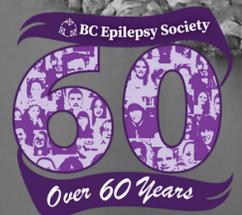


BC EPILEPSY SOCIETY ANNUAL REPORT 2020-2021



MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

2021 was an inspiring year of transition, both for our organization and for our epilepsy community.

Deirdre Syms came on as the Interim Executive Director in the Fall of 2021, and immediately started connecting with our clients and members of the epilepsy community. The goal was to gain an understanding of what our clients and members wanted and needed in order to lay the foundation to build the most effective epilepsy services organization possible.

As a result of these conversations, we shifted focus to an organization dedicated to providing more individual services to our clients and members, building partnerships with various community organizations, effectively advocating for change, and ensuring that the voices, perspectives, and experiences of those of us who live with epilepsy come through in our communications, education, and programming. These voices and experiences have been key to helping others understand our daily life, so if you would like to share your stories, please get in touch!

It is our privilege to provide programs and advocate for the epilepsy community in British Columbia. The community of support we have build has been nothing short of phenomenal. We look forward to continually improving our programming and services in response to the needs of our clients and the epilepsy community and providing those services for many years to come!

DEIRDRE SYMS

EXECUTIVE DIRECTOR
BC EPILEPSY SOCIETY

TREVOR YOUNG

CHAIRMAN OF THE BOARD
BC EPILEPSY SOCIETY



2021

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, who 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 10 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. The Board consists of the following individuals:

- Trevor Young, MBA - Chair
- Dan O'Brien, CPA, CA - Treasurer
- Shaun Rodgers - Secretary
- Dr. Harinder Dhaliwal, MBBS, FRCPC - PAC Chair
- Steven Fruitman, LLB - Director
- Kasi Lubin - Director
- Jacci Sandler - Director
- Sal Toor - Director
- Deirdre Syms - Executive Director

PROFESSIONAL ADVISORY COMMITTEE (PAC)

The PAC is the BC Epilepsy Society's 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. The PAC consists of the following members:

- Dr. Harinder Dhaliwal, MBBS, FRCPC - PAC Chair
- Dr. Linda Huh, MD, FRCPC
- 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. Sherrill Purves, MD, PhD, FRCPC, FAAN
- Dr. Jennifer Percy, MD, FRCPC
- Dr. Cyrus Boelman, MD, FRCPC

BC EPILEPSY SOCIETY STAFF

- Deirdre Syms, Executive Director
- Sonia Ali, Provincial Manager of Programs and Services
- Paul Naswell, Film and Media Specialist
- Jas Lachar, Support Services Coordinator
- Christine Jamieson, Impact Speaker
- Ronda Foden, Bookkeeper
- Rachel Taverner, Community Engagement & Admin Assistant
- Kevin Ball, Media Production & Admin Assistant
- Chris Lal, Epilepsy Peer Support Lead

PROGRAMS & SERVICES

CLINIC SUPPORT SERVICES:

Through our Clinic Support Services program, BC Epilepsy Society staff assist people living with epilepsy and their families at BC Children's Hospital, Vancouver General Hospital and Surrey Memorial Hospital by connecting them with our services and/or finding the appropriate community resources to meet their individual needs.

CONNECTING WITH OTHERS:

The BC Epilepsy Society offers people living with epilepsy and their families, friends, and loved ones the opportunity to meet other inspirational people who truly understand life with epilepsy. Whether we are laughing together or sharing tips and tricks we have learned along the way, connecting with others makes the journey much more fun! In 2021, we offered the following groups:

- In-Person Peer Support Group
- Online Peer Support Group
- Epilepsy Friends Forever (EFF)
- BC Epilepsy Parents Network (BCEPN)
- Family Peer Group
- Young Adult Peer Group



THIS GROUP LITERALLY CHANGED MY LIFE.

Support Group Participant

PROJECT UPLIFT:

Project UPLIFT (Using Practice and Learning to Increase Favourable Thoughts) teaches mental health coping skills to people living with epilepsy. In 2021, we launched the second session of this program, which is an 8-week program with sessions facilitated by a trained facilitator and a mental health professional, one of whom must live with epilepsy. The BC Epilepsy Society is proud to have the only trained Project UPLIFT facilitator in the entire province on its staff.

