



PRESS RELEASE

FOR IMMEDIATE RELEASE

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BC Epilepsy Society Calls on BC Government to Step Up

Vancouver, BC – The BC Epilepsy Society is calling on the government of British Columbia and the Ministry of Health to step up and support the more than 40,000 British Columbians living with epilepsy. Currently, 3 out of every 4 British Columbians are being sent out of province for epilepsy brain surgery and in 2019 the British Columbia Ministry of Health cut funding for British Columbia's one and only neuropsychiatrist attached at the epilepsy clinic.

In response to the ongoing crisis, the government of British Columbia allocated a negligible \$1.79 per person for 2020 to support programs and services that are desperately needed to save lives. Without greater investment from government and recognition of this crisis, the number of patients who suffer Sudden Unexpected Death in Epilepsy (SUDEP) will only grow as they die while waiting for treatment.

"Despite being one of the most common neurological conditions, epilepsy currently receives the least funding and research dollars in British Columbia," says Kim Davidson, CEO and Executive Director of the BC Epilepsy Society. *"We aim to expose the failures of our current support systems and share emotional stories from families and individuals who have been devastated by epilepsy."*

In order to draw attention to this crisis, the BC Epilepsy Society is debuting a docuseries on epilepsy "What If ... Documentary Series™" created by the I AM A VOICE for Epilepsy Awareness campaign. Premiering in Vancouver on March 26, this twelve-part series examines the impact of living with epilepsy in a "have-not-province" without appropriate support systems. The BC Epilepsy Society follows families and individuals along their heart wrenching journeys to find a cure and grapple with the loss of family members gone too soon.

Ricks Family Feature Story: Jared Ricks was a young musician from Victoria, British Columbia. In December 2018, Jared tragically passed away at the age of 23 as the result of SUDEP. At the time of his passing, Jared was on waitlists in four different provinces for epilepsy brain surgery, including his home province of British Columbia.

MacWilliams Family Feature Story: Mackenzie MacWilliams was a young man from Surrey, British Columbia. In April 2019, Mackenzie tragically passed away at the age of 27 as the result of SUDEP. Mackenzie's wife was the one who found him at home unconscious and not breathing and called 911. A month after his passing, his wife, Amber, now widow, and his nine-month old son, Luke, accepted Mackenzie's posthumous degree after crossing the stage at his convocation ceremony on his behalf.

About BC Epilepsy Society

Since 1959, the BC Epilepsy Society, has been proudly serving the over 40,000 British Columbians living with epilepsy and their families and helping to raise awareness of epilepsy around the world. Our mission is to empower, educate and support British Columbians living with epilepsy and their families, and support research to make their lives easier.

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GAPS IN OUR HEALTH SYSTEM

- More than 40,000 people live with epilepsy in British Columbia and 3,200 are newly diagnosed every year.
- British Columbia has 2 epilepsy beds for population of 4.8 million.
- 3 out of every 4 British Columbians are being sent out of province to Alberta and Ontario for epilepsy brain surgery.
- In 2019, the British Columbia Ministry of Health cut funding for British Columbia's one and only neuropsychiatrist at the epilepsy clinic. All other Canadian Health Ministries have funded several neuropsychologists and neuropsychiatrists at their epilepsy clinics.
- Thousands could benefit from Ketogenic Diet, Cannabidiol (CBD), Vagus Nerve Stimulation (VNS) Surgery in BC, yet, in 2019, only 16 people had the life-changing procedure.
- British Columbia is the only province where patients must pay out of pocket for Brivlera, a medication that is used in the treatment of refractory (treatment-resistant) focal epilepsy.
- British Columbia does not have a single system navigator for people living with epilepsy to aid youth aging out of the child system into the adult system; to aid those with new diagnoses of epilepsy; to aid people with refractory (treatment-resistant) epilepsy; or to aid people in any other situations requiring support.
- All other Canadian provincial governments have funded several system navigators for people living with epilepsy.
- There are no clinical guidelines for the management of epilepsy in British Columbia.

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