

AUGUST 2021

**THE BC ADULT
EPILEPSY
CRISIS**

REPORT PREPARED BY:

BC Epilepsy Society

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MESSAGE FROM THE CEO

"This report was created to tell the story of adult epilepsy in BC, the black mark on Canadian health care. This report will better inform the public about the adult epilepsy crisis and how, over decades, it became a politicized, orphaned disease in BC. In contrast, Alberta has 3 adult epilepsy clinics and 10 adult epilepsy beds with a population of 4.4 million; whereas BC has only 1 adult epilepsy clinic and only 4 adult epilepsy beds with a population of 5.1 million. In this report, we have identified what the issues are and have offered attainable solutions which will improve diagnostic, surgical, prescription, and therapeutic access to save lives. More importantly, there exists a time-sensitive opportunity to add adult epilepsy beds and expand clinical, diagnostic, and surgical services within Royal Columbian Hospital's \$1.49 billion Redevelopment Project. Thank you in advance for reading this report, [signing our petition](#) and becoming informed."

-Kim Davidson, CEO, BC Epilepsy Society

FUELING BC'S ADULT EPILEPSY CRISIS



EPILEPSY BEDS

BC's adult epilepsy clinic at Vancouver General Hospital has only 4 epilepsy beds in their Seizure Investigation Unit whereas Seizure Investigation Units in other provinces with similar (and sometimes lower) epilepsy populations have the same amount (and sometimes more) epilepsy beds. Please see Appendix 1 for a chart detailing this information.



PRESCRIPTION COVERAGE

There should be universal access to epilepsy medications across Canada, but in BC, there are several that are not approved or covered. This causes adult epilepsy patients to either pay out-of-pocket or move to other provinces, away from their families in BC to access life-saving epilepsy medications. Please see Appendix 2 for a list of epilepsy medications that are not covered in BC.



STAFFING SHORTAGES: NEUROSURGEONS

BC's adult epilepsy program only has a 0.3 epilepsy neurosurgeon while adult epilepsy programs in other provinces have a number of neurosurgeons attached to the programs. This is why patients requiring surgery often sit on 2-3 year long waitlists or are sent out of province to Alberta, Ontario, and Quebec for surgery at their own expense.



STAFFING SHORTAGES: NEUROPSYCHOLOGISTS

BC's adult epilepsy program only has a 0.5 epilepsy neuropsychologist to help adults with epilepsy with issues related to mental health. Adult epilepsy programs in other provinces have a number of neuropsychologists attached to the programs.

FUELING BC'S ADULT EPILEPSY CRISIS



STAFFING SHORTAGES: NEUROPSYCHIATRISTS

BC's adult epilepsy program has no epilepsy neuropsychiatrists to help adults with epilepsy with issues related to the effects of epilepsy medications on the brain and comorbid mental health diagnoses. Adult epilepsy programs in other provinces have a number of neuropsychiatrists attached to the programs.



STAFFING SHORTAGES: NURSES

BC's adult epilepsy program has only 2 epilepsy nurses. More adult epilepsy nurses are needed in BC's Adult Epilepsy Clinic and Adult Seizure Investigation Unit. Adult epilepsy programs in other provinces have many more nurses attached to the programs (per capita).



STAFFING SHORTAGES: TECHNICIANS

The adult Seizure Investigation Unit within BC's adult epilepsy program needs more Electroencephalography (EEG) technicians to read EEGs. Adult epilepsy programs in other provinces have many more EEG technicians attached to the programs (per capita).



STAFFING SHORTAGES: SOCIAL WORKERS

BC's adult epilepsy program has no social workers attached to the program to link adult epilepsy patients to community resources and provide counselling and support services. Adult epilepsy programs in other provinces have social workers attached to the programs.

FUELING BC'S ADULT EPILEPSY CRISIS



STAFFING SHORTAGES: PHARMACISTS

BC's adult epilepsy program has no pharmacists attached to the program to assist adult epilepsy patients with issues related to their epilepsy medications. Adult epilepsy programs in other provinces have pharmacists attached to the programs.



STAFFING SHORTAGES: OCCUPATIONAL THERAPISTS

BC's adult epilepsy program has no occupational therapists attached to the program to assist adult epilepsy patients in BC with any struggles they may be facing due to epilepsy in regards to the essential tasks of daily living. Adult epilepsy programs in other provinces have occupational therapists attached to the programs.



STAFFING SHORTAGES: VOCATIONAL REHABILITATION COUNSELLORS

BC's adult epilepsy program has no vocational rehabilitation counsellors attached to the program to assist adult epilepsy patients in BC with epilepsy-related struggles regarding employment and/or careers. Adult epilepsy programs in other provinces have vocational rehabilitation counsellors attached to the programs.



