



BC EPILEPSY SOCIETY

ANNUAL REPORT
2018/2019



BC Epilepsy
Society

I AM A
VOICE
FOR EPILEPSY AWARENESS™



MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

Greetings on behalf of the Board of Directors,

What a fantastic year we have had!! 2019, was indeed, a pivotal year. We've been reflecting on how much you've helped us accomplish. You have made it possible for us to evolve to a new era of health promotion, social awareness and service reach. Because of your dedication and support, BCES programs and services remain free of charge to people living with epilepsy and their loved ones.

We are so proud of our Team and all the people that have worked so hard this year to impact the people we serve. There will always be new challenges, but we will continue to innovate and address those challenges by adding new programs and services to maximize our provincial reach to those in need. From every one of us at BC Epilepsy Society, the support workers on the front line, the operations staff working diligently behind the scenes, the Board, the Professional Advisory Committee, and most importantly, from our clients, thank you for your unwavering support in helping us provide life-changing, essential services to those living with epilepsy.

Thank YOU for building legacies and saving lives.



KIM DAVIDSON
CEO & EXECUTIVE DIRECTOR
BC EPILEPSY SOCIETY



DAN O'BRIEN
CHAIRMAN OF THE BOARD
BC EPILEPSY SOCIETY



MISSION

To empower, educate and support British Columbians living with epilepsy and their families, and support research to make their lives easier.

VISION

Improving Lives. Inspiring Courage.

HISTORY

The BC Epilepsy Society was incorporated as a registered charity on August 17, 1959, under the leadership of pediatric neurologist Dr. Norman Auckland.

Dr. Auckland believed that the more people living with epilepsy understood their epilepsy, the more they could help themselves.

BC Epilepsy Society programs and services today remain true to Dr. Auckland's original vision of support and education.

WHAT IS EPILEPSY?

Epilepsy is a medical condition that causes recurring seizures.

A seizure is the sudden, brief and temporary disturbance of electrical activity in the brain.

It has been found that 1 in 12 people will experience a seizure during their lifetime and that 1 in 100 people will develop epilepsy during their lifetime.

Epilepsy affects approximately 1% of the population, with over 65 million people living with epilepsy worldwide; over 3.2 million people living with epilepsy in the United States; over 380,000 people living with epilepsy in Canada; and over 50,000 people living with epilepsy in British Columbia.



BOARD OF DIRECTORS

The BC Epilepsy Society has a volunteer Board of Directors that develops and leads our strategic direction. The BC Epilepsy Society Board of Directors oversee several working committees that help implement strategic plans with the support of staff.

- Dan O'Brien, CPA, CA - Chair
- Trevor Young, MBA - Treasurer
- Steven Fruitman, LLB - Secretary
- Dr. Linda Huh, MD, FRCPC – PAC Chair
- Katy Fairley - Director
- Kasi Lubin - Director
- Jacci Sandler - Director
- Shaun Rodgers - Director
- Kim Davidson - CEO & Executive Director



PROFESSIONAL ADVISORY COMMITTEE (PAC)

The PAC is our longest-standing committee, comprised of a team of members, each playing a professional role across a variety of disciplines involving epilepsy, who volunteer their time to assess and revise our resources, programs, and services to keep them current and accurate.

- Dr. Linda Huh, MD, FRCPC - PAC Chair
- Dr. Mary Connolly MB, BCh, BAO, FRCP(C), FRCP(I), FRCP(Edin)
- Dr. Chantelle Hrazdil, MD, FRCPC
- Dr. Anita Datta, MD, FRCPC
- Dr. Jing Ee Tan, PhD, ABPP-CN
- Dr. Islam Hassan, MBChB, MMedSc, MRCP(UK), MRCPsych, FRANZCP, FRCPC
- Dr. Sherri Purves, MD, PhD, FRCPC, FAAN
- Sharon Peinhof, RN, BSN

BC EPILEPSY SOCIETY STAFF

- Kim Davidson, CEO & Executive Director
- Paul Naswell, Executive & Administrative Assistant
- Sonia Ali, Provincial Manager of Programs and Services
- Jas Lachar, Support Services Coordinator
- Chris Lal, Epilepsy Peer Support Lead
- Deirdre Syms, Epilepsy Education & Outreach Worker (Victoria)
- Christine Jamieson, Impact Speaker
- Chris Winwood, Epilepsy Education & Outreach Worker (Prince George)
- Alea Andaya, Epilepsy Community Outreach & Program Coordinator
- Londyn Skinner, Executive & Administrative Assistant
- Ronda Foden, Bookkeeper
- Cynthia Liu, Summer Events Coordinator



PROGRAMS AND SERVICES

PARTNERSHIP WITH NEUROLOGY CLINIC, BC CHILDREN'S HOSPITAL

Our partnership with the Neurology Clinic at BC Children's Hospital is now in its 15th year. BC Epilepsy Society staff assist people living with epilepsy and their families in connecting with our services and/or finding the appropriate community support to meet their individual needs.

