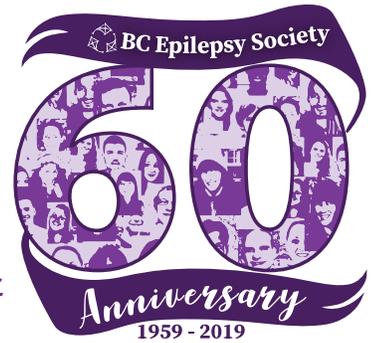




BC Epilepsy Society



Welcome to the OCTOBER 2019 edition of the BC Epilepsy Society Newsletter.

INSIDE: I AM A VOICE Website Launches, BCES Turns 60 ... AND MORE!



iamavoiceforepilepsy.com

As part of our 60th Anniversary celebrations, we are excited to announce the launch of the website for our **I AM A VOICE for Epilepsy Awareness™** campaign, which is our international initiative dedicated to raising awareness of epilepsy and decreasing the stigma associated with epilepsy around the world.

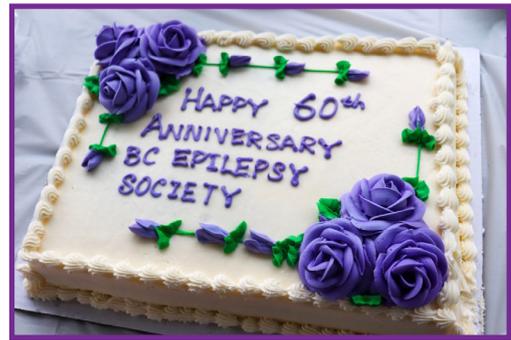
On the website you can learn more about the **I AM A VOICE for Epilepsy Awareness™** campaign, keep informed about some of the exciting things we have on the horizon and see our international reach by finding out about our champions and about the events we have participated in.

Check out the **I AM A VOICE for Epilepsy Awareness™** website today at iamavoiceforepilepsy.com ! Also don't forget to follow the **I AM A VOICE for Epilepsy Awareness™** campaign on Facebook on Twitter and on Instagram.

facebook.com/IAmAVoiceforEpilepsyAwareness

twitter.com/IVoicefor

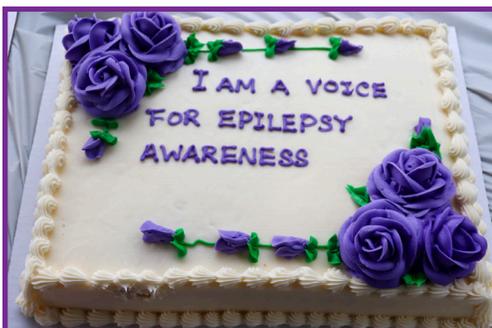
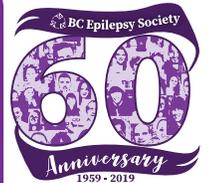
instagram.com/iamavoiceforepilepsy



BCES TURNS 60!

Since 1959, the BC Epilepsy Society has proudly served people living with epilepsy and their families in BC and has worked to raise awareness of epilepsy around the world. In August, we achieved a milestone of 60 years of service in the province. Here's to 60 years of the BC Epilepsy Society and here's to 60 more years!

To celebrate this momentous occasion, on Saturday September 21st, staff and board of the BC Epilepsy Society welcomed BC Epilepsy Society members, including people living with epilepsy and their families, to a celebratory picnic. Everyone joined in partaking in delicious food, conversations with friends, both old and new, and fun games and activities. Check out some photos from the picnic below:





BCES is Moving!

**ON DEC 1, BCES will be at
610 - 4180 Lougheed Hwy, Burnaby,
BC, V5C 4B3**

The BC Epilepsy Society will be moving to a new office on December 1st. The address of the new office is 610 - 4180 Lougheed Highway, Burnaby, BC, V5C 4B3. We are so excited for the move and we know that members of the BC Epilepsy Society will be too!