STAFFING SHORTAGES: DIETITIANS

There are no dietitians attached to BC's adult epilepsy program to provide the medical intervention necessary for the Ketogenic Diet as a potential epilepsy therapy option for adult epilepsy patients in BC. Adult epilepsy programs in other provinces have dietitians attached to the programs.

FUELING BC'S ADULT EPILEPSY CRISIS



INVESTING IN THE LATEST TECHNOLOGY

The BC Ministry of Health has not invested in the latest technology for BC's adult epilepsy program, including Laser Interstitial Thermal Therapy (LITT), which provides a minimally invasive surgery option for patients with drug-resistant epilepsy. Adult epilepsy programs in other provinces invest in the latest technology, including LITT and many others.



TREATMENTS AND THERAPEUTICS: VAGUS NERVE STIMULATION (VNS)

VNS is an epilepsy therapy option that can limit and even eliminate seizures. Within BC's adult epilepsy system, VNS surgeries are capped despite the fact that it is a simple procedure that the province already has expertise in. BC completes only 3.3 procedures per million population while Ontario completes 9.3 procedures per million population.



TREATMENTS AND THERAPEUTICS: KETOGENIC DIET

The Ketogenic Diet is a medically supervised therapy that can limit and even eliminate seizures. BC currently has a successful pediatric epilepsy Ketogenic Diet program but has no adult epilepsy Ketogenic Diet program. Compare this to Ontario which has an adult epilepsy Ketogenic Diet program.



COMMUNITY FUNDING

In 2021, the BC Provincial Government funded the BC Epilepsy Society \$110,000 to serve the over 50,000 people living with epilepsy in BC, only \$2.20 per person with epilepsy per year. Compare this to Ontario where Epilepsy Ontario was funded \$267 million in 2018 by the Ontario Provincial Government.

INFRASTRUCTURE

**1.3 MILLION
PEOPLE**

Vancouver Coastal
Health Authority serves
this population

**5.1
MILLION
PEOPLE**

live in the province of
British Columbia



BC's adult epilepsy crisis is perpetuated by the fact that the adult epilepsy program in BC currently sits within Vancouver Coastal Health Authority, a regional health authority, rather than sitting within Provincial Health Services Authority (PHSA), where it belongs. *All other adult epilepsy programs in Canada have a provincial mandate - all but BC. In BC, autism, stroke, cancer, diabetes or pediatric epilepsy would never sit within a regional health authority and neither should adult epilepsy.*

Vancouver Coastal Health Authority has the one and only provincial adult epilepsy clinic in BC with only 4 adult epilepsy beds for a population of 5.1 million. **In comparison, Alberta has 3 adult epilepsy clinics with 10 adult epilepsy beds for a population of 4.4 million.**

The adult epilepsy clinic in BC is stuck in a health authority that has a mandate of serving a region of 1.3 million people, with no provincial oversight or accountability through PHSA. Please see Appendix 3 for a chart detailing the current structure of adult epilepsy in BC.

INFRASTRUCTURE

**1.9 MILLION
PEOPLE**

Fraser Health
Authority serves this
population

**\$1.49
BILLION**

Estimated cost of the Royal
Columbian Hospital
Redevelopment Project funded
by the BC Provincial
Government, Fraser Health
Authority and the Royal
Columbian Hospital
Foundation



