# **2020 Annual General Meeting**

Date: July 22, 2020 Time: 5:00 pm

Location: 4932 Mt. Lehman Rd, Abbotsford, BC V4X 1Y3



# The Center for Epilepsy and Seizure Education in BC

### **A Seizure Free Tomorrow**

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"We would like to acknowledge the traditional ancestral unceded shared territory of the Sumas First Nation and Matsqui First Nation. These two First Nations are part of the Stó:lō Nation. The Stó:lō people have lived in the Fraser Valley for 10 000 years. It is for this reason that we acknowledge the traditional territory in which we reside."

# **2020 Annual General Meeting**

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# **2020 Annual General Meeting**

# Agenda

- 1. Welcome and call to order
- 2. Member Attendance
- 3. Adoption of Agenda
- 4. Previous minutes March 6, 2019
- 5. President's Report
- 6. Treasurer's Report
- 7. Approval of 2019 Audited Financials
- 8. Appointment Michael P. Forcier, CGA. Accountant for 2020
- 9. Old Business
- 10. New Business-Bylaw change
- 11. The appointment of legal services for 2020



## The Center for Epilepsy and Seizure Education in BC

### **Board of Directors**

President - Ted Downey

Chairman - Dr. Dayan Muthayan Secretary - Supriya Bhargavan

Treasurer - Flo Dohms
Director - Judy Ross



## **Staff Listing**

**Executive Director - Laura Cherrille** 

Client Support Coordinator - Rupinder Bhatti

Administrative Assistant - Catherine Ohlsson

### The Center for Epilepsy and Seizure Education in BC

### A Seizure Free Tomorrow

### **Our Mission Statement**

We are dedicated to providing support, information, and education for families and individuals who live with epilepsy, their support staff, educational personnel, friends, co-workers, health care providers and anyone else affected by epilepsy.

#### Goals:

To educate children and adults who witness a seizure not to be afraid and to provide them with the essential information and first aid skills that will furnish them with the self-confidence to correctly manage a seizure. To minimize the social stigma for children and individuals who live with epilepsy.

To ensure there is access to support, educational materials and programs that will enhance self-care and quality of life for those who live with epilepsy. To establish and deliver educational programs that will maintain a flow of information to the public, government and community agencies, schools and medical professionals surrounding epilepsy.

These programs will also identify access to support for those affected by epilepsy.

#### **Our Activities Statement:**

- 1) To identify, advocate, educate and create awareness surrounding epilepsy and the needs of those we represent.
- 2) To assist those we represent in obtaining access to support for school, work and at home.
- 3) To network and create links for those we represent with government and other support agencies .
- 4) To create and produce educational materials in multimedia formats.

# **Presidents Message**

Dear Members,
Thanks to all our members, those attending and those unable.
As of today, we are up against another medical curveball, nothing new to those with epilepsy.
With this being our 20 <sup>th</sup> year, we continue our support of those with epilepsy through individual and group support situations. With our education and awareness we are now able to reach further than those in a face-to-face situation. We are able to do this through the use of internet platforms; an exciting step.
I would like to thank our Executive Director Laura Cherrille, and our Client Support Coordinator Rupinder Bhatti for your continued support by shouldering the load keeping our offices moving forward through the most unusual times. My heartfelt thanks to you both.
Also to our Board Chair Dr. Dayan Muthayan for not only his professional work, but his Board guidance, and making his home available for today's AGM. Our Secretary Supriya Bhargavan, Treasurer Flo Dohms, Board Member and substitute in the Secretary role Judy Ross and my thanks as well to Dr. Abhishek Purohit who has stepped down because he has taken up a fellowship at the University of Toronto.
Last but not least to BC Gaming for their financial support as without them we would have a very hard time existing.
My thanks to all of you for attending today and I look forward to our next year ahead.
Sincerely,
Ted Downey
President

### **Treasurers Note**

#### **Treasurers Report**

The past year has been another challenging one, but also a rewarding one. With the help of our faithful supporters, especially the Community Gaming Grant Division, we have been able to continue to help those living with Epilepsy and the people around them who are affected by it. We could not do this without you!

