

Dear

I am writing to you today as one of your constituents in the riding. For many people living with epilepsy, it is the devastating emotional, social and psychological stresses of epilepsy – not just the challenges of seizure control – that often leave the deepest scars. This can lead to a number of negative factors for people living with epilepsy, including social isolation, depression, suicide, family breakdown, job loss and living in poverty, among many others.

In fact, despite being one of the most common neurological conditions, epilepsy currently receives the least funding and research dollars and has the least recognition, education and awareness in society. This can lead to increased stigma towards people living with epilepsy, which has a severe, negative and debilitating impact on their mental health and well-being and overall quality of life.

People living with epilepsy in British Columbia are at a further disadvantage. Within the healthcare system in British Columbia, there are many inequities associated with the care and support provided to people living with epilepsy, especially when compared with other provinces in Canada.

British Columbia has been described as a “have not province” due to a lack of infrastructure and systemic breakdowns, causing the already compromised people living with epilepsy in British Columbia to become the casualties of a homegrown crisis. This has led to the below disparities:

- **14,000 People in BC have Drug-Resistant Epilepsy**
 - 35% of people living with epilepsy in BC (14,000 people) have drug resistant epilepsy
 - Less than half of these people are considered to be appropriate candidates for epilepsy surgery
 - The remaining 7,000+ people are suitable for alternative therapies, such as the Ketogenic Diet, Cannabidiol (CBD), Vagus Nerve Stimulation (VNS) Surgery, etc.
 - The procedure for implanting the VNS takes one-hour and is a relatively simple procedure that health care professionals in BC already have expertise in
 - However, funding is currently being capped to limit the number of implants
 - There are thousands who could benefit from this procedure in BC, yet, in 2019, only 16 people had the life-changing procedure
- **Approximately 3,200 people in BC are newly diagnosed with epilepsy every year**
- **Beds in Seizure Investigation Units for Epilepsy Diagnostics**
 - **BC has 2 epilepsy beds with a population of 4.8 million**
 - Alberta has 8 epilepsy beds with a population of 4.3 million
 - Manitoba has 2 epilepsy beds with a population of 1.4 million
- **Brain Surgeries in the Adult Population Frequently Being Sent Out-of-Province**
 - **3 out of every 4 people living with epilepsy in BC are being sent out of province to Alberta and Ontario for epilepsy brain surgery**
 - There is also a very long waitlist for brain surgeries occurring both in and out of province

- **Neuropsychology and Neuropsychiatry**
 - In 2016 and 2017, the BC Epilepsy Society funded the annual salary of one neuropsychologist attached to the epilepsy clinic in BC
 - This expenditure was an unsustainable financial burden to the BC Epilepsy Society
 - This financial burden should not have fallen on the BC Epilepsy Society, a non-profit charitable organization, but should have been the purview of the BC Ministry of Health
 - **In 2019, the BC Ministry of Health cut funding for BC's one and only neuropsychiatrist attached to the epilepsy clinic**
 - All other Canadian Health Ministries have funded several neuropsychologists and neuropsychiatrists at their epilepsy clinics

- **Pharma, Drugs and Medications**
 - **BC is the only province that is not approved for Brivlera, a medication that is used in the treatment of refractory (treatment-resistant) focal epilepsy**
 - People living with epilepsy in BC must pay out-of-pocket to use the medication, creating immense financial burdens and causing some people living with epilepsy in BC who need the medication to move to Alberta, where it is covered

- **System Navigators for People living with Epilepsy and their Families**
 - **BC 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

- **Clinical Guidelines for the Management of Epilepsy**
 - Ontario has the "Ontario Clinical Guidelines for the Management of Epilepsy", which provides information on supports in the health care and social services system for people living with epilepsy
 - **No such guidelines exist in BC**

Please see the below table to view the current funding crisis in British Columbia:

Disease	2020 BC Government Grant Amount	2020 BC Government Gaming Grant Amount	Total Amount of Funding from BC Government	# of People in BC
Multiple Sclerosis*	\$252,900	\$526,000	\$778,900**	10,000
Muscular Dystrophy*	\$270,827	\$103,000	\$373,827**	4,000
Cerebral Palsy*	\$56,623.20	\$427,500	\$484,123.20**	4,500
Epilepsy	\$0	\$126,000	\$126,000	40,000+

*It has been found that more people have epilepsy than those who have Multiple Sclerosis, Muscular Dystrophy and Cerebral Palsy, combined. **In fact, even if you multiplied the numbers from those conditions by 2, you would still not reach the dire numbers of epilepsy.**

****The government of British Columbia awarded \$1,626,850.20 to help the 18,500 individuals living with Multiple Sclerosis, Muscular Dystrophy and Cerebral Palsy in British Columbia yet they awarded only \$126,000 to help the over 40,000 individuals living with epilepsy in British Columbia.**

Due to the above, it becomes clear that there is an epilepsy crisis in British Columbia. With your help, we hope to:

- Raise much-needed awareness about epilepsy as a disease
- Shine a light on the hardships that people living with and affected by epilepsy in British Columbia are going through
- Impact policy change at the highest level
- Inform funding decisions to promote social justice and systemic reform across all sectors including, but not limited to, legal, medical, public health, education and employment
- Improve infrastructure for:
 - More SIU epilepsy beds
 - Several neuropsychologists and neuropsychiatrists attached to epilepsy clinics
 - More neurosurgeons (we have two)
 - More research dollars
 - Several system navigators (we have none)
 - Job protection and support
 - Access for legal assistance
 - Special designations for epilepsy supports in education
- **SAVE LIVES!**

We desperately need your help in the fight to raise awareness of the epilepsy crisis in British Columbia. Thank you for your time and consideration. I look forward to hearing back from you soon on this important topic.

Sincerely,