The new office space is larger than our current space, which will enable us to better house our In-Person Peer Support, our Epilepsy Friends Forever (EFF) and our BC Epilepsy Parents Network (BCEPN) groups.

bcepilepsy.com/programs/peer-support

bcepilepsy.com/programs/epilepsy-friends-forever-eff

[http://bcepilepsy.com/programs/
bc-epilepsy-parents-network-bcepn](http://bcepilepsy.com/programs/bc-epilepsy-parents-network-bcepn)

Also, the larger office allows us to have a dedicated filming space so we will be able to increase the amount of filming that we can do and the quality of our videos, so our YouTube channel and social media platforms will soon have even more amazing content for all of you to view!

Not only that, but the size of our new office space means that we will also be able to finally launch a volunteer program with enough space for a whole crew of BC Epilepsy Society volunteers! Stay tuned for more information on that!

The location of the new space is also amazing and accessible by public transit, being just steps away from Gilmore Skytrain Station. This means that our members and the people living with epilepsy that we serve will be able to get to our office easily!

If you want to see the new space, you should join us for our Open House and End of Year Party on December 14th from 11:00 AM to 1:00 PM. Members of the BC Epilepsy Society will be able to tour the new office so stay tuned for more information on that!

**Open House and End of Year Party
December 14th from 11:00 AM to 1:00 PM.
Members of the BC Epilepsy Society will be
able to tour the new office!**

Stay tuned for more information on that!



Giving Back To The BC Epilepsy Society

bcepilepsy.com/donations/making-a-donation

The BC Epilepsy Society is grateful to all of our donors who help to ensure that people living with epilepsy in BC are provided the help and support that they need to live full, positive lives. In fact, without the financial support of our donors, we simply would not be able to develop and deliver the many services on which our members rely. To learn more about the various ways you can donate to the BC Epilepsy Society, for more information, visit bcepilepsy.com/donations/making-a-donation

In addition to donating, there are many other ways that you can give back to the BC Epilepsy Society, such as running a campaign in your community to raise funds and awareness for the BC Epilepsy Society. If this sounds like something you would be interested in participating in and you would like to find out more, please contact us at 604-875-6704 or info@bcepilepsy.com.



**Epilepsy
Friends
Forever
October Session!**

We are excited to announce that the October session of **Epilepsy Friends Forever (EFF)** will be held on **Sunday October 27th**.

This event will be Halloween themed so we encourage everyone to dress up in their best superhero costume, with a purple theme for epilepsy!

We invite children and youth living with epilepsy between the ages of 6 and 17 to join us for this special EFF session on **Sunday October 27th**.

For more information, please email sonia@bcepilepsy.com



We are excited to announce that the BC Epilepsy Parents Network (BCEPN) will be returning on a new date! The BCEPN is a monthly in-person support group for parents of children with epilepsy.

Details are as follows:

Date: Third Thursday of every month
Time: 6:30 PM to 8:00 PM

Location: #2500 - 900 West 8th Avenue,
Vancouver, BC V5Z 1E5

The October session of BCEPN will be held on
Thursday October 17th.

Please email sonia@bcepilepsy.com to register.
<http://bcepilepsy.com/programs/peer-support>



We are excited to announce that BC Epilepsy Society staff member Jas Lachar will be continuing the Online Support Group, which allows people living with epilepsy to meet in an online videochat format to get better connected and strengthen their support networks.

Details are as follows:

Date: First Monday of every month
Time: 7:00 PM to 8:00 PM

For more information or to register, please email Jas at
jasdeep@bcepilepsy.com.

<http://bcepilepsy.com/programs/peer-support>



As part of our 60th Anniversary celebrations, we are proud to announce the launch of the BCES Men's Circle!

Imagine a circle of men going through similar experiences as you, who listen to what you have to say and hear the very best in you, even when you may not be able to find it in yourself. Imagine a circle of brothers who not only hear your words, but also hear your voice, your emotions and your energy. Imagine a circle of supporters who want nothing more to lift you up and help you in your time of need.