PARTNERSHIP WITH EPILEPSY CLINIC, VANCOUVER GENERAL HOSPITAL

Our partnership with the Epilepsy Clinic at Vancouver General Hospital is now in its 5th year. BC Epilepsy Society staff assist people living with epilepsy by connecting them with our services and/or finding the appropriate community support to meet their individual needs.

PARTNERSHIP WITH JIM PATTISON OUTPATIENT CLINIC, SURREY

Our partnership with the Jim Pattison Outpatient Clinic at Surrey Memorial Hospital is now in its 3rd year. BC Epilepsy Society staff assist people living with epilepsy by connecting them with our services and/or finding the appropriate community support to meet their individual needs.



PROGRAMS AND SERVICES

PARTNERS IN TEACHING

Our provincial Partners in Teaching program delivers educational workshops to schools, workplaces and other organizations across BC. We customize workshops on facts and myths about epilepsy and seizures; how to recognize and respond to a seizure, including the steps of seizure first aid; and the psychosocial implications of living with epilepsy, including the potential impacts on learning and behaviour. In addition, resource kits containing educational and informational materials are provided to each group. We are excited about the growth of this program year after year.

TOTAL NUMBER OF WORKSHOPS DELIVERED: 91
TOTAL NUMBER OF PARTICIPANTS REACHED: 2300

This program serves all communities across BC. This is done either remotely or in person.

- **PARTICIPANTS INCLUDED:**
 - **Elementary School Teachers: 385**
 - **Secondary School Teachers: 260**
 - **Student Presentations: 540**
 - **Early Childhood Educators: 35**
 - **Education Assistant Program Students: 180**
 - **Summer Camp Staff: 50**
 - **Community Agencies: 450**
 - **University Presentations: 350**
 - **Workplace Staff: 50**



PROGRAMS AND SERVICES

SUPPORT GROUPS

BC Epilepsy Society Support Groups allow people living with epilepsy and their families, friends, and loved ones to get better connected and strengthen their support networks while providing them with the opportunity to meet with and get advice from other individuals with whom they share similar experiences and who are going through similar journeys as them.

BC EPILEPSY SOCIETY SUPPORT GROUPS OFFERED

- **IN-PERSON PEER SUPPORT GROUP:**
 - Now in its 15th year, this group is a vibrant peer-led community made up of people living with epilepsy supporting each other on their respective journeys with epilepsy.
- **ONLINE PEER SUPPORT GROUP:**
 - This group is an option for people who cannot attend the in-person group due to location, health, or logistics. This group has been very well attended and continues to grow.
- **EPILEPSY FRIENDS FOREVER (EFF):**
 - EFF sessions provide friendship, understanding, education, and support in a fun and creative environment for children and youth living with epilepsy who are between the ages of 6 and 17.
- **BC EPILEPSY PARENTS NETWORK (BCEPN):**
 - BCEPN sessions allow parents, guardians and caregivers who have children living with epilepsy to share their experiences and get advice from others who are going through similar situations as them.
- **BCES MEN'S CIRCLE:**
 - Introduced in 2019, this group is for people living with epilepsy who identify as men.
- **BCES WOMEN'S CIRCLE:**
 - Introduced in 2019, this group is for people living with epilepsy who identify as women.
- **BCES YOUNG ADULTS CIRCLE:**
 - Introduced in 2019, this group is for young adults living with epilepsy who are between the ages of 18 and 24.