Project UPLIFT uses cognitive behavioural therapy (CBT) and mindfulness to help people living with epilepsy better manage mental health and teaches many valuable skills that have been proven to improve depression, stress, anxiety, psychological well-being, and quality of life in people living with epilepsy.

NEW DIAGNOSIS GROUP:

In 2021, we launched the first session of our New Diagnosis Group program, which provides interactive sessions that gives participants who have been recently diagnosed with epilepsy the opportunity to learn more about their epilepsy and the practical matters they will need to know, combining medical information with practical recommendations from the real-life experiences of facilitators living with epilepsy.

PROGRAMS & SERVICES

PARTNERS IN TEACHING:

Through our Partners in Teaching program, the BC Epilepsy Society delivers free educational workshops to schools, workplaces and other organizations across BC. Our workshops focus on facts and myths about epilepsy and seizures; how to recognize and respond to a seizure, including the steps of seizure first aid; other safety considerations to do with epilepsy and seizures; 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.

In 2021, due to the ongoing COVID-19 Pandemic, all in-person workshops were cancelled and were instead replaced with workshops delivered via distance means using Zoom. In 2021, we delivered 38 workshops to more than 692 participants.

BC EPILEPSY SOCIETY BOOK CLUB:

In 2021, the BC Epilepsy Society launched a book club for people living with epilepsy where we met over Zoom and read and discussed the book *Daring Greatly* by Brene Brown. The participants enjoyed not only reading the book but also enjoyed the company of the book club very much!

MINDFUL MOVEMENT WITH DELA:

In 2021, the BC Epilepsy Society launched an 8-week online yoga class for people living with epilepsy called The Mindful Movement with Dela hosted by registered yoga instructor, Dela Coutts from Kamloops, BC. The participants took part in hour long yoga classes every week and enjoyed learning about some of the various ways that yoga can help reduce seizures.



THANK YOU BCES FOR ALL YOU DO [AND] MAY YOU CONTINUE YOUR WORK IN EDUCATING SCHOOLS ABOUT EPILEPSY!

Partners in Teaching Participant



THANK YOU FOR THIS PROGRAM AS YOGA MAKES A HUGE DIFFERENCE FOR STRESS MANAGEMENT, ESPECIALLY FOR PEOPLE WITH EPILEPSY.

Mindful Movement with Dela Participant

PROGRAMS & SERVICES

BC EPILEPSY SOCIETY BURSARY PROGRAM:

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 78 bursaries since 2007.

BC EPILEPSY SOCIETY CAMP SUBSIDIES PROGRAM:

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.

RESOURCES - INFORMATION SHEETS:

The BC Epilepsy Society website is home to over 75 Information Sheets on a wide range of topics related to epilepsy, available in English and translated into five additional languages.

RESOURCES - BLOG AND SOCIAL MEDIA:

In 2020, we uploaded over 68 blog posts to the BC Epilepsy Society website on a variety of epilepsy-related topics. Social media posts are uploaded regularly on Twitter, Facebook and Instagram.

COMMUNITY PARTNER - KIDS UP FRONT:

This partnership of 10 years builds community by allowing us to offer people living with epilepsy and their families the opportunity to access recreational, educational, entertainment, and sports events at no charge.



**THANK YOU BCES FOR ALL YOU
DO FOR FAMILIES LIKE US!**

BC Parent

INTRODUCING CHRISTINE'S CORNER

In 2021, the BC Epilepsy Society introduced the Christine's Corner section on our website, featuring articles written by Christine Jamieson, who works for the BC Epilepsy Society as an Impact Speaker and who is also a person living with epilepsy who holds the titles of Miss BC 2018/2019 and Miss Canada 2019. Christine's Corner articles posted in 2021 included:

- Welcome to Christine's Corner with the BC Epilepsy Society
- The Tile Key Fob and How It Has Saved my Sanity with my Memory Loss
- Three Ways to Make Eggs Without Using Your Stove!
- How Practicing Yoga Helps with Epilepsy
- Sleep and Epilepsy
- Books for Dealing with Stress
- Pill Organizers – They Don't Have to Be Boring!
- The Calm App – The Best Money I Spent in the Past Year!
- Epilepsy and Anxiety
- Dating with Epilepsy
- 3 Easy Ways to Spread Awareness on Purple Day
- 3 Purple Recipes to Celebrate Purple Month!
- Ever Think About Joining a Support Group? Do It!
- The Pros and Cons of Epilepsy Facebook Groups
- Spring Mocktail Recipe
- Having COVID Cabin Fever? Here's my Biggest Tip to Beat It
- Mindfulness and Breathing
- The Benefits of Having Pets When You Live with a Chronic Illness
- Podcast Feature – Ten Percent Happier Podcast
- Daily Positive Affirmations
- The Reasons to Consider Going for a Walk
- Is it a "Bones" Day or a "No Bones" Day?
- Four Tips for Being More Positive
- Epilepsy in the Holiday Season

Christine's
Corner

BC EPILEPSY SOCIETY

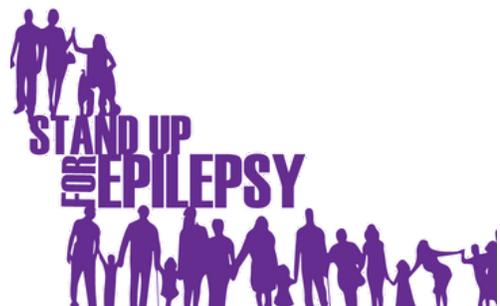


BCES MEDIA PRODUCTIONS

In 2021, the BC Epilepsy continued media products to educate, inform, and inspire, including:

- **Epilepsy Expert Webinar Series**
 - Professionals in various fields provide presentations via Zoom Webinars on a variety of topics that impact the daily lives of people living with epilepsy
- **Voice Epilepsy™ Podcast Series**
 - Podcast episodes that present information on a variety of topics related to epilepsy, advocacy, therapeutics, law, employment, surgery, mental health, stress and stigma, among many others.
- **Facebook Frames**
 - Frames on the BC Epilepsy Society's Facebook page allowed social media users to raise epilepsy awareness while showing support for people living with epilepsy.
- **#ishare2care Contest**
 - Our #ishare2care Contest from 2020 was brought back in 2021. Social media users uploaded a photo of how they were raising awareness of epilepsy during March with the hashtag #ishare2care and were automatically entered in a draw for a chance to win one of three \$100 gift cards at the end of March. Many amazing photos were posted using the #ishare2care hashtag to celebrate Epilepsy Awareness Month and PURPLE DAY® in 2021!
- **BCES Pumpkin Contest**
 - The BCES Pumpkin Contest was created in October 2021 to help raise awareness of epilepsy. Social media users uploaded a photo of their purple painted pumpkin or their pumpkin with an epilepsy-related carving and were automatically entered in a draw for a chance to win a \$25 gift card at the end of October.

VOICE EPILEPSY™



BCES EDUCATIONAL INITIATIVES

EPILEPSY EXPERT WEBINAR SERIES:

Through the BC Epilepsy Society's **Epilepsy Expert Webinar Series**, professionals in various fields provide presentations via Zoom Webinars on a variety of topics that impact the daily lives of people living with epilepsy (ex. health, law, employment, etc.). This allows you to get up-to-date and accurate information.

The following webinars in the **Epilepsy Expert Webinar Series** were presented in 2021:

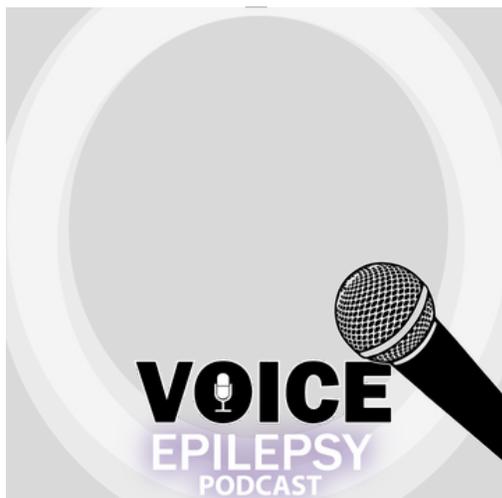
- **Sexual Health and Epilepsy** presented by **Dr. Harinder Dhaliwal, MBBS, FRCPC** and **Dr. Jennifer Percy, MD, FRCPC**
- **Pediatric Epilepsy Surgery** presented by **Dr. Mary Connolly, MB, BCh, BAO, FRCP(C), FRCP(I), FRCP(Edin)**
- **Adult Epilepsy Surgery** presented by **Dr. Chantelle Hrazdil, MD, FRCPC**
- **Seniors and Epilepsy** presented by **Dr. Sherrill Purves, MD, FRCPC, FAAN**

