

BC Epilepsy Society

Welcome to the May 2019 edition of the BC Epilepsy Society Newsletter. INSIDE: Bursary Applications Now Being Accepted, Expo Recap .. AND MORE!



CHRISTINE JAMIESON WINS MISS CANADA!

e at the BC Epilepsy Society are excited to announce that Christine Jamieson was crowned Miss Canada at the 2019 Miss Canada pageant held in March 2019! Christine, who was crowned Miss BC at the 2018 Miss BC pageant held in July 2018, is a person living with epilepsy and an epilepsy advocate.

Christine was diagnosed with epilepsy at the age of 16 and has been using her platform as Miss BC to raise awareness of epilepsy in the community. She is eager to continue and expand upon the work she has been doing and use her new platform as Miss Canada to create positive change around epilepsy awareness.

We are so grateful for Christine's support of our I AM A VOICE for Epilepsy Awareness campaign (which is a BC Epilepsy Society initiative to decrease stigma and help people become more aware of epilepsy) and for the recent keynote address she did at our first annual I AM A VOICE for Epilepsy Awareness Expo!

Congratulations to Christine on your amazing win!



Book a Partners in Teaching Workshop Today!

pilepsy is a condition that is still misunderstood by many people. In fact, some people may have misconceptions, outdated views or inaccurate information about epilepsy, which can affect how epilepsy is viewed in society.

Through our Partners in Teaching program, the BC Epilepsy Society strives to improve the way that epilepsy and seizures are understood, regarded and dealt with. Partners in Teaching focuses on raising awareness of epilepsy; going over facts about epilepsy and refuting the myths; teaching people how to recognize and respond to a seizure; and providing training on seizure first aid and safety.

Partners in Teaching consists of free educational workshops delivered to schools across BC and paid workshops delivered to other organizations across BC. To find out more about Partners in Teaching, find it online at bcepilepsy.com/programs/partners-in-teaching.

To book a Partners in Teaching workshop at your school or organization, find it online:

bcepilepsy.com/programs-1/workshop-request-form-2

BCES IN THE MEDIA

Kim Davidson, Executive Director of the BC Epilepsy Society was featured in the media, receiving a radio spot on Red FM to promote our campaigns and events to their listeners and being featured on Breakfast Television alongside Vida Spa President, Allison Hegedus. Find out more about her Red FM appearance and her Breakfast Television appearance at: bcepilepsy.com/events/bc-epilepsy-society-on-red-fm and bcepilepsy.com/events/bc-epilepsy-society-breakfasttelevision-wednesday-march-13th









Be an Epilepsy Advocate for **Your Family!**

f you have a family member living with epilepsy, you can be an epilepsy advocate for your family to raise awareness of epilepsy, help your family and impact the lives of others living with and affected by epilepsy. If you want to be an epilepsy advocate for your family and are looking for ways to do so, check out some of our tips below:

- Use information about epilepsy to increase your own knowledge and educate others in the community about epilepsy
- Use our I AM A VOICE campaign, which is a BC Epilepsy Society initiative designed help you be a voice for people with epilepsy in your community
- Download and print out our I AM A VOICE banner and upload a picture of you and your family holding it to social media with the hashtag #bcepilepsyvoice
- Purchase I AM A VOICE shirts for the entire family from the BC Epilepsy Society online store and wear them proudly to show that you are a voice for epilepsy awareness



If you choose to be an epilepsy advocate for your family, you are in some pretty great company, like actor Greg Grunberg, who frequently advocates for his son who has epilepsy as well as others with epilepsy. Since his son was diagnosed with epilepsy at the age of 7, more than 15 years ago, Greg Grunberg has become a prominent figure in the epilepsy community. He partners with various epilepsy organizations and even uses his fame to bring special celebrity guests to his video series and website, Talk About It! that raises awareness of epilepsy. In November 2018, he was a speaker at the Epilepsy Awareness and Education Expo at Disneyland in November and spoke on behalf of LivaNova and the VNS therapy and how it has helped his son and many others who have drug resistant epilepsy. Find out more about his speech here: www.businesswire.com/ news/home/20181126005045/en/

We hope that all people with family members living with epilepsy will become epilepsy advocates for their family so that we are able to raise awareness about epilepsy in our communities!

Women and Epilepsy



It is important to discuss the ways in which epilepsy affects women specifically. It has been found that women living with epilepsy will face unique health challenges that men living with epilepsy do not face. This means that, in addition to the health challenges commonly associated with epilepsy that are faced by both men and women, women will also face additional challenges.

Some women living with epilepsy may not even be aware of these health challenges. This is why we all need to be better informed about what these health challenges are and how we can combat them. Some of these health challenges can include (but are not limited to the following):

- · Issues related to puberty and adolescence (such as hormones, menstruation, etc.)
- · Issues related to reproductive health (such as sexual health, contraception, pregnancy, etc.)
- · Issues related to parenting (such as breastfeeding, childminding, etc.)
- · Issues related to aging (such as menopause, bone health, etc.)
- Issues related to certain anti-epileptic medications

Find out more at:

bcepilepsy.com/programs/women-in-mind











EXPO & AGM



ast Monday, April 29th, the BC Epilepsy Society hosted our first annual I AM A VOICE for Epilepsy Awareness Expo, an educational event centered around knowledge exchange and health promotion. Guests gathered at the Italian Cultural Centre in Vancouver to learn about epilepsy, neurology, disabilities, mental health and related topics and to hear from inspirational figures, medical professionals, lawyers and many more!