This is what the BCES Men's Circle is all about.

As a man living with epilepsy, you may be concerned about how epilepsy will affect your life or fear that you are dealing with epilepsy alone or feel as though you are the only person living with epilepsy. At the **BCES Men's Circle**, each man's pain, issues or concerns are recognized and validated.

Sharing your experiences during the BCES Men's Circle and learning from others will help put your mind at ease because the more you learn about epilepsy and how to cope with it, the less that epilepsy will be a huge concern in your life.

Listening to others share their experiences during the BCES Men's Circle will introduce you to new possibilities of behaving during and dealing with various situations related to epilepsy because so much wisdom can be found from others.

The BCES Men's Circle will take place on the second Thursday of every month from 7:00 PM to 9:00 PM at the BC Epilepsy Society office.

The first session of the BCES Men's Circle will take place on Thursday October 10th.

For more information and to learn how to register, please visit
<http://bcepilepsy.com/programs/bces-men-s-circle>





SETTLING INTO SCHOOL WITH EPILEPSY

We are about a month into the school year and it is a very exciting time for students. However, for parents, ensuring that your child has a positive experience at school can be stressful and if you are the parent of a child who has a medical condition like epilepsy, this can be even more daunting. If you are the parent of a child living with epilepsy, check out our tips below to help make settling into school more bearable:

Tip 1 – INFORM THE SCHOOL: As a parent, you are your child's best advocate, who knows them and their needs the best and it is important to communicate these needs with the adults that are charged with their care. You should meet with the principal and vice principal of your child's school as well as your child's teachers and any other staff members who supervise your child throughout the school day and provide them with information – both verbal and written – about your child's epilepsy. You may choose to give them information on the type of epilepsy that your child has; what their seizures typically look like; the frequency of their seizures, including the date of their last seizure; any seizure triggers they have; the names and dosages of their medications, including any pertinent side effects; and the protocol for seizure first aid.

Tip 2 – EDUCATE THE SCHOOL: All staff members at the school should be educated about epilepsy and seizures so that they can be better informed on how to deal with issues, should they arise. The BC Epilepsy Society provides free workshops, information and materials to schools through our **Partners in Teaching** program, which goes over seizure types and first aid, safety considerations, and ways that schools can support the academic and developmental needs of students with epilepsy. Find out more about the **Partners in Teaching** program at www.bcepilepsy.com/programs/partners-in-teaching and request a workshop for your school: <http://bcepilepsy.com/programs-1/workshop-request-form-2>

Tip 3 – PREVENT STIGMA AND BULLYING: For students living with epilepsy, stigma and bullying can be a serious concern. The more people learn about epilepsy and help to educate others, the easier it will be to dispel common myths about epilepsy to fight stigma and bullying. Check out our list of age-appropriate resources that can help children and youth get a better understanding of epilepsy at bcepilepsy.com/files/information-sheets/Classroom-materials-about-epilepsy-package.pdf.

You can also learn more about our **I AM A VOICE for Epilepsy Awareness™** campaign here: bcepilepsy.com/get-involved1/i-am-a-voice/i-am-a-voice-campaign which is our international initiative designed to help people become more aware of epilepsy and decrease stigma.

Tip 4 – GET SUPPORT: Epilepsy can too often be an isolating condition, which is why it is important to ensure that you have support networks in place. **Epilepsy Friends Forever (EFF)** bcepilepsy.com/programs/epilepsy-friends-forever-eff provides friendship, understanding, education and support in a fun and creative environment for children and youth living with epilepsy and the **BC Epilepsy Parents Network (BCEPN)** bcepilepsy.com/programs/bc-epilepsy-parents-network-bcepn is a support group for parents who have children living with epilepsy.