VOICE EPILEPSY™ PODCAST SERIES:

The **Voice Epilepsy™** podcast series introduces a variety of topics related to epilepsy, including medications, treatment, law, employment, surgery, mental health, stress, and stigma, among many others. Whether you are a person living with epilepsy or you have a personal or professional interest in epilepsy, the **Voice Epilepsy™** podcast series is for you! You can find the **Voice Epilepsy™** podcast series on Podbean, iTunes, Google Play, Spotify, etc.

The following episodes of the **Voice Epilepsy™** podcast series were released in 2021:

- Epilepsy and Memory
- Epilepsy and Daily Life
- Epilepsy and Seizure Triggers
- Interview with Cassidy Megan, Founder of Purple Day®
- Canada-Wide Neurodevelopmental Study Seeks BC Family Participation
- University of Victoria Study Seeks BC Family Participation
- Interview with Chuck Carmen, Executive Director of the Epilepsy Association and Founder of EpilepsyU and EpilepsyStore



BC EPILEPSY SOCIETY PARENT/CAREGIVER SURVEY

In June 2021, the BC Epilepsy Society released the Parent/Caregiver Epilepsy Needs Assessment Survey so that we could find out what parents and caregivers of people with epilepsy need to ensure that we can best help them and the people that they provide care to through our programs and services

45%

of respondents were the parent/caregiver to a child or youth living with epilepsy

53%

of respondents were the parent/caregiver to an adult living with epilepsy

2%

of respondents were the parent/caregiver to a senior living with epilepsy

67%

of respondents were the parent or legal guardian to the person they care for

17%

of respondents were the partner or spouse to the person they care for

16%

of respondents were another family member of the person they care for



HE NEEDS A FRIEND SO BADLY TO HELP LIGHTEN THE BURDEN OF BEING AND FEELING ALONE.

Survey Respondent

BCES IN THE COMMUNITY

International Epilepsy Day Expo

On February 8th, 2021, people around the world celebrated International Epilepsy Day and the BC Epilepsy Society took part by having several BC landmarks lit up purple in honour of International Epilepsy Day and by hosting a free online event featuring talks and presentations on a wide variety of epilepsy-related subjects, including:

- How to raise awareness of epilepsy while doing advocacy work in the community
- How to recognize and respond to a seizure, including seizure first aid and other safety considerations regarding seizures and epilepsy
- The various provincial and federal disability benefits available for people living with epilepsy and how to apply for them
- Provincial resources available for people living with epilepsy in BC



International Purple Day® for Epilepsy Awareness

On March 26th, in honour of International PURPLE DAY® for Epilepsy Awareness, many buildings and landmarks across BC were illuminated purple to help raise awareness of epilepsy. Also, just like 2020, PURPLE DAY® in 2021 still looked different due to the ongoing COVID-19 Pandemic. In response to this, the BC Epilepsy Society brought back our #ishare2care campaign from 2020 in an effort to use social media to bring people together as they were unable to get together in person on PURPLE DAY®. To participate in our #ishare2care campaign, participants took a photo of how they were raising awareness of epilepsy on PURPLE DAY® and uploaded it to their social media account using the hashtag #ishare2care. Many amazing photos were posted using the #ishare2care hashtag to celebrate PURPLE DAY® in 2021! We were also lucky enough to partner with two corporations (Gold's Gym and Rumble Boxing) for some great PURPLE DAY® initiatives in 2021.



BC EPILEPSY SOCIETY 2022 AWARDS OF DISTINCTION

2022 CHAMPION FOR CHANGE AWARD

The BC Epilepsy Society is pleased to announce that Jacqueline Martin is the recipient of our 2022 Champion for Change Award.

Jacqueline is a person with epilepsy who naturally raises awareness of epilepsy in everything she does, particularly with anything sports related. She believes everyone with epilepsy can continue to play the sports they love, even if things need to be modified in order to do it. A natural athlete, she trains at Rumble Boxing and teaches yoga at Oxygen Yoga. She connects organizations with the BC Epilepsy Society to build bigger awareness campaigns and fundraising campaigns.