I want to give a huge thank you to our staff, who have gone above and beyond to keep us going, to our faithful volunteers for their sacrifice of time and effort. Thank you to the individuals and their families who entrust us to give them help and walk along side them. Thank you to the schools and businesses that invite us to tell them about Epilepsy and its effect on lives.

There has been much done to educate the public about Epilepsy, to help reduce the stigma surrounding the condition. But there is still much to be done. It is our privilege to serve in this capacity.

Respectfully Submitted

Flo Dohms, Treasurer

The Center for Epilepsy and Seizure Education in BC

Horence Dohms

## **Election of Directors**

# **Proposed Slate of Directors 2020/2021**

Ted Downey

Dr. Dayan Muthayan

Flo Dohms

Supriya Bhargavan

**Judy Ross** 

## **Proposed Executive**

Ted Downey- President

Dr. Dayan Muthayan- Chair, Vice President

Flo Dohms-Treasurer

Supriya Bhargavan-Secretary

## **Our Major Events**

## Summer Magic Dance

On June 15, 2019, we hosted our annual dance at the Legacy Banquet Hall in Abbotsford. The night was full of amazing live music, games and fun! We appreciate "No Code Blue" for coming out and keeping our guests dancing all night.

Thank you to our generous sponsors and partners for supporting this event. The funds raised at this dance has assisted us in fulfilling our mission statement.









## **Our Donors and Sponsors—with Thanks**





## **Corporate Sponsors/ Donors**

WESTJET ABBOTSFORD CENTER

MCDONALD'S HARD ROCK CASINO

VANCOUVER AQUARIUM VANCOUVER THEATRESPORTS

SANDPIPER RESORT MEMENTO MORI STUDIOS

HARRISON HOT SPRING RESORT PACIFIC NATIONAL EXHIBITION

& SPA

**BC LIONS** 

FUSION HAIR SPA EVERYTHING WINE

BE FLAWLESS BEAUTY BAR

**OLD ABBEY ALE** 

**NUMBERS UNLIMITED** 

ABBOTSFORD INTERNATIONAL

ROYAL BC MUSEUM AIR SHOW

SOBEYS (SAFEWAY) COSTCO

SALON KISMET FIELDHOUSE BREWING

DOLLARAMA CANADIAN TIRE—ABBOTSFORD

CAPILANO SUSPENSION BRIDGE RUSTY'S AUTO TOWING LTD

"We acknowledge the financial support of the Province of British Columbia."



H.O.P.E. Campaign Program – In supporting our H.O.P.E Campaign, you are changing the story around epilepsy, and you are breaking the silence for so many living in the shadows of epilepsy. We are truly grateful to all of you! Together we will provide HOPE for many.

# Guardians of H.O.P.E. – Monthly Donors

We started Guardians of HOPE for our monthly donors and continue to build on this campaign for 2020 .

The monthly contributions will be put toward important programming areas, such as: client support, education, public awareness and public policy. Through these programs, we will one day realize our mission: A seizure free tomorrow.

# Patrons Of H.O.P.E. – Yearly Donors

Our Patrons of HOPE are donators who contribute annually for more than two consecutive years. Our patrons are dedicated donors who are committed to supporting us on an ongoing basis.

# Champions Of H.O.P.E. – Volunteers

Our volunteers who donate their valuable time/services. A Champion is often a financial donor as well, but we want to recognize the donation of time in a separate category. Our volunteers really are champions!

**THANK YOU!** 

## **Jaymie-Lynn Robertson Memorial Fund**

A very special thank you to Chad Robertson and Belinda McIsaac for their continued support of our programs in loving memory of their daughter, Jaymie-Lynn Robertson.

We are so very grateful for all that you do.





Special thanks to Hub International Barton for their continued philanthropy to help us support, raise awareness for and educate families affected by epilepsy.

