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I AM A
VOICE

FOR EPILEPSY AWARENESS

EXPO & AGM

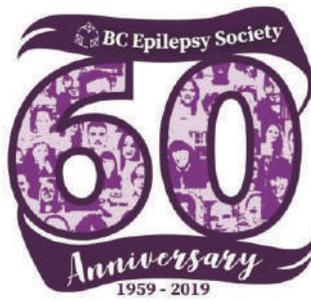
#bcepilepsyvoice

BC Epilepsy Society

60

Anniversary

1959 - 2019



60th ANNIVERSARY TRIBUTE WELCOME

Dear Friends,

On behalf of our Board of Directors, our Professional Advisory Committee and the entire staff of the BC Epilepsy Society, I would like to thank you for joining us to commemorate '60 Years of Improving Lives and Inspiring Courage.'

The I AM A VOICE for Epilepsy Awareness Expo & AGM is a true celebration of our past, present, and future. It is an opportunity to acknowledge 6 decades of service and creating brighter futures.

It is also a time to take a glimpse into our particularly proud I AM A VOICE for Epilepsy Awareness campaign, a movement started in BC, by the BC Epilepsy Society in 2018. Over the past year, the BC Epilepsy Society has partnered with individuals and groups in both Canada and the United States to drive the impact of Epilepsy Awareness forward for international impact and uptake.

The campaign has travelled through Canada, the United States, Australia and Asia. The campaign goes beyond having conversations about epilepsy ... it's a bigger voice about the global complexities of re-engineering the manner in which epilepsy organizations engage with one another. It serves to have a collective impact to work collaboratively with a multitude of partners to make measurable differences in addressing the lack of Canadian and International awareness and funding equity for Epilepsy related services, testing and research.

In the spirit of celebration, I would like to thank each of you for attending the first I AM A VOICE for Epilepsy Expo & AGM. In gratitude, I thank the truly extraordinary speakers – curiosities piqued, outlooks broadened, and beliefs challenged. Finally, I extend a special thanks to all of our EXPO sponsors and partners. Your contributions are invaluable to this organization and for those attending today.

I look forward to your continued friendship by helping our efforts to Be A Voice for Epilepsy.

Enjoy your day,

A handwritten signature in black ink that reads "Kim Davidson".

Kim Davidson
Executive Director
BC Epilepsy Society



PRIME MINISTER • PREMIER MINISTRE

April 29, 2019

Dear Friends:

I would like to extend my warmest greetings to everyone celebrating the 60th anniversary of the BC Epilepsy Society at the I am A Voice for Epilepsy Awareness Expo & AGM.



Since 1959, the BC Epilepsy Society has provided support to people living with epilepsy and their families. This event brings over 500 delegates together to share their experiences and raise awareness. This milestone also offers a wonderful opportunity to reflect upon the history of your organization, to celebrate its many achievements and to set goals for the future.

I would like to thank the BC Epilepsy Society for organizing this event, and for highlighting the many contributions those living with epilepsy make to our communities. You can take pride in your efforts to ensure the well-being of your fellow citizens.

On behalf of the Government of Canada, I offer my best wishes for an enjoyable anniversary celebration and continued success.

Sincerely,

The Rt. Hon. Justin P. J. Trudeau, P.C., M.P.
Prime Minister of Canada



A MESSAGE FROM
PREMIER JOHN HORGAN

As Premier of the Province of British Columbia, it is my pleasure to welcome everyone to the BC Epilepsy Society's *I Am A Voice for Epilepsy Awareness Expo and AGM*.

This event is a wonderful opportunity for people to learn more about epilepsy, neurology, and related topics. The BC Epilepsy Society has lined up a fantastic array of speakers from various sectors, from civic leaders to healthcare professionals. I have no doubt that these panels and workshops will provide a wealth of valuable knowledge and resources that can be put to great use in the lives of the attendees.

I would also like to congratulate the BC Epilepsy Society as it celebrates its landmark 60th anniversary. People living with epilepsy make significant contributions to their communities, and the initiatives and education provided by organizations like the BC Epilepsy Society help ensure that our province is a healthy and supportive place for everyone

I wish you all the best for a fantastic event!



