opportunity for bereaved families to participate in research**

My name is Jasmine from Siena Consulting and I'm working with Canuck Place Children's Hospice on a family needs assessment of pediatric palliative care across the province.

For this study we are interviewing families of children with life-threatening conditions, including neurological disorders. We are talking both with families who are already on the Canuck Place program and with families who have never received Canuck Place services. The aim of the study is to understand the experiences and needs of families of children with life-threatening conditions and to identify strengths and gaps in the health and social systems.

I'm writing to ask for your help in reaching out to bereaved families who have not been connected to Canuck Place. Currently we are inviting families to participate in the study via Canuck Place's Facebook and Twitter accounts, and I'm wondering if you might also be willing to share information about this study through your social media channels.

We're asking families to follow this link to register: <https://www.canuckplace.org/canuck->

[place-childrens-hospice-study/](#)

Kind regards,

Jasmine Chipman Koty

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*The BC Epilepsy Society is a non-profit, charitable organization,  
which provides education, advocacy, and support.*