You can also check out our resources **School and Parent Partnerships and Understanding Students with Epilepsy: Tips for Teachers** for more information. bcepilepsy.com/files/information-sheets/Understanding-Students-with-Epilepsy-Tips-for-Teachers.pdf

We hope that you and your child have a successful school year!



The BC Epilepsy Society was featured in the media recently, with Executive Director, Kim Davidson, appearing on Global News on July 24th, 2019 and on Red FM on September 9th, 2019. Kim discussed seizures and epilepsy with their respective audiences during these appearances following the tragic passing of actor, Cameron Boyce, who passed away as a result of Sudden Unexpected Death in Epilepsy (SUDEP) on July 6th, 2019.

At each media appearance, Kim expressed her deepest condolences to Cameron Boyce's family, friends and fans and shed some light on epilepsy, which is still a very misunderstood condition. She also provided important statistics, such as that there are over 65 million people living with epilepsy around the world, that 1 in 100 people will develop epilepsy in their lifetime and that SUDEP affects approximately 1 to 2 of every 1000 people with epilepsy annually.

During her Global News interview, Kim also presented a mind-blowing statistic: that in the United States, the number of deaths attributed to epilepsy equals the number of deaths attributed to either breast cancer or traffic accidents, annually!

During her Red FM interview, Kim also provided valuable information on seizure first aid, which, considering that 1 in 12 people will experience a seizure at some point in their life, is important for people to know about so they can help someone having a seizure.

To find out more about her interview on Global News, please click [here](#). To find out more about her interview on Red FM, please click [here](#). The BC Epilepsy Society would like to extend our gratitude to Global News and Red FM for giving Kim Davidson the opportunity to speak to their respective audiences about seizures, epilepsy and SUDEP. We hope that other media outlets in Vancouver will pick up this important story as well. If any members of the media would like to reach out to the BC Epilepsy Society for media coverage, please contact the BC Epilepsy Society via telephone at 604-875-6704 or via email at info@bcepilepsy.com.

About 30% of people with epilepsy have refractory epilepsy, meaning that their seizures are not completely controlled by medications or by other treatments.

A research study has found that some people who have refractory epilepsy may have autoimmune epilepsy. What this means is that their epilepsy is caused by an overactive immune system that causes antibodies to attack proteins in their brain.

People with autoimmune epilepsy share similar characteristics, including high seizure frequency; short seizure duration; seizures while sleeping; a variability of seizure type with multifocality; rare postictal confusion; seizures in the temporal lobe; changes in memory, behavior and cognition; and epilepsy and seizures that are refractory to medications or other treatments.

When a person with epilepsy has the above characteristics, autoimmune epilepsy should be considered as a possible diagnosis and testing should be done to determine whether or not the person has autoimmune epilepsy as they may be able to be treated with immunotherapy. In fact, it has been found that immunotherapy may be able to reduce the overactivity of the immune system, better control seizures and make a huge difference in the lives of people with refractory autoimmune epilepsy.

If you have refractory epilepsy with similar characteristics to what was listed in this blog post, you may want to talk to your healthcare provider about getting testing done to see if you have autoimmune epilepsy and if you may be able to be treated with immunotherapy.

For more information on autoimmune epilepsy, check out the research study at www.ncbi.nlm.nih.gov/pmc/articles/PMC5817820/

EPILEPSY AND MENTAL HEALTH AND WELL-BEING



As epilepsy can have a profound affect on mental health and well-being, it is important to influence positive mental health in people living with epilepsy. Here are some ways that you can help:

Learn about the effect of epilepsy on mental health:

- It has been found that 1 in every 3 people living with epilepsy also experience mental health issues. Find out more about the effect that epilepsy has on mental health issues, such as depression: bcepilepsy.com/files/information-sheets/Depression_and_Epilepsy_2016.pdf and anxiety: bcepilepsy.com/files/information-sheets/Stress_Management_2016.pdf

Encourage people living with epilepsy and their families, friends and loved ones to join a support group:

- It has been found that receiving regular support can positively influence mental health and well-being. The BC Epilepsy Society offers Peer Support for adults living with epilepsy bcepilepsy.com/programs/peer-support Epilepsy Friends Forever (EFF) for children and youth living with epilepsy; bcepilepsy.com/programs/epilepsy-friends-forever-eff and the BC Epilepsy Parents Network (BCEPN) for parents of children living with epilepsy bcepilepsy.com/programs/bc-epilepsy-parents-network-bcepn

Encourage people living with epilepsy and their families, friends and loved ones to seek out help from a professional:

- It has been found that when people living with epilepsy received treatment not only for their seizures, but also for their mental health issues, they had better seizure control and a greater quality of life. You may choose to see a registered clinical counselor, a psychologist a psychiatrist, a neuropsychologist or a neuropsychiatrist. Seeing a neuropsychologist or a neuropsychiatrist may be the best option as they have specialized training in neurological disorders and how they affect mental health

Raise awareness of epilepsy to reduce stigma:

It has been found that stigma can lead to significant mental health issues for people living with epilepsy and their families, friends and loved ones, therefore, it is important to combat stigma. Through our international I AM A VOICE for Epilepsy Awareness™ campaign, iamavoiceforepilepsy.com, you can educate yourself and others about epilepsy to raise awareness of epilepsy and reduce stigma.

It is important to take the necessary steps to influence positive mental health and well-being in people living with epilepsy to allow them to live full, positive lives



The BC Epilepsy Society is Proud of the Government of Saskatchewan for Funding the First Epilepsy Monitoring Clinic in Saskatchewan



The BC Epilepsy Society is proud of the government of Saskatchewan for funding the first Epilepsy Monitoring Unit in Saskatchewan. With its four dedicated telemetry beds, the forthcoming Epilepsy Monitoring Unit at Saskatoon's Royal University Hospital will serve the over 10,000 people living with epilepsy in Saskatchewan. The government of Saskatchewan will put forward \$1.3 million for the Epilepsy Monitoring Unit, with the Royal University Hospital Foundation planning to raise an additional \$1.2 million.

Saskatchewan Minister of Health Jim Reiter stated that "[the Saskatchewan government] is committed to improving access to high-quality health care services for people with epilepsy [in Saskatchewan]." The CEO of the Royal University Hospital Foundation, Arla Gustafson, added that "For people living with epilepsy, this is life-changing" as the Epilepsy Monitoring Unit will be able to "improve [the] ability [of the Royal University Hospital] to assess and determine if patients are candidates for surgery." Additionally, Dr. Jose Tellez, who has been lobbying for an Epilepsy Monitoring Unit in Saskatchewan for over a decade, was quoted as saying that this is "a historical day for patients with epilepsy in the province."

The Epilepsy Monitoring Unit is aimed to be opened sometime in the 2020-21 year. With the generous help of the provincial government of Saskatchewan and the Royal University Hospital Foundation, the Epilepsy Monitoring Unit will make a huge difference in the lives of the over 10,000 people living with epilepsy in Saskatchewan. Kim Davidson, Executive Director of the BC Epilepsy Society stated that "We are very proud of the government of Saskatchewan for taking such a vested interest in the lives of the people living with epilepsy in their province. We hope that the government in BC will see what Saskatchewan has done and follow suit with the health care needs of the people living with epilepsy in BC." Kim Davidson, on behalf of the BC Epilepsy Society, hopes to have conversations with BC Premier John Horgan and BC Minister of Health Adrian Dix about how to improve the lives of the over 40,000 people living with epilepsy in BC.

To find other news and press releases by the BC Epilepsy Society visit: bcepilepsy.com/news/news-updates

Rachel's Story

EARLY LIFE AND DIAGNOSIS:

My name is Rachel-Anne de Guzman. I currently live in BC, but I was born in the Philippines in 1978. My mother immigrated to Canada in the early 1980's to study and work as a nurse, with my father and I immigrating to Canada in 1982. Shortly after we arrived in Canada, my sister, Sharon was born and we all lived in BC, where my father worked as a Corrections Officer and my mother worked as a Dialysis Nurse.