HONOURABLE JOHN HORGAN
PREMIER OF BRITISH COLUMBIA



**PERSONAL MESSAGE AND GREETINGS FROM
HONOURABLE ADRIAN DIX
MINISTER OF HEALTH**

I AM A VOICE FOR EPILEPSY AWARENESS EXPO & AGM

April 29, 2019

I would like to welcome the over 500 delegates joining together at the BC Epilepsy Society's 60th annual anniversary celebration and AGM, 'I Am A Voice for Epilepsy Awareness.'

Epilepsy affects approximately one in 100 Canadians and it's estimated that one in 12 people will experience a seizure in their lifetime. It's one of the most common neurological conditions, and yet remains one of the least-understood and under-recognized, with about 70% of cases no known cause can be found.

While British Columbians enjoy one of the highest life expectancies in Canada, and the government through the Ministry of Health, supports this by providing leadership in health research and health promotion, it is important that there is a strong support network for those living with epilepsy in the province. I congratulate the BC Epilepsy Society on reaching 60 years of service to British Columbians living with epilepsy and their families.

It's important to note that people live full, engaged lives while also having epilepsy, and many who are diagnosed also contribute greatly to their communities, organizations, workplaces and families. I noted that many have contributed their stories to the BC Epilepsy Society's page, and that while they have overcome challenges, they are living life to the fullest and in doing so, they enrich the lives of others.

I offer you my best wishes for an inspiring, thoughtful and productive gathering.

Sincerely,

Adrian Dix
Minister of Health



HONOURABLE JODY WILSON-RAYBOULD,
MEMBER OF PARLIAMENT *for* VANCOUVER GRANVILLE

GREETINGS



I am delighted to send my warmest greetings to the staff, board of directors, volunteers, and supporters of the BC Epilepsy Society as you gather for the *I Am A Voice for Epilepsy Awareness Expo & AGM* and celebrate the organization's 60th anniversary.

Since 1959, the BC Epilepsy Society has proudly served British Columbians of all ages living with epilepsy. Your dedication to serving those living with this disorder and their families make the BC Epilepsy Society a valued organization in our province. Today's event is a wonderful opportunity to reflect on and celebrate the work that has continued Dr. Norman Auckland's legacy.

As the proud Member of Parliament for Vancouver Granville, I wish to acknowledge the significant contributions that people living with epilepsy in our riding make to the social and economic fabric of our community. Thanks to the six decades of service from the BC Epilepsy Society and its supporters, our constituency—indeed, our city and province—are today, welcoming and inclusive spaces that benefit from the full participation of our diverse society, including people living with epilepsy.

I regret that my parliamentary duties in Ottawa prevent me from joining you in person today, but please know that my thoughts are with you all on this special occasion. Congratulations on your milestone anniversary and best wishes for a productive and successful day of activities.

Gilakas'la.

A handwritten signature in black ink, appearing to read "Jody Wilson-Raybould", written in a cursive style.

Hon. Jody Wilson-Raybould, P.C., Q.C., M.P.
Member of Parliament for Vancouver Granville

April 29, 2019



THE ANITA KAUFMANN FOUNDATION

Educating the public NOT to fear epilepsy and seizures

GLOBAL SPONSOR OF PURPLE DAY®



April 29, 2019

Hello Friends,

Since 1959, the BC Epilepsy Society has tirelessly provided information, advocacy and support to people with epilepsy and their families in the province of British Columbia. We would like to extend a heartfelt congratulation to the BC Epilepsy Society for reaching a milestone of 60 years of service.

We would also like to welcome everyone to this year's *I Am A Voice For Epilepsy Awareness Expo & AGM* and mention how proud we are to share in today's exciting event!

On behalf of the Anita Kaufmann Foundation, we would like to thank the BC Epilepsy Society for everything that they do to promote epilepsy awareness & education!

Not only does the BC Epilepsy Society help those living with and affected by epilepsy in British Columbia; they also have done much to raise awareness with their I AM A VOICE For Epilepsy Awareness campaign across Canada, in the US and internationally.

Kim Davidson, I am honored to call you a friend and to join together, in our journey to raise awareness of epilepsy around the world!