PROGRAMS AND SERVICES

BLOG

We upload regular blog posts to the BC Epilepsy Society website on a number of epilepsy-related topics. Blog posts uploaded in 2019 included:

- Epilepsy and the Family
- Stigma & Epilepsy
- Dating and Epilepsy
- Join the CADTH Patient and Community Advisory Committee!
- Preventing the Bullying of Students with Epilepsy
- BC Epilepsy Society Partners With Vida Spa!
- Purple Month at Vida
- BC Epilepsy Society Partners with GOLD'S GYM!
- Purple Month at GOLD'S
- Christine Jamieson Wins Miss Canada!
- Women and Epilepsy
- BC Epilepsy Society on Breakfast Television
- BC Epilepsy Society on Red FM March 18th
- Epilepsy 101 & Seizure First Aid - Two Free Workshops Open To The Public!
- BCES Advocates for Tavia Marlatt to Receive Care at Home
- Epilepsy Awareness on Purple Day™!
- The BC Epilepsy Society Advocates For Tavia Marlatt To Have A Care Plan At Discharge
- I AM A VOICE for Epilepsy Awareness Expo on April 29th
- I AM A VOICE for Epilepsy Awareness Expo: A Great Success!
- BCES 2018 A Year in Review
- Sabrina's Story
- Tips for Mothers with Epilepsy
- Tips for Mothers of Children with Epilepsy
- BCES & The Vida Spa Mindful Massage
- Tips for Fathers with Epilepsy
- Tips for Fathers of Children with Epilepsy
- Cameron Boyce Passes Away Due to a Seizure
- Become More Informed About Seizures
- BCES at Surrey Fest Downtown!
- BCES At Pride!
- 2019 #HikeForEpilepsy Challenge!
- BC Epilepsy Society on Global News July 24th
- BC Epilepsy Society's 60th Anniversary Picnic
- Back to School with Epilepsy
- BC Epilepsy Society on Red FM September 9th
- The Effect of Epilepsy on Mental Health and Well-Being
- What Is Autoimmune Epilepsy?
- SUDEP Action Day is October 23rd!
- A Focus on Epilepsy Support Groups
- Issues for Girls with Epilepsy
- Information on the Access RDSP Program
- Canadian Federal Election on October 21st!
- Information on the new SenTiva VNS Device
- Staying Safe with Epilepsy on Halloween!
- The Importance of Care for Veterans with Epilepsy
- Epilepsy and the Holiday Blues
- Epilepsy & Travel
- Track Your Seizures in the New Year!



PROGRAMS AND SERVICES

INFORMATION SHEETS

We have over 75 Information Sheets on our website on a wide range of topics related to living with epilepsy. These Information Sheets are reviewed and updated regularly with the assistance of our Professional Advisory Committee (PAC) and are available in English, French, Vietnamese, Chinese, Korean, and Punjabi.

E-NEWSLETTER

We have a regular online correspondence with our constituents through our monthly e-newsletter, which features current and relevant information on various epilepsy-related topics, and is circulated to over 5,500 members via email.

BURSARIES

Bursaries for post-secondary education are awarded annually to youth with lived epilepsy experience to use towards an array of post-secondary educational and trade school opportunities. We have awarded a total of 72 bursaries since 2007.

CAMP SUBSIDIES

Camp subsidies awarded annually give children and youth living with epilepsy the opportunity to go to summer camp programs. This allows children to learn and grow as individuals and gain meaningful connections with others.

KIDS UP FRONT

This partnership, of 8 years, builds community by allowing us to offer people living with epilepsy and their families the opportunity to access entertainment and sports events at no charge.



I AM A VOICE FOR EPILEPSY AWARENESS™ EXPO

The first annual **I AM A VOICE for Epilepsy Awareness™ Expo** was held on April 29th, 2019, where speakers came together from across Canada, the United States and Europe – including lawyers, medical professionals and people living with epilepsy – to share their knowledge and experiences on various topics related to epilepsy during this full-day event on knowledge exchange and health promotion.

Speakers included:

- Kim Davidson, the CEO & Executive Director of the BC Epilepsy Society
- Christine Jamieson, Miss Canada 2019 and Miss BC 2018/2019
- Cassidy Megan, Founder, International Purple Day™ for Epilepsy Awareness (Halifax, NS)
- Amanda Plomp, marathon runner (Victoria, BC)
- Fran Turauskis, Founder, Seize Your Adventure (United Kingdom)
- Tyler Barton, a professional golfer, ordained minister and engineer (Dallas, TX)
- Allison Hegedus, an author and the President of Vida Spa

Presenters included:

- Rosalyn Best Clark, Registered Clinical Counsellor, presenting on depression, anxiety and epilepsy
- Leena Yousefi, YLaw Group presenting on family law and epilepsy
- Jay Spiro, Yeager Employment law presenting on employment law and epilepsy
- Kelly Anderson, the Epilepsy Surgery Program Nurse at BC Children's Hospital presenting on Epilepsy 101
- Cameron Finlay, LivaNova presenting on VNS Neuromodulation Therapy (Toronto, ON)

Prior to the **I AM A VOICE for Epilepsy Awareness™ Expo** taking place, other events with similar topics taking place in Canada were about neurology as a whole - whereas this event was solely about epilepsy; were mainly geared towards professionals - whereas this event was geared towards professionals, people living with epilepsy and their families and members of the general public; and were put on by pharma companies - whereas this event was put on by a non-profit charitable organization. All of these reasons make the **I AM A VOICE for Epilepsy Awareness™ Expo** the first international epilepsy expo of its kind in Canada.

EXPO & AGM



A YEAR OF GROWTH FOR BC EPILEPSY SOCIETY!

2019 has been a **SPECTACULAR** year of growth



Deidre Syms

EXPANSION TO VICTORIA

In October 2019, we absorbed the Epilepsy Program at *HeadWay Epilepsy and Parkinson's Centre* in Victoria. Through this, we were able to expand our programs and services to Victoria and Vancouver Island. As a result, we were able to double the programs and services in Victoria and on Vancouver Island. This transition also included hiring former HeadWay employee, Deidre Syms in the role of Epilepsy Education & Outreach Worker on Vancouver Island.



Chris Winwood

EXPANSION TO PRINCE GEORGE

In October 2019, thanks to grants from the City of Prince George and the Prince George Community Fund, we were able to expand our programs and services to Prince George and brought Chris Winwood to our team in the role of Epilepsy Education & Outreach Worker in Prince George.

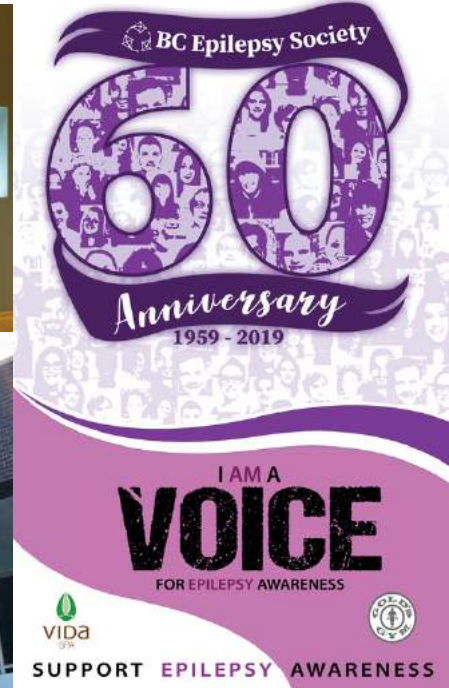
OFFICE MOVE

In December 2019, we moved offices from Vancouver to Burnaby to a larger office space, which gives us space to host more support groups and client services as well as for filming, podcasting and more! This new location also has great parking and is within steps to public transit which makes it a lot easier for our constituents to get to than our old office space.



BC EPILEPSY SOCIETY CAMPAIGNS

Our **March Purple Month!**[™] campaign encouraged the public to be more aware of epilepsy not just on *International PURPLE DAY*[™] for Epilepsy Awareness on March 26th but every day in March. During our **March Purple Month!**[™] campaign, our partners and sponsors Vida Spas and GOLD'S GYM joined us in several epilepsy awareness initiatives.



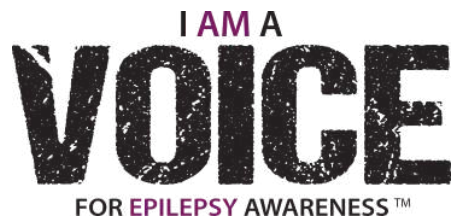
Eat Your Way ... Through Purple Day![™]



Our **Eat Your Way ... Through Purple Day**[™] campaign worked with restaurants during *Purple Month* in March and on *International PURPLE DAY*[™] for Epilepsy Awareness on March 26th to get people talking about epilepsy, raise awareness of epilepsy in the community and inform people living with epilepsy that they are not alone.