When I was 11, I was diagnosed with epilepsy. It was first detected after I collapsed while performing at a school concert. After being rushed to the hospital, I underwent many tests, which included an MRI, CT, EEG and blood work. Eventually, these tests indicated that the cause of my collapse was that I suffered from epilepsy, although the tests were unable to show conclusively where in my brain my seizures originated.

Soon after being diagnosed, while taking part in a swimming lesson, I had a seizure and nearly drowned. I was rescued by lifeguards who had to provide me with CPR in order to resuscitate me.

In the years following my diagnosis, both the frequency and types of seizures I was suffering from increased. The frequency increased to an average of four major seizures per month and the types of seizures I was suffering from grew to include tonic-clonic, atonic, absence and focal impaired awareness seizures.

In the early years, I was prescribed a variety of anti-epileptic drugs (AEDs), all which provided me with little benefit and

led to some serious side effects. I also tried the Ketogenic Diet but had to end it as it proved unsuccessful in treating my condition.

Following my diagnosis, my parents had difficulty accepting that I had epilepsy, as our family had no prior history with epilepsy. So, in order to receive a second opinion, my parents took me to the United States to see an Epileptologist and, following further tests, they were able to confirm the original diagnosis that I had received in Canada.

Although I know that my parents loved my sister and myself equally, part of my problem as a child with epilepsy was the fact that I believed I wasn't good enough as I failed to meet the high expectations of my parents, especially in comparison



to my sister who was both academically and otherwise a high achiever. This led me to become indecisive and lose confidence in myself, resulting in low self esteem which I am still working hard to overcome to this day.

SCHOOL:

Post-diagnosis, I attended many schools, which included two elementary and four secondary schools. The reasons I changed schools as often as I did was mainly due to the constant disappointment of my parents in my academic performance and their hope in finding a school for me that could accommodate my needs and improve my performance. Constantly changing schools caused me considerable stress by making it difficult in trying to

meet their expectations academically, keeping friends and always feeling like an outsider. Despite all of these challenges I did eventually graduate from high school.

Following my high school graduation, I pursued a career in early childhood education and as a care aide. I chose this career as I anticipated that I would greatly enjoy working with children, seniors and persons with disabilities. Despite my own disability, I was able to graduate with a long-term care aide diploma from Gateway College and a Certificate in Early Childhood Education from Douglas College. My choice of career has proven to be a good decision as the joy I have received in working with and helping others has been a great benefit in my life.

EMPLOYMENT:

I found it more difficult than I had initially expected to find a long-term position of employment in my chosen field. At first, I handed out a lot of resumes and completed a number of interviews all with little confidence of landing full time employment in my field. I did eventually land a few jobs at daycare centres which I greatly enjoyed but unfortunately, I had several seizures on the job site which eventually led me to being laid off due to the perception of my employers that I posed a risk both to the children I supervised and myself.

At this point I began to lose hope that I would ever be able to find stable employment in my field. With this added stress, my frequency of my seizures increased. At this point my Epileptologist helped me successfully apply for disability support.

Starting in 2017, my seizures improved significantly so that, by 2019, with the approval of my Epileptologist, I began working part time as a care aide with certain conditions.

MY FAMILY:

I met my now-husband Jhun in 1996. We began living common-law in 2000 until we married in 2018. We have two daughters together, Joanne-Faith, born in 2000, and Kiyanna-Gail, born in 2005.

continued on next page

I have taught both of my daughters' seizure first aid so that if I had a seizure they wouldn't panic and knew what to do. We are blessed and eternally grateful that both children are healthy and have shown no indication that they have inherited epilepsy.

Joanne-Faith is now 19 years old and is working two part time jobs in order to pay for her tuition to become a psychologist. Kiyanna-Gail is now 14 years old and is an excellent student who is also a competitive dancer.