Sincerely,

Debra Josephs
Executive Director

P.O. Box 11, New Milford, NJ 07646 • Tel. 201-655-0420 • www.akfus.org

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I AM A
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FOR EPILEPSY AWARENESS

EXPO SCHEDULE of EVENTS

9:00 AM BREAKFAST

9:30 AM WELCOME

9:50 AM

Keynote Address

Christine Jamieson, Miss Canada 2019 & Miss BC 2018

10:10 AM

Video Conversation with Cassidy Megan

Founder, International Purple Day™ for Epilepsy Awareness

10:15 AM

Musical Performance

Emma Knelson, Singer/Songwriter

10:20 AM

Amanda Plomp

Marathon Athlete

10:40 AM

Video Conversation with Fran Turauskis

Founder, Seize Your Adventure

10:50 AM COFFEE/TEA BREAK

11:00 AM

Video Conversation with Tyler Barton

Professional Golfer

11:20 AM

Depression & Anxiety

Rosalyn Best Clark, MoC, MEd, RCC, Ros Best Clark Counselling

11:50 AM

Cheque Presentation

John Ribalkin, Chalet Lights

I AM A
VOICE

FOR EPILEPSY AWARENESS

EXPO SCHEDULE of EVENTS

12:00 PM LUNCH

12:40 PM

Family Law, Custody Law & Epilepsy
Ronak Leena Yousefi, YLaw Group

1:00 PM

Employment Law & Epilepsy
Jay Spiro, Yeager Employment Law

1:30 PM COFFEE/TEA BREAK

1:40 PM

Allison Hegedus
President, Vida Spa
Author, Unashamed and Unafraid: My Journey with Epilepsy

2:00 PM

Musical Performance
Emma Knelson, Singer/Songwriter

2:05 PM

Epilepsy 101
Kelly Anderson, RN, BSN, BC Children's Hospital

2:35 PM

VNS Neuromodulation Therapy
Cameron Finlay, LivaNova

3:05 PM

Annual General Meeting
Kim Davidson, Executive Director, BC Epilepsy Society
Dan O'Brien, Chairman of the Board, BC Epilepsy Society



Kim Davidson, BA, MA Executive Director, BC Epilepsy Society: Kim has over 25 years of counselling, community building and executive leadership experience at both the local and provincial level in three sectors: education, social services and healthcare. She has dedicated her professional life, both through employment and volunteering, to empowering and advocating for children, youth and families in a variety of contexts, including epilepsy and mental health. Kim is an inspirational leader that possesses the lived experience perspective of having epilepsy when she was younger.



Keynote Speaker: **Christine Jamieson**, Miss Canada 2019: Christine Jamieson uses her platforms both as Miss Canada and as Miss BC to positively influence the people around her, inspire others, and raise awareness, education, and funding for epilepsy, a condition she has had since the age of 16. Helping to grow her community and giving back are at the core of her values. She believes in impacting the world for the better and devotes herself to this alongside some amazing organizations, including the BC Epilepsy Society. She is determined to help change the landscape of epilepsy treatment and programs across Canada and works on the front lines of epilepsy awareness, education, and research.



Cassidy Megan, Founder, International PURPLE DAY™ for Epilepsy Awareness: In 2008, as a child, Cassidy Megan started Purple Day™ to raise awareness for epilepsy and to let people living with epilepsy know that they are not alone. Today, eleven years later, Purple Day™ is celebrated worldwide, with countless individuals wearing purple on March 26th of each year and taking part in epilepsy awareness activities and events. Cassidy's hopes to increase epilepsy awareness; reduce the stigma affecting people with epilepsy; and empower people with epilepsy to take action in their communities.



Emma Knelson: Emma Knelson is a 19-year-old singer, songwriter, model and hockey player from Ladysmith, BC. She is proud to be a voice for epilepsy awareness and will be performing at the I AM A VOICE for Epilepsy Awareness Expo & AGM.



Amanda Plomp, Marathoner: As a young woman living with epilepsy, Amanda knows that she could have a seizure at any moment. Her epilepsy has not stopped her from running in races and marathons all over the world. When her seizures occur, Amanda loses control of her body; whereas on the other hand, when Amanda runs, she is control – of her route, pace and distance. Epilepsy is always on Amanda's mind, but – for a person who was once told she would probably never be able to live independently – running has become her way of rejecting life's limitations.



Fran Turauskis, Founder, Seize Your Adventure: After being diagnosed with epilepsy in 2015, Fran hiked the Camino de Santiago, solo. Since then, she has worked more adventure into her life. Fran advocates for epilepsy awareness in the adventure community and talks about the benefits of adventure for people with epilepsy. In 2017, she founded Seize Your Adventure, promotes adventure tourism. The goal of Seize Your Adventure is to use the power of adventure to spread epilepsy awareness; to showcase people who don't let epilepsy map their lives; to normalize epilepsy through a shared passion of the outdoors; and to advocate the benefits of adventure to everyone.