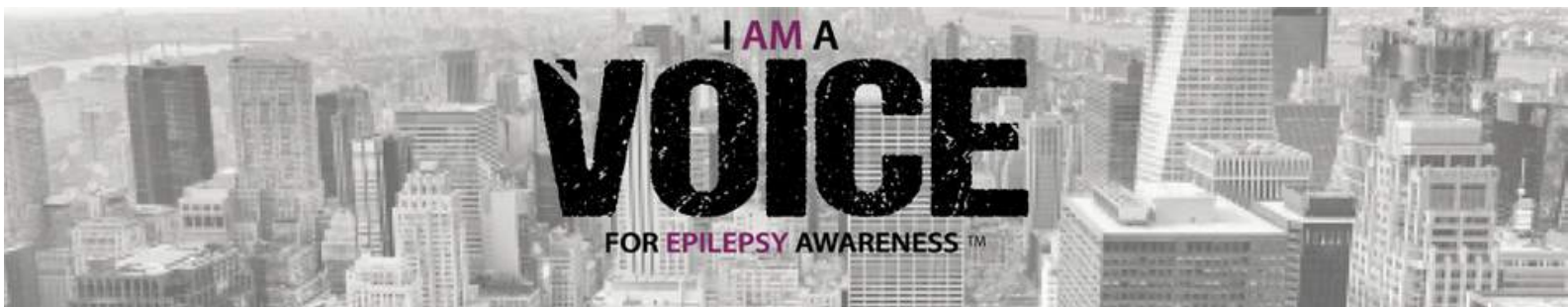
BC EPILEPSY SOCIETY CAMPAIGNS

In 2019, we launched a new 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.



The **I AM A VOICE for Epilepsy Awareness™** website educates and informs the public by featuring our media productions, including our What If ... Documentary Series™, our Voice Epilepsy™ podcast and E-News™ broadcasts on epilepsy-related news.

The **I AM A VOICE for Epilepsy Awareness™** website also contains information on our international reach, our amazing partnerships and the exciting events we are involved in.





I AM A VOICE

FOR EPILEPSY AWARENESS™



BC EPILEPSY SOCIETY CHAMPION FOR CHANGE

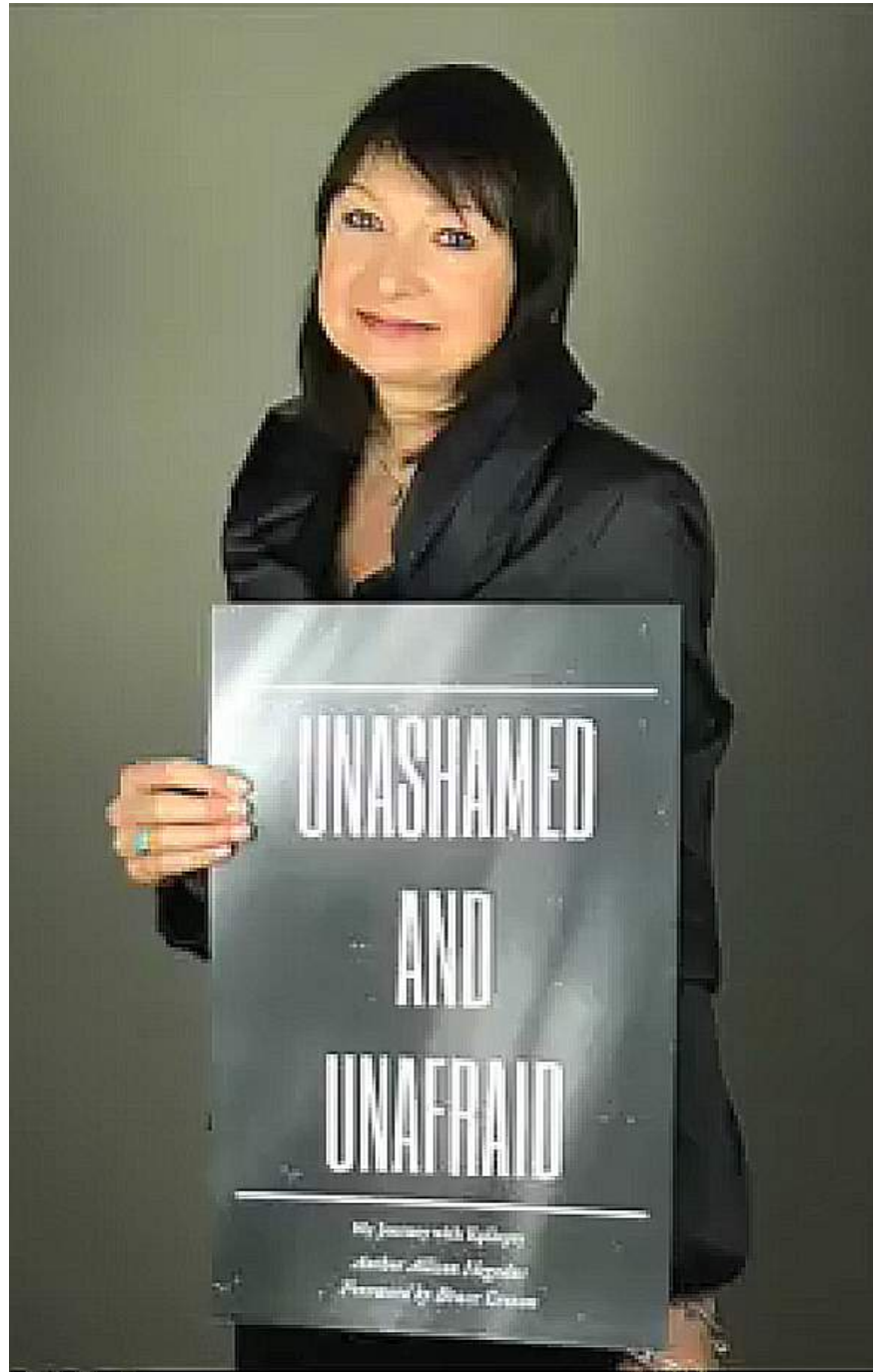
The BC Epilepsy Society is pleased to announce that our first **Champion for Change Award** will be awarded to **Allison Hegedus**, the President of Vida Spa.