Your dedication to the epilepsy community is inspiring, Jacqueline! Thank you for all you do!

Congratulations Jacqueline!



BC EPILEPSY SOCIETY 2022 AWARDS OF DISTINCTION

2022 COMMUNITY SPIRIT CORPORATE AWARD

The BC Epilepsy Society is pleased to announce that Rumble Boxing is the first recipient of our 2022 Community Spirit Corporate Award.

Rumble Boxing is an organization that is dedicated to giving back the community.

During International PURPLE DAY® for Epilepsy Awareness on March 26th, 2021, we were proud to work alongside Rumble Boxing as they raised awareness of epilepsy by donating a wonderful prize pack, including a pair of purple boxing gloves, for a giveaway to our social media followers. We look forward to working with Rumble Boxing now and in the future.

Congratulations to Rumble Boxing!



BC EPILEPSY SOCIETY 2021 AWARDS OF DISTINCTION

2022 COMMUNITY SPIRIT CORPORATE AWARD

The BC Epilepsy Society is pleased to announce that Gold's Gym is the second recipient of our 2022 Community Spirit Corporate Award.

During International PURPLE DAY® for Epilepsy Awareness on March 26th 2021, we were proud to work alongside Gold's Gym as they raised awareness of epilepsy by turning their social media purple.

In the past, Gold's Gym has donated a portion of membership sales to BC Epilepsy Society and helped us co-host a free seizure first aid workshop for gym employees and patrons.

We look forward to working with Gold's Gym now and in the future.

Congratulations to Gold's Gym!



BC EPILEPSY SOCIETY 2022 AWARDS OF DISTINCTION

2022 PURPLE HEART AWARD

The BC Epilepsy Society is pleased to announce that Marika is the recipient of our 2022 Purple Heart Award for exemplary youth in the community.

Marika has been involved with the BC Epilepsy Society through our Epilepsy Friends Forever (EFF) program and our Young Adult Peer Group.

Marika uses her lived experience of epilepsy to raise awareness of epilepsy, advocate for people with epilepsy, and make a profound difference in the epilepsy community by posting on her Seizure Soldiers Instagram account, being an influencer for Epilepsy Canada, and through her work on the BC Youth Parliament where she recently presented a Parliament Member Resolution for more research money for epilepsy.

We look forward to seeing what you will do in the years to come! Congratulations Marika!





Donors, Funders & Sponsors

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UCB Canada Inc.

Raymond James Foundation

Norm Beddow Estate

Telus Friendly Future Foundation

Telus Cares Foundation

RBC Financial Group

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Vancity Community Fund

Wadell Family Foundation

Kids Up Front

SafeFleet

United To End Bullying

The Edith Lando Charitable
Foundation

United Way Fraser Valley

United Way Calgary

Bourquin Printers

Children's Foundation

Asociazone Culturale

CKNW Orphans Fund

Benevity Community Fund

Hamber Foundation

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United Way Central and Northern

Vancouver Island

Fruitvale Community Chest

G&F Financial Group Foundation

Provincial Employees Community
Services Fund

United Way Toronto

Gordon Howe Estate

Unipharm and Medicine Centre
Pharmacies

Al Roadburg Foundation

Magellan Law Corporation

PostNet Vancouver

BC Gaming Grant

YOUR FINANCIAL SUPPORT IS A LIFELINE TO MORE THAN 50,000 PEOPLE THAT NEED BC EPILEPSY SOCIETY

Without the financial support of donors, we simply would not be able to develop and deliver the many programs and services on which our members rely. There are many ways that you can make a donation to the BC Epilepsy Society. Please click the links below for more information:

- [Donate to the BC Epilepsy Society](#)
- [Donate in Memory, Honour, or Celebration](#)
- [Leave a Gift in Your Will](#)
- [Matching Gift Programs](#)
- [Monthly Donations](#)
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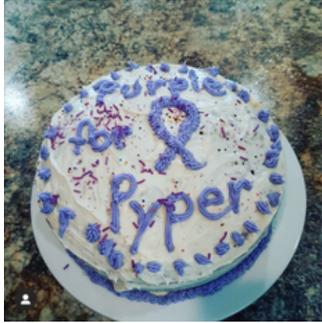
Thank you to our donors!