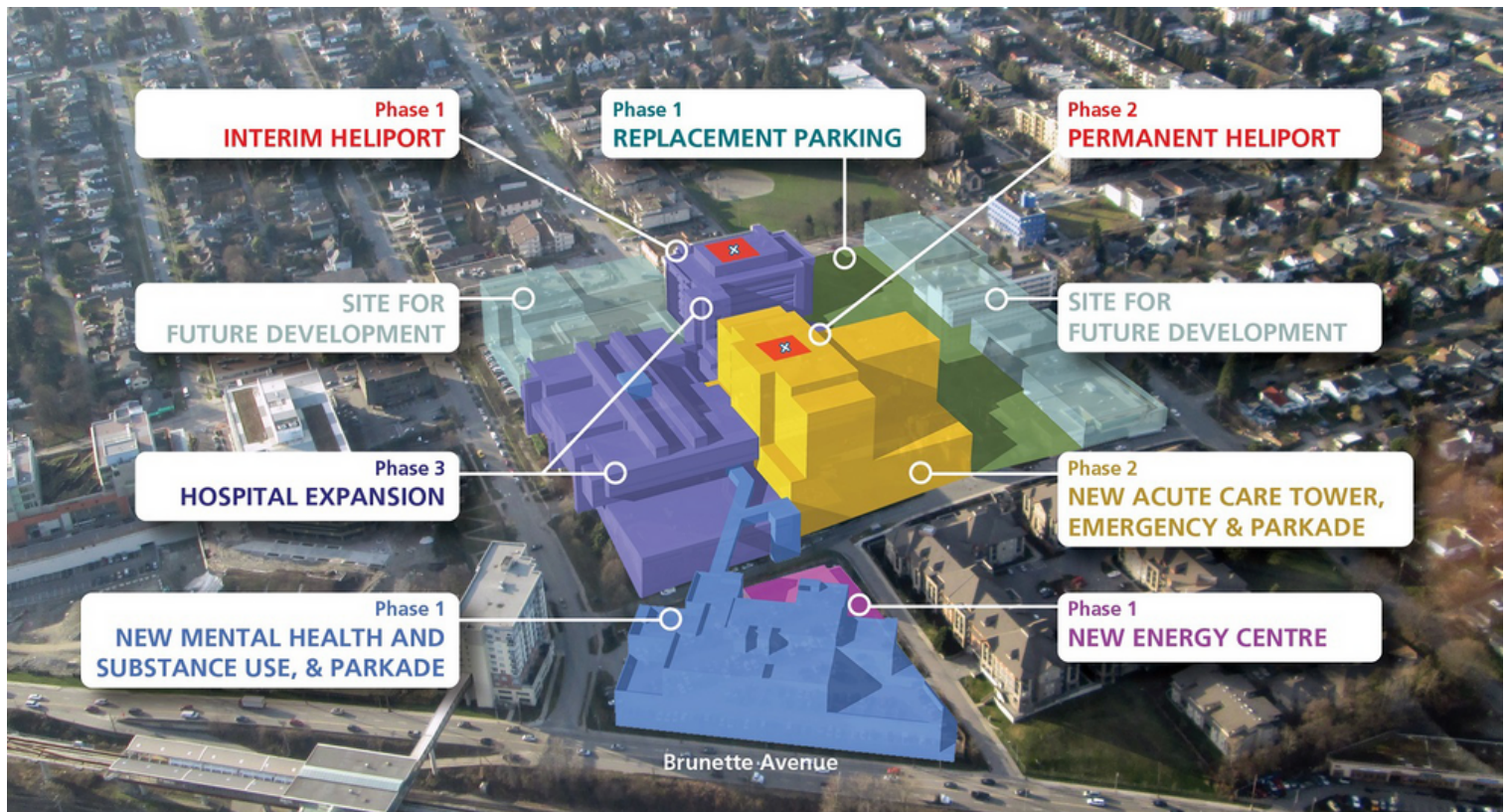
Fraser Health Authority, which serves a region of 1.9 million people, has a regional adult epilepsy program at the Jim Pattison Outpatient Care & Surgery Centre but they currently have **ZERO adult epilepsy beds**. *However, they do have the capacity to expand their adult epilepsy program; operationalize 2 adult epilepsy beds; and start an adult Ketogenic Diet program.*

Additionally, at Royal Columbian Hospital, there is capacity to create an adult epilepsy Seizure Investigation Unit with a minimum of 8 adult epilepsy beds. Furthermore, brain surgeries are currently being conducted at Royal Columbian Hospital, so they have the capacity necessary to also perform adult epilepsy brain surgeries. **There is currently no plan to incorporate an adult epilepsy clinic at Royal Columbian Hospital during the redevelopment project.**

INFRASTRUCTURE

ROYAL COLUMBIAN HOSPITAL REDEVELOPMENT PROJECT:

Royal Columbian Hospital's three-phase redevelopment project is estimated at \$1.49 billion and is funded by the BC Provincial Government, Fraser Health Authority and the Royal Columbian Hospital Foundation. **There is currently no business plan to incorporate an adult epilepsy clinic or adult Seizure Investigation Unit at Royal Columbian Hospital.**



PHASE 1 (2016-2020):

- New mental health facility
- Prepare hospital infrastructure for bed capacity expansion coming in Phase 2

PHASE 2 (2020-2025):

- Expand hospital's bed capacity
- Construction of a new acute care tower, including upgrades to emergency

PHASE 3 (2023-2026):

- Upgrade and expand areas to support beds and services added in Phase 2

Because BC's adult epilepsy program sits within Vancouver Coastal Health Authority and not within PHSA where it belongs, Fraser Health Authority has not included the expansion of adult epilepsy services in the Royal Columbian Hospital Redevelopment business plan. **The BC Provincial Government must incorporate at least 8 adult epilepsy beds into the bed capacity expansion and create an adult Seizure Investigation Unit and adult epilepsy clinic at Royal Columbian Hospital.**

We need you to write to your MLA and to your MP to demand that these essential options are looked into and considered.

INFRASTRUCTURE

Adult epilepsy needs provincial oversight in BC through Provincial Health Services Authority (PHSA), which works in partnership with all regional health authorities under the direction of the Minister of Health.

The lack of infrastructure with adult epilepsy in BC has led to one health authority having all of the epilepsy beds in the province despite having only a quarter of BC's population.