MY HEALTH NOW:

Currently, my health is pretty good. The type of seizures that I am primarily experiencing have been identified as refractory and nocturnal. In recent years, I have only experienced absence or focal seizures on the rare occasion. I am experiencing two to three seizures per month with each seizure lasting a few seconds up to a minute and a half. Through experience and consultation with my Epileptologist, we have begun to identify the most likely primary triggers are stress, lack of sleep, worrying and overthinking. The AEDs that I am currently taking to control my epilepsy include Aptiom, Lamictal and CBD Hemp Oil, as well as a few vitamins and supplements. I also take Lorazepam after each seizure in order to prevent more from occurring.

The three stages of a seizure are aura, ictal and post ictal. During the aura stage – the physical and emotional events someone experiences prior to a seizure – I usually tend to say “Help, I think I'm going to have a seizure” or I call out a person's name and then have quick blackouts, similar to an atonic seizure. During the ictal stage – the seizure itself – I experience uncontrollable jerking movements of my legs and arms, make garbled noises, and most often have loss of bladder control.

During the postictal stage – the recovery stage – I experience headaches and am very confused about where I am and what just happened. I am also very sleepy and feel embarrassed due to my loss of bladder control and everyone staring at me.

In 2014, I went to Calgary to undergo related testing in hopes of identifying the areas of the brain where my seizures originated. The results of this testing were reviewed by a team of as many as ten epileptologists. Although they were unable to determine the precise location of my seizures, they were able to determine it was coming from somewhere in the occipital, frontal and temporal lobes.

Based upon the results of that testing, the team of Epileptologists recommended that I undergo brain surgery; however, I opted not to go ahead with the surgery.

As far as the future is concerned, I am currently on the wait list for an invasive EEG video monitoring and possibility of temporal lobectomy surgery.

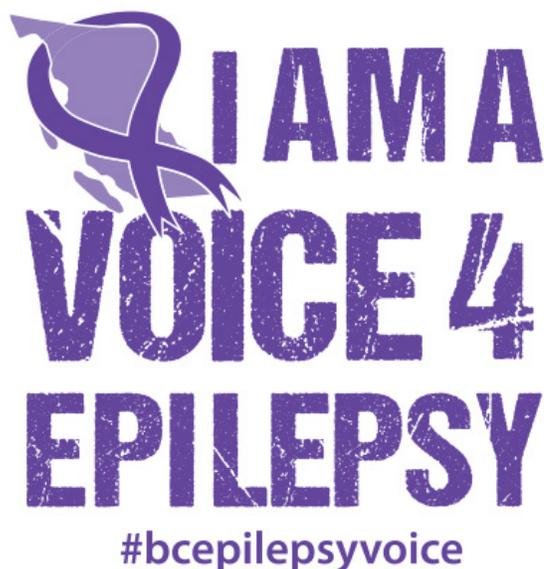
CHALLENGES AND COPING STRATEGIES:

There were many challenges I encountered and coping strategies I developed in dealing with my epilepsy. The challenges were injuries, some emergency visits to the hospital and the dentist, poor memory, lack of concentration, depression, anxiety, embarrassment, the cost of medications and having to rely on public transit.

The coping strategies I have developed that I believe help me include looking up inspirational quotes, praying, talking to members of my support system, attending an epilepsy support group and doing research about epilepsy in order to increase my knowledgeable about my condition.

WISDOM AND MOTIVATION:

I hope my story can serve to educate others who struggle with their own disabilities so they will be able to enjoy life as I now do. I have learned, and I truly believe that life is a precious gift. I have also come to understand that although an obstacle such as epilepsy can pose a significant challenge, for anyone who is able to conquer that challenge the confidence that you gain can become your greatest strength. In the end I say to have faith that you will become stronger, wiser, and more confident.



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

ON DEC 1, BCES WILL MOVED TO
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