**Thank you** to all the contributing Insurance Companies in 2019:

The Boiler Inspection and Insurance Company



# **Program & Volunteer Statistics**

Program	Statistics
Education & Awareness	<ul> <li>Provided 25 presentations to         ⇒ 1120 participants regionally (e.g. Surrey, Abbotsford, Mission, North Vancouver, Chilliwack) &amp; assisted by 1 volunteer who gave 6 hours of time.</li> <li>Ketogenic Diet Livestream Presentation for 10 in person attendees &amp; 200 viewers.</li> <li>Annual Purple Day Walk for Awareness (120 attended)         ⇒ 19 volunteers providing 89.5 hours         In kind value of \$1790.00</li> <li>15 Resource packages sent out to various towns in Northern BC, the Okanagan, and in the greater Vancouver area.</li> </ul>
Client Support	<ul> <li>Provided a total of         ⇒ 1233.5 hours in client support hours for 84 clients         served from all over the province         This included in person support, telephone support and email         support.</li> <li>Mandala Rock Painting Art Livestream         ⇒ 20 clients in person and 250 viewers online for a total of         270 participants.</li> </ul>
Volunteer	<ul> <li>Fundraising         ⇒ 15 volunteers providing 85 hours of support             In kind value of \$1700.00     </li> <li>Administration         ⇒ 6 volunteers providing a total of 280.75 hours             In kind value of \$5615.00     </li> <li>Repairs and Maintenance         ⇒ 1 volunteer providing 4 hours of support-             In kind value of \$80.00     </li> <li>Practicum Student         ⇒ 84 hours given in all areas of the Center             In kind value of \$1680.00     </li> <li>Total Volunteers: 42 positions providing 543.25 hours with an in-kind value of \$10,865.00</li> </ul>

### **Client Support Services**

The Center for Epilepsy and Seizure Education in BC is committed to improving the lives of people who live with epilepsy, which is the fourth most common neurological disorder that affects people of all ages.

Some risk can be mitigated through education and counselling. Patient education also increases self-confidence. It provides knowledge and tools to enable more active participation in health care, and preparation to self-advocate, ultimately improving health outcomes and quality of life. People who come to us range from the overwhelmed newly-diagnosed patient, to the person who has had epilepsy for a longer time but faces depression, hurdles at work, difficulty at school, or social isolation. Public misunderstandings of epilepsy can cause challenges that are often worse than the seizures. We also provide services to parents and other family members of people living with epilepsy. There is an ongoing need for Client Services.

### Mandala Rock Painting - Client Support through Art Expression

Our Mandala Rock Painting evening on July 9, 2019 was a great success! Our Center was packed with budding artists, who, under the instruction of the fabulous artist, Freda Lombard of Zealous Art, were soon producing works of serious beauty. Freda did a fantastic job of explaining the technique in a calm manner, making every one of us feel relaxed and ready to express our inner artist. As we painted our rocks, Freda offered praise and suggestions, fine-tuning our technique. Her quiet enthusiasm and gentle humor were contagious and helped us overcome our fears and embrace our own vibrant and perfect individualities. Thank you so much Freda for making this an exceptional and memorable evening. And thank you to all our attendees for sharing your artistic journeys with us.



In 2019 The Center for Epilepsy and Seizure Education in British Columbia continued to extended its reach to many communities throughout the province. Every encounter increases our exposure to the community at large and expands awareness of who we are and what we can do to help individuals and families living with epilepsy. We reach out to the community in many ways.

#### **Our Client Support Services Program provides:**

- Individual and family support— This may be as brief as a question, or an hour-long session. All encounters follow a client-led model where the needs felt by the individual dictate the direction of the session. Clients access this service via face-to-face sessions, email and telephone conversations.
- Client group support through art expression.
- A package of resource materials for parents and children who are newly diagnosed.
- Advocacy at work and in school settings.
- Case assessment and referral resources.
- A quarterly e-newsletter that provides updates from the Center for Epilepsy and can include any new informative articles and links.
- Opportunities for children with epilepsy to attend summer camp where they expand the horizons of their capabilities and experience the fun and activities that would otherwise be unavailable to them.
- Preparation and resources for doctors visits.