Why are adult epilepsy programs, clinics, beds, surgeries, treatment options, and therapy options not spread across all health authorities?

PHSA spreads services and resources to populations across BC; evaluates and monitors provincial health care; and provides resources to hire and recruit doctors and health care staff. PHSA is monitored by the Minister of Health and is accountable to government whereas Vancouver Coastal Health Authority, where adult epilepsy currently sits, is not monitored nor accountable.

We need you to help epilepsy doctors, patients and families by writing to your MLA and MP to demand that the adult epilepsy program is moved from Vancouver Coastal Health Authority to PHSA where it belongs.



“

We went to Montreal for scope brain surgery as it was not offered in BC.

-BC Caregiver of Adult Epilepsy Patient

“

A flight of 2 hours to get to BC's adult epilepsy clinic and then having to stay in a hotel room for a period of time ... it is expensive.

-BC Caregiver of Adult Epilepsy Patient



WHAT IS NEEDED IN BC?

- Divest adult epilepsy from Vancouver Coastal Health Authority to the Provincial Health Services Authority (PHSA) for provincial oversight
- Royal Columbian Hospital Redevelopment business plan to include adult epilepsy clinic and adult Seizure Investigation Unit
- Improved adult epilepsy infrastructure in BC
- Creation of provincial guidelines for epilepsy care as seen in Ontario and Quebec
- Access to functional adult epilepsy clinics within all health authorities
- Create a business plan for all health authorities that will be providing adult epilepsy surgeries and services to enable hospital foundations to secure donor funding
- Increased number of adult epilepsy beds per capita - BC needs 10 more beds (2 at the Jim Pattison Outpatient Care & Surgery Centre and 8 at Royal Columbian Hospital)
- Address staffing shortages:
 - 2 full-time adult epilepsy neurosurgeons away from VGH (0.3 currently attached to VGH)
 - 3 adult epilepsy neuropsychiatrists (none attached to epilepsy at Adult Epilepsy Clinic in BC)
 - 3 adult epilepsy neuropsychologists staffing (0.5 currently attached to Adult Epilepsy Clinic in BC)
 - 8 adult epilepsy social workers (none in BC)
 - 8 additional adult Electroencephalography (EEG) Technicians
- Responsive Neurostimulation (RNS) for adult with epilepsy in BC
- Access to the latest technology including Laser Interstitial Therapy (LITT), Stereoelectroencephalography (SEEG) and others
- Ketogenic Diet program for adults with epilepsy in BC
- Doing between 26-30 VNS surgeries a year and not 8 - No cap on VNS implants and surgeries
- Medications to be covered for epilepsy as is in other provinces in Canada (ex. Brivlera does not have PharmaCare or Special Authority coverage in BC)
- Reduced wait times for in-province epilepsy therapeutics and surgeries
- Mental health support in communities
- Funding for community epilepsy programs and services (BC Epilepsy Society)

"If universal adult epilepsy health care actually existed in Canada, British Columbians wouldn't be suffering like they are." -Kim Davidson



“

This is key. Epilepsy is way too common for everyone to come to Vancouver. Instead, it should be a [provincially] coordinated effort.
-BC Neurologist - 2021 Neurologist Needs Assessment Survey

“

Many of my patients would likely not have been highly disabled and then dead if surgery was available in a timely fashion.
-BC Neurologist - 2021 Neurologist Needs Assessment Survey



"I AM STRUGGLING TO UNDERSTAND HOW A HOSPITAL FOUNDATION COULD DIMINISH EPILEPSY NUMBERS YEAR AFTER YEAR IN THEIR SOCIAL MEDIA ... "

-KIM DAVIDSON

The VGH + UBC Hospital Foundation has diminished the epilepsy numbers in BC consistently over four years

Annual Report 2017-2018



For Ruth and Don James, witnessing their daughter's struggle led them to learn about epilepsy — which affects 40,000 British Columbians.

Source:
<https://vghfoundation.ca/app/uploads/2018/12/Annual-Report-2017-18-web.pdf>

In 2018, the VGH + UBC Hospital Foundation reported there were 40,000 people living with epilepsy in BC.

Source: <https://vghfoundation.ca/app/uploads/2018/12/Annual-Report-2017-18-web.pdf>

Epilepsy Patient Uses Second Chance at Life to Help Others

MARCH 25, 2019

Source:
<https://vghfoundation.ca/2019/03/25/epilepsy-patient-uses-second-chance-at-life-to-help-others/>

More than 32,000 adults in BC are diagnosed with epilepsy, and a large percentage could benefit from surgical treatments. Between misdiagnosis, wait times, and experimenting with different medications, patients like Natasha can wait years for effective treatments as they suffer from increasingly debilitating symptoms.

In 2019, the VGH + UBC Hospital Foundation reported there were 32,000 people living with epilepsy in BC.