Tyler Barton, Professional Golfer: Tyler was diagnosed with epilepsy at a young age, however he never let it limit him in achieving his goals. He is a two-time World Long Drive Golfing Champion as well as an Engineer, Ordained Minister and a proud husband and father. He is also an epilepsy advocate, partnering with the BC Epilepsy Society on numerous occasions. Tyler's goal is to share his story of growing up with epilepsy and how it has affected his life to help others by raising awareness of epilepsy and empowering people with epilepsy.



Rosalyn Best Clark, MoC, MEd, RCC, Ros Best Counselling: Rosalyn Best Clark helps accompany people as they struggle with big life transitions and concerns. She went into clinical counselling in order to help clients move from frustration to contentment and progress towards their goals. She completed her Master of Counselling Degree at the Adler School of Professional Psychology, her Diploma in Guidance Studies at the University of British Columbia, her Master of Education at Simon Fraser University, and her Adlerian Certification at the Adler Centre in Vancouver. She has received extensive training on courses for clinical counsellors, including couples counselling, trauma reprocessing, dementia care and end of life studies.



Ronak (Leena) Yousefi, YLaw Group: Chosen as one of the Top 25 Most Influential Lawyers in Canada, Leena is the founder of YLaw Group, a family law firm in British Columbia. She has been counsel on several cases in British Columbia, including precedent setting cases on child abduction, property division, spousal support, child custody, child alienation and child support in BC. She grew up with the vision of helping people and, to this day, nothing makes her happier than leading her clients through the storm and into the next chapters of their lives. To her, family law is not about winning or losing, it is about her clients knowing they have a trustworthy and capable lawyer who will do anything to ensure they are fully protected and represented in court or in settlement negotiations.



Jay Spiro, Yeager Employment Law: Jay helps businesses and non-profit employers manage their workforces effectively and lawfully. His strength is in collaborating with employers to develop practical solutions and courses of action that achieve their goals. He also advocates for employees who have been wrongfully dismissed or who are facing constructive dismissal, helping them enforce their legal rights and obtain the best outcome possible outcome. Clients appreciate his calm, level-headed advice and support through challenging and difficult employment situations. He enjoys educating people on the legal do's and don'ts of human resource management and delivers presentations to industry associations and groups.



Allison Hegedus, President, Vida Spa and Author, Unashamed and Unafraid: My Journey with Epilepsy: Allison joined the workforce in the 90's, working for various cosmetics and esthetician companies before finding her niche in the spa industry in 1999. She joined Vida Spas as a Regional Director before being promoted to President in 2006. Allison was diagnosed with epilepsy when she was a teenager and never allowed her epilepsy to discourage her from achieving her goals, whether personal or professional. She has also authored a book, Unashamed and Unafraid: My Journey with Epilepsy, which will be released in the Fall of 2019.



Kelly Anderson, RN, BSN, BC Children's Hospital: Kelly is a Nurse Clinician in the Epilepsy Surgery Program at BC Children's Hospital and is a member of the Canadian Association of Neurosciences Nurses and Canadian Epilepsy Nursing Group. Through her career, she has had the opportunity to speak at several conferences stressing the importance of epilepsy education as a part of treatment; she also continues to be involved in the education of family and staff as well as the care and coordination of the epilepsy monitoring, surgery and VNS programs. Her areas of particular interest are access to epilepsy surgery, transition to adult medicine and psychological impacts of refractory epilepsy.



Cameron Finlay, LivaNova: Cameron Finlay is the National Education Manager for LivaNova, the manufacturer of the VNS Therapy system. His background spans over 35 years in medical technology, initially at the Hospital for Sick Children in Toronto, before joining industry in 1990. The majority of his work has been in the cardiac field, but he later moved into the realm of neurology, specifically the advanced treatment of drug-resistant epilepsy. He brings a lifetime of experience working with patients with implantable technology to his presentations, allowing for an informal but informative educational event.

NOTES

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NOTES

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EXPO & AGM

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 **BC Epilepsy Society**



Anniversary

1959 - 2019

2017/18 Annual Report

Improving lives. Inspiring courage.