#### **Accessibility**

Our services are provided free of charge. Epilepsy profoundly affects not only the individual, but the entire family. Services extend to family members, friends and interested parties. We travel throughout the lower mainland to deliver services, especially when required to visit a workplace or school. Beyond the lower mainland we are able to connect with clients through telephone, Skype, email and Facebook.

### **Community Connections**

#### **Lower Mainland**

Abbotsford Richmond
Aldergrove Rosedale
Burnaby Surrey
Chilliwack Vancouver
Coguitlam White Rock

Delta Langley Maple Ridge Mission

New Westminster North Vancouver Port Coquitlam Port Moody

### Southern Vancouver Island

Nanaimo

Victoria & Salt spring Island



### **Education & Awareness**

"Knowledge is power. Information is liberating. Education is the premise of progress, in every society, in every family" Kofi Annan

The words of Kofi Annan ring true with the beliefs of The Center for Epilepsy. The more knowledge people have about epilepsy and seizures, the more we can remove social stigma and barriers for those living with this neurological condition. The world is indeed in need of change in the way people with epilepsy are perceived and understood. Statistics indicate that individuals who either have epilepsy or had epilepsy in childhood, are underemployed and achieve lower educational outcomes than their peers. Our mandate is to reduce misinformation and educate the public to diminish unfair perceptions and prejudice. Misconceptions, even unintentional, can create undo difficulty in school, work, and social relationships. The end result is loneliness, social isolation and depression.

In 2019, we reached many various groups of people through presentations and workshops. We work hard to maximize understanding by tailoring each presentation to the needs and level of each audience. Our talks meet or exceed best practice guidelines for educational presentations established by the Canadian Epilepsy Alliance.

### **Ketogenic Talk**

On April 29, 2019, we live streamed our first Ketogenic Diet talk by Sepideh Sarbazi, MSc, RD.

Sepideh is a registered dietitian with the College of Dietitians of BC and Dietitians Canada. She has a Master of Science in Human Nutrition and has worked in both hospital and outpatient clinics under the Vancouver Coastal and Fraser Health Authorities. Currently, Sepideh is a Home Health Dietitian with Vancouver Coastal Health working as part of an interdisciplinary health care team, providing nutrition assessment, counselling, education, and care planning to clients. She also enjoys giving presentations on topics of interest, such as the ketogenic diet, to clients and groups. Her mission is "to provide the audience with credible and evidence based nutrition related practices and to lighten the stress and confusion over the endless stream of nutrition information, myths and doubts, they are targeted by".



We had over 280 views on the livestream video and consider it a great success. We look forward to continuing our Ketogenic Talk series online in 2020 .

### **Education & Awareness**

Our workshops are always well received. Apart from children in school, all participants fill out evaluation forms about the quality of information presented. On a scale of one to ten, the overall average rating for quality of information is 9.2. When asked about the most important thing learned in the workshop, the two most frequent answers concern seizure first aid and seizure recognition. When asked to comment on what they liked about the workshops people responded:

"The symptoms and triggers for a seizure, the first aid guidelines, and the video teaching aids were very helpful! An excellent and informative presentation" - ECE Instructor

"Learning that it is not contagious" - Youth Worker in training

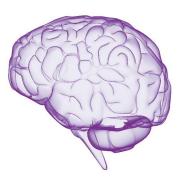
"The variations of seizures, and how to comfort/ attend to the person after the seizure" - EA in training

"Previously, I thought that all seizures were on the ground shaking. I didn't know there were so many different types!" - EA in training









## **Purple Day**

### Purple Day 2019

Purple Day, March 26, is the National Day for epilepsy awareness. It began with an 8 year old girl, Cassidy Megan, with epilepsy from Nova Scotia who felt isolated and alone because she couldn't talk to anyone about epilepsy because none of her friends knew what it was. Cassidy started Purple Day to teach her friends that she was as capable as they were. She also wanted other children with epilepsy to know that they did not need to feel alone. The Purple Day movement, which began in 2008 is now a global initiative and supported by the Center for Epilepsy as one of our major awareness efforts.