> Watch our video recap of the event on our Facebook page.



First, our Executive Director, Kim Davidson, welcomed everyone, thanking the sponsors and partners who helped make the day possible; the presenters and speakers who would soon be sharing their knowledge and stories with us; and all of the attendees for coming together to be VOICES for epilepsy. She also mentioned the work that the BC Epilepsy Society has done for the past 60 years to support people living with epilepsy and their families and to raise awareness of epilepsy not just in BC and Canada but around the world.



Kim then introduced Councillor Christine Boyle, who said a few words about the event and the BC Epilepsy Society on behalf of the Mayor and City Council of Vancouver.

A representative shared words on behalf of The Honourable Jody Wilson-Raybould, who was unable to attend the event in person.





Next, keynote speaker, Christine Jamieson took to the stage to talk about her struggles with epilepsy and mental health and about how she uses her platforms both as Miss BC 2018/2019 and as Miss Canada 2019 to be a VOICE to awareness of epilepsy in the community.



After that, Cassidy Megan, the founder of International PURPLE DAY™ for Epilepsy Awareness, joined us from Nova Scotia via video chat, to discuss the importance of epilepsy awareness and the need to be a VOICE for epilepsy in our communities.



Attendees were then treated to the musical stylings of **Emma** Knelson, a singer/songwriter from Vancouver Island, who sang the first of her two songs of the expo, singing a cover of A Thousands Years.

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After this, Amanda Plomp, a marathon runner living with epilepsy, took to the stage to discuss her epilepsy journey as well as her story about running in races and marathons around the world. She mentioned how she is much more than just a person living with epilepsy and how she is much more than an athlete ... she is a VOICE.

After that, Fran Turauskis, the founder of Seize Your Adventure, joined us from the UK via video chat. She discussed her epilepsy journey and how doing solo hikes and other adventures post-diagnosis, inspired her to start a website and podcast platform to feature adventure tourism by people living with epilepsy all around the world. She also mentioned her 30 at 30 initiative of doing 30 adventures in the year she turns 30 and invited any attendees who would like to participate – whether in person or remotely - to join her in this adventure!





After a short break, professional golfer, engineer and ordained minister, Tyler Barton joined us from Texas via video chat. He discussed being diagnosed with epilepsy at a young age and how he competed to become a 2x World Long Drive champion. He also mentioned how he became a VOICE for epilepsy and how much he believes in what the BC Epilepsy Society does for people living with epilepsy and to raise awareness of epilepsy.

After this, a presentation on *Depression and Anxiety* was done by registered clinical counsellor, Rosalyn Best Clark from Ros Best Counselling. She mentioned that positive mental health is not just influenced by receiving support from others but also by providing support to others. She also talked about the importance of the BC Epilepsy Society to help the mental



health of people living with and affected by epilepsy, through our support groups, our Epilepsy Friends Forever (EFF) program and our BC Epilepsy Parents Network (BCEPN) program.



Just before breaking for lunch, the BC Epilepsy Society was awarded a cheque from Chalet Lights, totaling just over \$17,000 in donations!



After lunch, a presentation on Family Law, Custody Law and Epilepsy was done by Leena Yousefi from YLaw Group. She provided information on the parental rights of parents living with epilepsy, which was very helpful to many attendees.



After this, a presentation on Employment Law and Epilepsy was done by Jay Spiro from Yeager Employment Law. He provided information which was helpful not just for people living with epilepsy but also for people with other disabilities and/or other medical conditions.

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After a short coffee break, Allison Hegedus, President of Vida Spa and author, took to the stage to discuss her epilepsy story, how she became a VOICE for epilepsy and her career journey from being an esthetician, to a skin care sales rep, to a spa owner and finally to her current role as President of Vida Spa. She also discussed the book that she authored, entitled Unashamed and Unafraid: My Journey with Epilepsy, which will be released in Fall 2019, with 100% of proceeds going to the BC Epilepsy Society!

Attendees were again treated to the musical stylings of Emma Knelson, who sang the second of her two songs of the expo, singing a cover of Hallelujah.

> After presentation on Epilepsy 101 was done by Kelly Anderson, Epilepsy **Surgery Program** Nurse in the BC Children's

Neurology Clinic. She provided an informative talk on what epilepsy is, how epilepsy is diagnosed and treated and some important safety considerations to do with epilepsy.



The last presentation of the day was on VNS Neuromodulation Therapy and was done by Cameron Finlay from LivaNova. He presented on the implantable technology of VNS as a treatment option for epilepsy.