Annual Report

BC Epilepsy Society 2017/18 Annual Report

Message from the Chair & Executive Director

As the BC Epilepsy Society moves into its 60th year, we have been reflecting on the decades of supporting individuals living with epilepsy and their families through the struggles of daily living. One thing for certain is that the BC Epilepsy Society has had a significant impact on strengthening the fabric of our society.

Thousands of people have walked through our doors and we have helped them through the most intimate internal struggle. The impact of that moment in time can change the trajectory of a person's life, and subsequently the lives of their family members, their friends, their schools and their communities.

We continue to be inspired by the courage of the people who come to us in their time of need. They place their trust in our dedicated and committed staff, who, day after day, continue to be on the ground changing lives one day at a time. And our staff simply could not do this work without the tremendous commitment of our supporters. Every single one of you has played an important role in continuing to make the BC Epilepsy Society the lifeline it is for the thousands of people living with epilepsy in BC. Thank you. We are committed to continuing to make all communities the kind and caring communities that we all want.

We are blessed to have a dream team of staff, Board members and Professional Advisors associated with the BC Epilepsy Society. We both want to take a moment to thank you: to the people we serve, thank you for putting your trust in us; and to our donors, funders, and partners, thank you for putting your trust in us.

Sincerely,

Kim Davidson
Executive Director
BC Epilepsy Society

Dan O'Brien
Chairman of the Board
BC Epilepsy Society



Improving lives. Inspiring courage.



HISTORY

The BC Epilepsy Society was founded in 1959 by pediatric neurologist Dr. Norman Auckland, who believed that the more people with epilepsy understand their seizure disorders the better they will be able to help themselves.

VISION

Improving Lives. Inspiring Courage.

MISSION

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

2017/18 BOARD OF DIRECTORS

Dan O'Brien, CPA, CA, Chair
Trevor Young, MBA, Treasurer
Steven Fruitman, LLB, Secretary
Katy Fairley, Director
Kasi Lubin, Director

Linda Huh, MD, FRCPC, PAC Co-Chair
Stuart Cain, PhD, PAC, Co-Chair
Carmen Ekelund, Director
Kim Davidson, Executive Director

STRUCTURE

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

PROFESSIONAL ADVISORY COMMITTEE

Our longest-standing committee is comprised of a team of professional experts who volunteer their time to assess and revise our resources, programs, and services to keep them current and accurate.

Stuart Cain, PhD, Co-Chair
Linda Huh, MD, FRCPC, Co-Chair
Mary Connolly, MB, BCh, FRCP(C), FRCP(Edin)
Sherri Purves, MD, PhD, FRCPC, FAAN
Anita Datta, MD, FRCPC
Chantelle Hrazdil, MD, FRCPC

Jing Tan, PhD, ABPP-CN
Sharon Peinhof, RN, BSN
Islam Hassan, MBChB, MMedSc, MPsych,
MRCP(UK), MRCPsych, FRANZCP, FRCPC



Improving lives. Inspiring courage.



PROGRAMS & SERVICES

Partnership with BC Children’s Hospital Neurology Team

Our partnership with the neurology team at BCCH is now in its 14th year. BC Epilepsy Society staff assist families in connecting with our services or finding the appropriate community support to meet their individual needs. We are proud to have assisted over 2,000 families on their journey with epilepsy.

Partnership with Vancouver General Hospital, Epilepsy Clinic

We have entered our 4th year of service with the epilepsy clinic at VGH. BC Epilepsy Society staff provide a community presence and offer information on Society services, programs, and resources to patients living with epilepsy.

Partnership with Jimmy Pattison Outpatient Clinic at Surrey Memorial

We have entered our 2nd year of service with the Jimmy Pattison Outpatient Clinic. Our staff provide and offer information, resources, and referrals to community and government services.

Partners in Teaching

Staff delivered - workshops to teachers, students, child care providers, disability support workers and others. Workshops focus on facts and myths about epilepsy, recognizing and responding to a seizure, and the psychosocial implications of living with epilepsy. Resource kits containing educational and informational materials are provided to each group. The program continues to grow.

