

Improving Lives. Inspiring Courage.

December 13th, 2020

Dearest BCES Friends and Families,

As the end of the year approaches, I wanted to share an important message of hope with all of you. We know that COVID-19 is one of the most critical challenges, that crosses all domains of the human experience in recent history.

Early on, in March 2020, we endeavoured to dedicate ourselves to rethinking not only the way we work, but also how to pivot, and re-focus our limited resources to mitigate the impact and devastation that COVID-19 has had on the lives of people living with epilepsy in BC. We swiftly moved all of the in-person support groups to an online format and increased the frequency of groups; from March 2020 to June 2020, we delivered weekly online support groups. As the province opened up, your need for weekly groups (drop in attendance) was no longer necessary, and from June 2020 onwards, we have continued to run monthly online support groups. The provincial support groups that we offer include Online Peer Support, Family Peer Support, Young Adults Peer Support, BC Epilepsy Parents Network (BCEPN) and two sessions of Epilepsy Friends Forever (EFF). Please click [here](#) for more information on our online support groups.

2020 was an epic year of legacy building initiatives, health promotion, and advocacy for the epilepsy community in BC.

In February 2020, we started a petition on change.org advocating for the BC Provincial Government to put an end to the epilepsy crisis in BC. This petition can be found [here](#) and has now been signed by over 3,000 people who are all advocating for significant changes to the adult epilepsy system in BC.

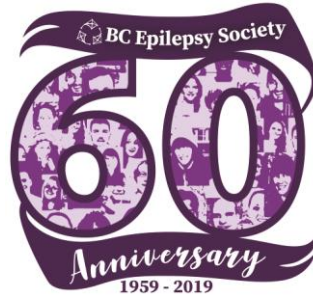
In September 2020, we created the **Your Voice Matters: Adult Epilepsy System Report Card** survey to give people living with and affected by epilepsy in BC the chance to share their experiences with the adult epilepsy system and assign a report card grade. Through your participation, *you* graded the adult epilepsy system in BC with an overwhelming F. The results from this survey and the failures of the adult epilepsy system in BC can be found [here](#).

As you are aware, the **What If ... Documentary Series™** was born out of necessity to highlight the lack of action and leadership from the BC Provincial Government. It includes over a dozen unsuccessful attempts to meet with government over a period of 26 months. During this time, the adult epilepsy crisis in BC worsened. Due to the government's inaction, British Columbian's continued to die (by SUDEP and suicide), go homeless, and seize without any medical interventions as they continued to wait years for the treatment and care that they so desperately needed. Our What If ... Documentary Series™ is an unprecedented social justice initiative for our advocacy for change. The episodes are an honest and fearless recount of what people living with and affected by epilepsy in BC are going through while navigating an under-funded and under-resourced system. In October (during the BC provincial election) and November 2020, four episodes of the What If ... Documentary Series™ were released, including episode 1: *FAILURE: The Black Mark on Canadian Health Care*, which now has over 50,000 views and can be viewed [here](#); episode 2: *PRISONER OF PURGATORY: The Jared Ricks Story*, which now has over 43,000 views and can be viewed [here](#); episode 3: *UNASHAMED AND UNAFRAID: The Allison Hegedus Story*, which now has over 15,000 views and can be viewed [here](#); and episode 4: *JESUS LOVES ME: The Mackenzie MacWilliams Story*, which now has over 13,000 views and can be viewed [here](#).

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2020 was also the year that we increased our provincial reach to the public through our social media accounts and media projects. Although our media productions have slowed due to COVID-19, we look forward to growing our media productions in 2021 to build an even stronger legacy.

In 2020, BCES created and produced four new brands within our revolutionary media production framework. I am proud to highlight our compelling media works that entertain, inform, and inspire:

- **Epilepsy Expert Webinar Series** – Neurologists, Epileptologists and other professionals in the field of epilepsy present their medical expertise through topic-focused webinar presentations.
- **What If ... Documentary Series™** – Documentary episodes expose the failings of the current infrastructure of the adult epilepsy system in BC through telling stories of people living with; dying from; and affected by epilepsy in BC. The Documentary sounds the alarm on the disparity between BC and all other provinces in Canada - adult epilepsy in BC is the black mark on Canadian healthcare. The Epileptologists & Neurologists (aka. our Heroes) are sadly trapped in a grossly under-resourced, under-funded adult epilepsy program that lacks provincial over-sight or government leadership to fix the problem. There is a successful template that has already been established and implemented in Ontario (Clinical Guidelines for the Management of Epilepsy) across the life span. The guidelines can be viewed [here](#).
- **Voice Epilepsy™ Podcast** – 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.
- **E-News™ Broadcasts** – Video broadcasts of epilepsy news updates, covering epilepsy-related international news stories from Google Alerts.

You have – and always will have – our continued commitment to use every avenue available to raise awareness, educate and advocate for more provincial and federal funding to address the deficiencies in British Columbia for therapeutics, medications, in-province brain surgeries, medical staffing, system navigators, equitable disability benefits and much more.

Look at the success that we managed to have during this pandemic. I can only imagine the momentum and success we will build from this point forward into 2021. We are fearless, we are one voice & we will get there!

I wish everyone health, wellness, and peace this December.

Warm regards,

Kim Davidson
CEO & Executive Director, BC Epilepsy Society
Founder, I AM A VOICE for Epilepsy Awareness™ campaign
Creator and Producer, What If ... Documentary Series™

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