Source: <https://vghfoundation.ca/2019/03/25/epilepsy-patient-uses-second-chance-at-life-to-help-others/>



VGH & UBC Hospital Foundation

March 26 · 🌐

[#PurpleDay2021](#) [#Epilepsy](#) [#EpilepsyAwareness](#)

Today,
there are more than 20,000 people living with epilepsy in BC—44% of which were diagnosed before the age of five.

Source:
<https://www.facebook.com/VGHUBCHospitalFoundation/photos/10165326803335077>

In 2021, the VGH + UBC Hospital Foundation reported there were 20,000 people living with epilepsy in BC.

Source: <https://www.facebook.com/VGHUBCHospitalFoundation/photos/10165326803335077>

In reality, there are over 50,000 people living with epilepsy in BC, NOT 20,000. According to the VGH + UBC Hospital Foundation, 30,000 people living with epilepsy disappeared between 2018 and 2021. So, where did 30,000+ British Columbians living with epilepsy GO?

REPORTING THE TRUE EPILEPSY NUMBERS

The province of BC has no transparency with epilepsy numbers whereas epilepsy numbers reported by other provinces, such as Alberta, are more accurate and accountable

The following information on the prevalence of epilepsy in Alberta from 2004-2019 was retrieved from the Alberta Interactive Health Data Application under the "Epilepsy – Age-Standardized Prevalence" dataset:

- 2004: 41,140
- 2005: 43,211
- 2006: 45,600
- 2007: 47,691
- 2008: 49,618
- 2009: 51,345
- 2010: 52,627
- 2011: 53,938
- 2012: 55,471
- 2013: 56,973
- 2014: 58,762
- 2015: 60,483
- 2016: 62,454
- 2017: 64,557
- 2018: 66,508
- **2019: 68,592 (with epilepsy)**

THESE NUMBERS INDICATE THAT EPILEPSY AFFECTS APPROXIMATELY 1.57% OF THE POPULATION OF ALBERTA, WHICH HAS 3 ADULT EPILEPSY CLINICS AND 10 ADULT EPILEPSY BEDS WITH A POPULATION OF 4.4 MILLION. THE PREVALANCE IN ALBERTA IS COMPARABLE TO BC, YET BC HAS ONLY 1 ADULT EPILEPSY CLINIC AND ONLY 4 ADULT EPILEPSY BEDS WITH A POPULATION OF 5.1 MILLION.

Source: http://www.ahw.gov.ab.ca/IHDA_Retrieval/redirectToURL.do?cat=6&subCat=304

According to the Public Health Agency of Canada (PHAC) and the Canadian Chronic Disease Surveillance System (CCDSS), **epilepsy affects approximately 1.47% of the population of BC.** However, specific epilepsy numbers as reported out of Alberta is currently not available in BC.

Source: <https://health-infobase.canada.ca/ccdss/data-tool/?G=59&V=17&M=2> (Epilepsy Numbers in BC)*

Source: <https://health-infobase.canada.ca/ccdss/data-tool/?G=59&V=18&M=2> (Active Epilepsy Numbers in BC)*

**Data from individuals aged 1 year and older.*

To be classified as epilepsy:

- For individuals aged 1-19 years: Three or more physician claims within two years, with at least 30 days between each claim
- For individuals aged 20 years and over: One or more hospitalizations, or three or more physician claims within two years, with at least 30 days between each claim

To be classified as active epilepsy:

- Once qualified as epilepsy: one or more hospitalizations or one or more physician claims within five years

EPILEPSY - DID YOU KNOW ...

KNOW THE NUMBERS

- **1% OF THE POPULATION HAS EPILEPSY, AT MINIMUM**
- **68% OF CASES OF EPILEPSY HAVE UNKNOWN CAUSE**
- **30% OF PEOPLE WITH EPILEPSY HAVE DRUG-RESISTANT EPILEPSY, WHERE SEIZURES ARE NOT CONTROLLED BY MEDICATION**
- **ANYONE CAN DEVELOP EPILEPSY AT ANY AGE OR STAGE OF LIFE**

YOU CAN DIE FROM EPILEPSY?

PEOPLE WITH EPILEPSY HAVE 3X HIGHER RISK OF EARLY MORTALITY AND 4X HIGHER RISK OF SUICIDE THAN THE GENERAL POPULATION.

SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP) IS THE LEADING CAUSE OF DEATH IN PEOPLE WITH POORLY CONTROLLED EPILEPSY, AFFECTING 1 TO 2 OF EVERY 1,000 PEOPLE WITH EPILEPSY ANNUALLY.

SEIZURES - NOT JUST EPILEPSY?