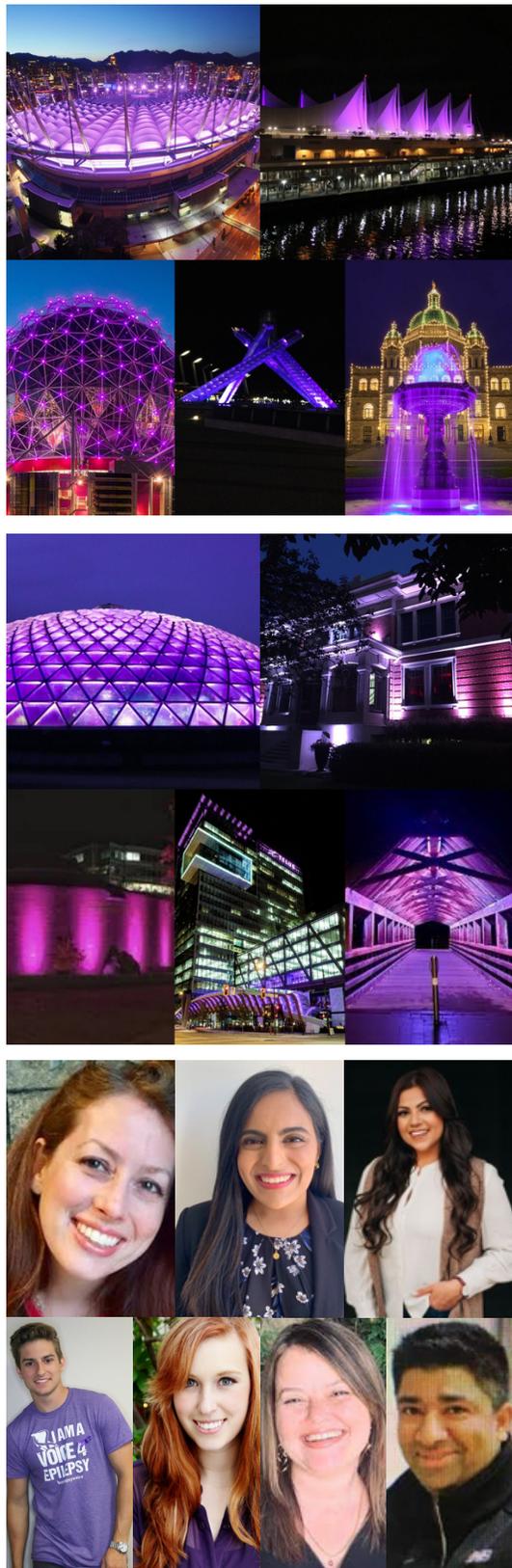
STOP BY AND SHOP AT OUR ONLINE STORE

Help us raise awareness for epilepsy by wearing our apparel! You can choose from a variety of options, including t-shirts, hats, stickers, and more! **Click [here](#) to visit the store and make your purchase today!**



We're turning purple
in support of
BC Epilepsy Society
and Purple Day





“

THANK YOU SO MUCH FOR THE WARM WELCOME I RECEIVED FROM EVERYONE THAT I HAVE CONNECTED WITH SO FAR. I AM HONOURED TO LEAD AN ORGANIZATION THAT IS COMMITTED TO MAKING POSITIVE CHANGE IN THIS PROVINCE FOR OUR EPILEPSY COMMUNITY.

AS SOMEONE WHO LIVES WITH EPILEPSY, I AM A PROUD PART OF THE EPILEPSY COMMUNITY MYSELF. THIS MAKES THE VISION AND MISSION OF THE BC EPILEPSY SOCIETY PERSONAL.

MY EFFORTS TO ADDRESS THE OBSTACLES THAT MANY OF US FACE ARE BASED ON MY OWN EXPERIENCES AND THE EXPERIENCES THAT THE EPILEPSY COMMUNITY SHARES WITH ME. WHEN WE WORK TOGETHER, WE CAN LEARN FROM EACH OTHER AND OVERCOME SOME OF THESE OBSTACLES.

-Deirdre Syms, BC Epilepsy Society Executive Director



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