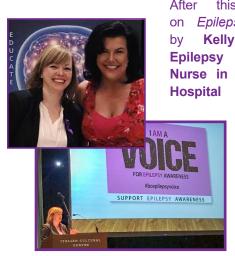
Attendees of the I AM A VOICE for Epilepsy Awareness Expo also got the chance to check out many booths at the event, including a booth by GOLD'S GYM, a photo booth that was enjoyed by many and a seizure virtual reality simulation put on by UCB!





We hope that everyone enjoyed the I AM A **VOICE for Epilepsy Awareness Expo! Videos of** the presentations will be shared on our website, YouTube channel and social media platforms, so keep an eye out for that!



















f you currently receive the Persons with Disabilities (PWD) Benefit and are about to turn 65, read on to find out what happens to your income once you turn 65.

Because the PWD Benefit requires individuals to pursue, accept and use other sources of income available to them, it is important to note that once people reach the age of 65, they are expected to switch to federal income benefits, also known as old age benefits.

To aid in explaining the transition from PWD benefits to old age benefits, Disability Alliance BC (DABC) has created a useful resource. Check out the online version of the resource at disabilityalliancebc.org/hs12b. If you would like a hard copy of the resource to be mailed to you, please contact Val at DABC at 604-875-0188 or feedback@ disabilityalliancebc.org.

We hope that this DABC resource helps people with epilepsy who are about to turn 65!



Bursary Applications Are Now Being Accepted for The 2019/2020 School Year!

ach year, the BC Epilepsy Society awards bursaries to people living with epilepsy in BC who are entering or who are in a post-secondary academic, vocational, arts, technical or technological program. Bursaries are awarded on the basis of educational commitment. volunteer work, and other achievements or interests. Bursaries can be applied towards tuition, books, oncampus housing, or other academic expenses.

To be eligible for a bursary, a student must demonstrate financial need, have a history of epilepsy, be 16 years or older, a Canadian citizen, and a current member of the BC Epilepsy Society. Please go online to bcepilepsy.com/get-involved1/become-a-member to become a member of the BC Epilepsy Society.

For more information about the bursary program, or to apply for a bursary, please go online to this link: bcepilepsy. com/donations/who-we-fund/bursaries



he BC Epilepsy Society would like to invite all people living with epilepsy to the various support programs that we offer. Please see below for further details:

In-Person Peer Support Group:

Sessions for young adults, adults and seniors with epilepsy. Takes place on the first Thursday of every month from 7:00 PM to 8:00 PM at our office at 2500 - 900 West 8th Avenue, Vancouver, BC V5Z 1E5.

Online Peer Support Group:

Sessions for young adults, adults and seniors with epilepsy. Takes place on the first Monday of every month from 7:00 PM to 8:00 PM in an online video chat format.

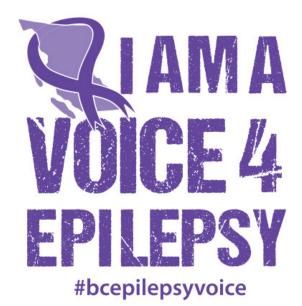
Epilepsy Friends Forever (EFF):

Provides a way for children, youth and adolescents with epilepsy to meet other children, youth and adolescents with epilepsy and allows them to have fun and relax with their peers, with whom they share similar experiences.

BC Epilepsy Parents Network (BCEPN):

BCEPN is a support group for parents of children with epilepsy and allows parents to share their experiences and get advice from others going through similar situations.

FIND OUT MORE: www.bcepilepsy.com/programs













EPILEPSY AWARENESS ON PU

arch 26th was Purple Day™, which is an international day for epilepsy awareness. Every year on Purple Day™, people in countries all over the world wear purple and participate in events and activities dedicated to raising awareness of epilepsy in our communities. Check out some information below to find out what the BC Epilepsy Society did to celebrate Purple DayTM and raise awareness of epilepsy!

On **Purple Day™**, we documented the amazing landmarks that lit up purple in honour of epilepsy awareness like Science World, the Olympic Cauldron and BC Place.

As part of our March is Purple Month! campaign, we also hosted two free workshops at GOLD'S GYM. Workshop participants were excited to learn more about epilepsy and seizures, how to recognize seizures when they occur and what to do if they witness a seizure.

Additionally, on **Purple Day™**, we had an information table at GOLD'S GYM with resources on epilepsy and a photo booth featuring our I AM A VOICE for Epilepsy Awareness campaign. Many people came to our table to ask questions about epilepsy and take photos to show that they are a voice for epilepsy awareness. Check them out below:











inally, on **Purple Day**™, members of our Brain in Mind club at Simon Fraser University hosted a purple-themed bake sale and urged everyone to increase their awareness of epilepsy. You can find out more about the Brain in Mind club here and check out some photos of their Purple Day™ bake sale below:





THROUGH

PURPLE DAY!

e hope that everyone had an amazing Purple Day™! Thank to everyone who posted their Purple Day™ photos and tagged us in them on social media!

Find out more about **Purple Day™** at **www.purpleday.org**

Our mailing address is: 2500 - 900 West 8th Avenue Vancouver BC V5Z 1E5

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WAY...





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