1 IN 10 PEOPLE WITHOUT EPILEPSY WILL HAVE A SEIZURE AT SOME POINT DURING THEIR LIFETIME

NON-EPILEPSY CAUSES OF SEIZURES CAN INCLUDE FEVER, THE USE OF ALCOHOL/DRUGS, IRREGULAR HEARTBEAT, LOW BLOOD SUGAR, LACK OF OXYGEN OR PSYCHOLOGICAL FACTORS

PUBLIC SAFETY ... SEIZURE FIRST AID?

THERE ARE NO NATIONAL PUBLIC SERVICE ANNOUNCEMENTS (PSA'S)/COMMERCIALS FOR SEIZURE FIRST AID.

WE KNOW WHAT TO DO WHEN SOMEONE IS CHOKING, WHEN SOMEONE HAS A STROKE BECAUSE PSA'S HAVE INFORMED US.

BUT NOT WHAT TO DO IF SOMEONE HAS A SEIZURE.

PSA'S FOR SEIZURE FIRST AID IS A HEALTH PROMOTION AND PUBLIC SAFETY INITIATIVE THAT IS DESPERATELY NEEDED TO SAVE LIVES.

100%

of respondents from our 2020 BC Adult Epilepsy Consumer Report Card Survey believe it is important for all people living with epilepsy in Canada to have equal access to timely, quality adult epilepsy health care, regardless of the province or territory in which they live

"BC DOES NOT HAVE A COMPREHENSIVE EPILEPSY CENTRE AS IS AVAILABLE IN OTHER PROVINCES THROUGHOUT THE COUNTRY. THE STRUGGLE IN BC IS REAL."

"I USED TO HAVE EVERY SEIZURE TYPE UNTIL SURGERY."

"I MAY EXPERIENCE UP TO 9 SEIZURES A DAY."

"I AM 6 MONTHS SEIZURE FREE AFTER MY SURGERY."

"DUE TO SEIZURES OR POSTICTAL STATE,

"PEOPLE MISUNDERSTAND EPILEPSY."

I AM SCARED OF THE HARM I MAY CAUSE

"I HAVE HAD ALL EPILEPSY

TO MYSELF AND OTHERS."

HEALTH CARE SERVICES DONE IN

"I HAVE ABOUT 75 SEIZURES A YEAR."

CALGARY SINCE I WAS 18."

"I AM THE CAREGIVER TO MY 33 YEAR OLD SON WHO

IS UNEMPLOYED DUE TO EPILEPSY."

"I AM UNEMPLOYED DUE TO STRESS-TRIGGERED SEIZURES."

"I CAN'T LIVE A NORMAL LIFE."

"DIFFICULTY MAINTAINING EMPLOYMENT.

"I GRIEVE THE LIFE I COULD HAVE

HAD TO DO A MIDLIFE CAREER CHANGE."

HAD. I WAS DIAGNOSED AT 6 AND

AM NOW 43 AND STILL FEEL THIS!"

"I HAVE TRIED DIFFERENT COMBINATIONS AND

DELIVERY METHODS OF MEDICATIONS OVER TIME AND

STILL HAVE UNCONTROLLED SEIZURES."

"I HAVE EXPERIENCED STIGMA AND BULLYING."

"IT TOOK TOO LONG TO GET A

"MEDICAL CARE IS SO LIMITED. I WAS PUT ON A LONG
WAIT LIST TO SEE A NEUROLOGIST IN PRINCE GEORGE."

DIAGNOSIS AS DOCTORS WERE

"IT'S HARD BEING A BURDEN AND MAKING OTHERS
FEEL GUILTY FOR MAKING YOU FEEL LIKE A BURDEN."

DISMISSIVE OF MY SYMPTOMS."

"I USE A WHEELCHAIR DUE TO FALLS FROM SEIZURES BUT CAN WALK FINE."

"I WAITED SIX YEARS TO GET INTO THE SEIZURE
INVESTIGATION UNIT."

"LOSS OF INDEPENDENCE."

"WHEN I LIVED IN ONTARIO, I SAW A NEUROLOGIST WITHIN A WEEK."

**"IN BC, THERE IS A LACK OF RESOURCES,
SUPPORT AND TREATMENT OPTIONS."**

"I WAS BOUNCED AROUND FROM SPECIALIST TO SPECIALIST. IT WAS A GONG SHOW."

"I HAVE EXPERIENCED STIGMA, BULLYING, DISCRIMINATION AND HARASSMENT."

"PEOPLE DON'T UNDERSTAND THAT EPILEPSY STILL AFFECTS YOU
EVEN IN THE ABSENCE OF CURRENT SEIZURING."

"NO ONE TALKS ABOUT EPILEPSY-RELATED DEATHS."

WHAT IS HAPPENING IN THE REST OF CANADA?