In 2019, we celebrated Purple Day at Mill Lake Park. 120 supporters attended with 19 volunteers who gave 89.5 hours of time. We appreciate everyone who came out to support us for our annual Purple Day Walk for Awareness! We had a great turnout and are looking forward to the next Purple Day Event!









### **Zajac Ranch**

One of the programs closest to our hearts is the subsidy we provide to children in order to attend Zajac Ranch summer camp. Zajac Ranch provides the opportunity for children with epilepsy to enjoy the friendships, fun and challenges of camp that other kids experience.

This year we sent 6 young adults to camp. Here is what one of the parents and campers had to say:

"As a parent, its always great to know he is in capable hands. Thankfully it was a cool week so that the heat did not affect his seizures. It's been a rough summer for that! Our PSW took a LOT of pictures with makes it easy to talk about camp with Mason.

I cannot say THANK YOU enough to The Centre For Epilepsy . Without that financial support, Mason would not get the benefit of this amazing experience at camp. I cannot express how grateful I am!! :D -" Parent of person with epilepsy







Thank you very much for my week at Zajac Ranch for Children Young Adult Camp Week #1. As usual I had an amazing time!

Right off I was happy to see my friend Natalie from years when I attended as a child. My favorite thing I did was horseback riding. Teddy and Cody were still there and I had a great ride on Teddy. He is a nice old guy! I got to pat Jasmine the donkey and Pebbles the pony and I enjoyed all the other animals.

I also really like archery although I am not good at it--- (I lost a couple of arrows) and I liked kayaking. We did a kayaking race and I didn't win but I had fun.

My mother and I talked about doing something challenging this week so I went high up on the high ropes, even though they scare me a bit. We also had a blast swimming in the lake which was cold but we liked floating around.

It makes me so happy that nice people give your organization donations to help people like me go to camp. I really appreciate it and so does my family

Thanks again for everything, - Hailey Grant





## **Purple Day Proclamation**



## Canada Province of British Columbia

### A Proclamation

ELIZABETH THE SECOND, by the Grace of God, of the United Kingdom, Canada and Her other Realms and Territories, Queen, Head of the Commonwealth, Defender of the Faith

### To all to whom these presents shall come - Greeting

WHEREAS Purple Day is a global effort dedicated to promoting epilepsy awareness in countries around the world, and

WHEREAS Purple Day was founded in 2008 by Cassidy Megan, a nine year old girl from Nova Scotia, who wanted people with epilepsy to know they aren't alone, and

WHEREAS epilepsy is the most common serious neurological condition, and

WHEREAS epilepsy is estimated to affect more than 50 million people worldwide, about 300,000 people in Canada, and approximately 40,000 people in British Columbia, and

WHEREAS the public is often unable to recognize common seizure types, and to respond with appropriate first aid, and

WHEREAS Purple Day will be celebrated on March 26 annually, during Epilepsy Awareness Month, to increase understanding, reduce stigma and improve the quality of life for our communities in British Columbia;

NOW KNOW YE THAT We do by these presents proclaim and declare that March 26, 2016, shall be known as

#### "Purple Day for Epilepsy Awareness"

in the Province of British Columbia.

IN TESTIMONY WHEREOF We have caused these Our Letters to be made Patent and the Great Seal of Our Province to be hereunto affixed.

WITNESS, The Honourable Judith Guichon, Lieutenant Governor of Our Province of British Columbia, in Our City of Victoria, in Our Province, this sixteenth day of March, two thousand sixteen and in the sixty-fifth year of Our Reign.

BY COMMAND.

Attorney General and Minister of Justice (counter signature for the Great Beal) Lieutenant Sobernor