For the past 3 years, Allison has volunteered her personal time at the BC Epilepsy Society and has provided one-on-one social and emotional support for individuals who are considering surgery or are in post-surgery recovery.

During our *March is Purple Month!*[™] campaign, Allison and Vida Spa partnered with us by launching the Mindful Massage, where \$22 of every Mindful Massage sold was donated to the BC Epilepsy Society.

Allison also donated items to be used in swag bags at the *I AM A VOICE for Epilepsy Awareness*[™] Expo and to be used as prizes at events that the BC Epilepsy Society took part in, including SurreyFest Downtown and the Vancouver Pride Festival.

Additionally, Allison is authoring a book, *Unashamed and Unafraid: My Journey with Epilepsy*, and has chosen to donate **100% of proceeds of every book sold to the BC Epilepsy Society.**



DONORS, FUNDERS & SPONSORS



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 John Ribalkin
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MAKE A DONATION SAVE A LIFE

Without the financial support of our donors, we simply would not be able to develop and deliver the many programs and services on which our members rely. Successes like our Partners In Teaching program and our website are created thanks to the financial support of donors.

There are many ways that you can make a donation to the BC Epilepsy Society:

- **ON OUR WEBSITE:** Visit www.bcepilepsy.com/ways-you-can-donate to donate on our website
- **ONLINE:** Donate to the BC Epilepsy Society through [PayPal Giving Fund Canada](#)
- **BY MAIL:** Mail a cheque to #610 - 4180 Lougheed Highway, Burnaby, BC V5C 4B3
- **BY TELEPHONE:** Call 604-875-6704 to donate using your Visa or MasterCard

THANK YOU TO OUR DONORS!



Purple Day March 26



Vancouver Pride



Brain in Mind Club at SFU











**"MOVING INTO 2020, WE
LOOK FORWARD TO
WORKING ALONGSIDE
GOVERNMENT TO ENSURE
THAT BC DOCTORS AND
HEALTH CARE PROVIDERS
WORKING WITHIN OUR ADULT
EPILEPSY SYSTEM ARE
PROPERLY RESOURCED WITH
ACCESS TO THERAPEUTICS,
TREATMENTS, MEDICATIONS,
SURGERIES AND
NEUROPSYCHOLOGICAL
STAFFING TO PROVIDE AN
OPTIMUM STANDARD OF
CARE FOR THEIR PATIENTS AS
SEEN IN THE REST OF
CANADA."**

-Kim Davidson, CEO & Executive Director, BC Epilepsy Society



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