Total number of workshops delivered: 77 Total number of participants: 1501

Early Childhood Educators:..... 25
Elementary School Teachers:285
Secondary School Teachers:160
Education Assistant Programs:169
Summer Camp Staff:..... 23
Other Community Groups:203
Student Presentation:318

Areas covered:

- **Surrey**
- **Vancouver**
- **Port Moody**
- **Langley**
- **Delta**
- **Burnaby**
- **North Vancouver**
- **New Westminster**
- **Delta**
- **Aldergrove**
- **Richmond**

Bursaries

Bursaries are awarded to youth with lived epilepsy experience. We have awarded 70 bursaries since 2007. BC Epilepsy Society Bursaries are awarded annually for youth to use towards an array of educational opportunities.

Kids Up Front

This partnership, of 7 years, allows us to offer families living with epilepsy the opportunity to access entertainment and sports events at no charge.

Camp Subsidies

Camp subsidies give children, youth and adolescents living with epilepsy the opportunity to go to fully accessible summer camp programs. This allows them to grow as individuals and gain meaningful connections with others.



E-Newsletter

Now in its 11th year, we have updated the look and feel of our monthly newsletter and continuously strive to circulate to over 2,500 members.

Blog

We have a regular online correspondence with our constituents through the blog section on the BC Epilepsy Society website.

Blogs posted include:

- Epilepsy in Older Adults
- The Health and Role of the Caregiver
- Considerations for Caregivers to Children with Epilepsy
- An Athlete's Courage: A Story of Traumatic Brain Injury (TBI) Recovery
- The Potential Benefits of a Seizure Service Dog
- Tips for Transitioning to Post-Secondary School
- Back to School for Children with Epilepsy
- October 23rd is SUDEP Action Day!
- BC Epilepsy Merchandise Now Available
- Remembrance Day is November 11th – Veterans & Epilepsy
- Coping with Epilepsy During the Holidays

Information Sheets

We have over 75 information sheets on a wide range of topics relating to living with epilepsy. They are updated at least every five years with the assistance of medical professionals at BCCH Clinic, VGH Clinic, Jimmy Pattison Outreach Clinic, BC Epilepsy Society office and on our website.

<http://bcepilepsy.com/resources/information-sheets>

MONTHLY SUPPORT GROUPS

Vancouver In-Person:

This group has been active for 15 years and is a vibrant peer led community helping each other on their respective journeys with epilepsy.

BC On-Line:

This is an option for people who cannot attend in-person due to location, health, or logistics. This group has been very well attended and continues to grow.

Epilepsy Friends Forever (EFF)

Epilepsy Friends Forever (EFF) was a new program introduced as a way for children, youth and adolescents living with epilepsy to meet other children, youth and adolescents living with epilepsy. EFF allows this community to have fun and relax with their peers, with whom they share common experiences. These sessions provide friendship, understanding, education and support in a fun and creative environment for children, youth and adolescents living with epilepsy.



BC Epilepsy Parents Network (BCEPN):

The BC Epilepsy Parents Network (BCEPN) is a support group for parents of children with epilepsy. These sessions allow parents to share their experiences and get advice from others going through similar situations.

Kootenay Region Support Group

The Kootenay Region Support Group is a new support group structured with an on-site group facilitator to provide emotional support, allowing



people to share their experiences and feelings, and learn from each other. Group discussions are focused around common experiences or concerns, and questions.



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Making A Donation

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.

Successes like our Partners In Teaching program and this website are created thanks to the financial support of friends like you.

Thanks for your support.

There are several ways to donate to the Society:

By Mail:

Send your cheques to the BC Epilepsy Society at #2500 – 900 West 8th Avenue, Vancouver, BC V5Z 1E5

By Phone:

Call us at (604) 875-6704

to donate using your Visa or MasterCard

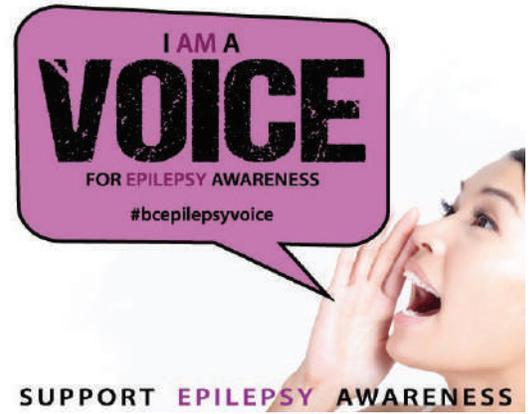
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www.bcepilepsy.com/donations/making-a-donation



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