ONTARIO: In 2014, Critical Services Ontario (CCSO), the Epilepsy Implementation Taskforce (EITF), and Provincial Neurosurgery Ontario (PNO) developed provincial guidelines for epilepsy care in Ontario. These guidelines have improved treatment and access to care for people with epilepsy in Ontario by ensuring that all people with epilepsy in Ontario have timely access to treatment, including surgery. The guidelines educate people with epilepsy in Ontario about their epilepsy and seizures, treatment options, resources for support, and self-advocacy efforts. Under these guidelines, anyone with epilepsy who is not seizure-free after trying two different anti-seizure drugs has drug-resistant epilepsy. The guidelines indicate that people with drug-resistant epilepsy should be offered a referral to an epileptologist (a neurologist specializing in epilepsy) at a specialized epilepsy centre to talk about their treatment options, including surgery, dietary therapy, immune therapy and brain and nerve stimulation. **BC does not have the infrastructure or the capacity to do this.**

"British Columbians living with epilepsy deserve the same quality of life and opportunities as those living with epilepsy in Ontario. We need these life-saving guidelines and the infrastructure they bring with them implemented in BC." -Kim Davidson

It should be noted that province of Ontario has the infrastructure necessary to manage the overall structure and delivery of these guidelines because both pediatric epilepsy and adult epilepsy have a provincial mandate in Ontario.

View the "Ontario Clinical Guidelines for the Management of Epilepsy" [here](#).

The Ontario Clinical Guidelines for the Management of Epilepsy are being translated into French to be replicated in Quebec.

ONTARIO
EPILEPSY GUIDELINES

No such guidelines currently exist in BC. However, there is already a framework in place for BC to use when implementing the necessary improvements to BC's adult epilepsy program.

“

He was on a waitlist in BC for 3 years. We then got him on other waitlists in Montreal, Edmonton, and Ontario and, at that point ... it was just disappointment after disappointment.

-Family Member of 23-year-old victim of Sudden Unexpected Death in Epilepsy (SUDEP)

“

He died waiting for surgery. If there perhaps had been more beds and been more availability, this could have been prevented.

-Family Member of 23-year-old victim of Sudden Unexpected Death in Epilepsy (SUDEP)

WHAT IS HAPPENING IN THE REST OF CANADA?



SASKATCHEWAN: In August 2019, Saskatchewan's Provincial Government committed to investing \$1.35 million operational funding each year starting in 2020-21 to establish a 4 bed adult epilepsy monitoring unit at Royal University Hospital in Saskatoon.

Source: <https://www.saskatchewan.ca/government/news-and-media/2019/august/19/epilepsy-unit>



MANITOBA: In May 2021 (during the COVID-19 Pandemic), Manitoba's Provincial Government invested \$4 million toward expanding HSC Winnipeg's adult epilepsy monitoring unit from 2 beds to 4 beds, purchasing new, state-of-the-art monitoring equipment, and providing technology-related upgrades.

Source: <https://news.gov.mb.ca/news/index.html?item=51227&posted=2021-05-10>

COMPARE THIS TO WHEN BC EXPANDED THE ADULT EPILEPSY MONITORING UNIT AT VANCOUVER GENERAL HOSPITAL FROM 2 BEDS TO 4 BEDS IN 2018. THE FUNDING NECESSARY FOR THIS EXPANSION WAS COMPLETED SOLELY BY DONORS TO THE VGH + UBC HOSPITAL FOUNDATION. NO FUNDING WAS PROVIDED BY THE BC PROVINCIAL GOVERNMENT.

“

I have not tried to refer to BC's adult epilepsy program as other BC Neurologists tell me it is best to just refer out of province.

-BC Neurologist - 2021 Neurologist Needs Assessment Survey

“

I refer to Alberta or to the US for timely care.

-BC Neurologist - 2021 Neurologist Needs Assessment Survey

“

I do not think they are trained in sEEG, LITT or other specific techniques nor have the resources.

-BC Neurologist - 2021 Neurologist Needs Assessment Survey



OUR ADVOCACY EFFORTS

Over the last three years, the BC Epilepsy Society has been tirelessly advocating for the over 50,000 people living with epilepsy in BC. We have made documentaries, appeared on the news, sent out press releases, put out petitions, done surveys, and so much more to sound the alarm on BC's adult epilepsy crisis to expose the truth and ultimately save lives. Please see some of our advocacy efforts at the links below:

DOCUMENTARIES:

- [FAILURE: The Black Mark on Canadian Health Care \(What If ... Documentary Series Episode 1\)](#)
- [PRISONER OF PURGATORY: The Jared Ricks Story \(What If ... Documentary Series Episode 2\)](#)
- [UNASHAMED AND UNAFRAID: The Allison Hegedus Story \(What If ... Documentary Series Episode 3\)](#)
- [JESUS LOVES ME: The Mackenzie MacWilliams Story \(What If ... Documentary Series Episode 4\)](#)

PODCASTS:

- [You Don't Want to Know the Truth – An Adult Epilepsy Crisis in BC](#)
- [Global Advocacy](#)
- [Interview with Cassidy Megan, Founder of Purple Day®](#)
- [Interview with Chuck Carmen, Executive Director of the Epilepsy Association and Founder of EpilepsyU and the EpilepsyStore](#)

PETITIONS:

- 2021 [Enact a BC Adult Epilepsy Business Plan for an Epilepsy Clinic at Royal Columbian Hospital](#)
- 2019 [End the Epilepsy Crisis in British Columbia](#)

SURVEYS AND REPORTS:

- 2021 Neurologists Needs Assessment Survey - Epilepsy (Report Coming Soon)
- 2021 Parent/Caregiver Epilepsy Needs Assessment Survey (Report Coming Soon)
- 2020 [BC Adult Epilepsy Consumer Report Card](#)
- 2020 [Disparities in Epilepsy Care and Funding in Western Canada Report](#)
- 2020 [The Ugly Truth about Epilepsy Funding for Adult Programs in BC](#)
- 2020 [The Epilepsy Crisis in BC Budget Consultation Report](#)

PRESS RELEASES:

- 2021 [Adult Epilepsy Crisis Continues to Worsen Under Decades of Inaction from BC Government](#)
- [2020 BC's Health Care Crisis Becomes Alberta's Burden](#)
- [2020 Call to Action for BC Media Outlets to Help Us Sound the Alarm, Expose the Truth, and Save a Life](#)
- [2020 The BC Epilepsy Society Launches Documentary Fourth Episode "JESUS LOVES ME: The Mackenzie MacWilliams Story"](#)
- [2020 The BC Epilepsy Society Launches Documentary Third Episode "UNASHAMED AND UNAFRAID: The Allison Hegedus Story"](#)
- [2020 The BC Epilepsy Society Launches Documentary Second Episode "PRISONER OF PURGATORY: The Jared Ricks Story"](#)
- [2020 The BC Epilepsy Society Launches the Documentary "FAILURE: The Black Mark on Canadian Health Care"](#)
- [2020 BC Government Receives Failing Grade in BC Adult Epilepsy Consumer Report Card](#)
- [2020 BC Epilepsy Society Calls on BC Government to Step Up](#)
- [2019 BC Epilepsy Society is proud of the government of Saskatchewan for funding the first Epilepsy Monitoring Unit in Saskatchewan](#)
- [2019 Epilepsy is the Blind Spot](#)

MEDIA APPEARANCES:

- [Kim Davidson Health Matters: Epilepsy on Global News](#)
- [Kim Davidson BC's Adult Epilepsy Crisis on Global News](#)
- [Kim Davidson BC's Adult Epilepsy Crisis on Shaw TV's Citizen's Forum](#)

HANSARD:

- [Transcript of Kim Davidson's presentation to the Select Standing Committee on Finance and Government Services for the 2021 Annual Budget Consultation](#)

MEETINGS WITH GOVERNMENT

Between 2018 and 2020, before COVID-19 was an issue in BC, the BC Epilepsy Society wrote countless letters to Premier Horgan, Health Minister Dix and the BC NDP only to be ignored.

After 26 long months, in June 2020, Kim Davidson was finally able to secure a meeting with Health Minister Dix. Please see the documentary **FAILURE: The Black Mark on Canadian Health Care** that details the journey of trying to secure a meeting with Health Minister Dix and Premier Horgan.

While the BC Epilepsy Society waited for responses to meeting requests, people with epilepsy in BC continued to die by SUDEP and suicide, go homeless, and seize without any medical interventions or therapeutics while suffering for years, waiting for the treatment that they so desperately needed.

Since the meeting with Health Minister Dix in June 2020, the BC Epilepsy Society has had limited contact with the BC Provincial Government:

- Number of Phone Calls: **14** *No returned messages on 18*
- Number of Emails: **11**
- Number of Videoconference Meetings: **2**
- Number of In-Person Meetings: **0**
- Actions taken by BC NDP to build a business plan to expand adult epilepsy beds and services to address the crisis: **NONE!**

UPDATE AUGUST 2021:

In April 2021, Kim received information that Health Minister Dix had rendered BC's adult epilepsy crisis as "Resolved". Kim called to inquire about this report and Ministry of Health (MoH) staff told her they would look into it and get back to her. Kim has emailed and called MoH 4 times since then and has not heard back since May 2021.

2022 BUDGET CONSULTATION PROCESS:

The BC Epilepsy Society's request to present at the 2022 Budget Consultation Process has been denied.



ROLL CALL CAMPAIGN

In October 2020, during the BC Provincial Election, the BC Epilepsy Society began a Roll Call Campaign where we requested meetings with all candidates running in the BC Provincial Election to inform them about BC's adult epilepsy crisis.

We wanted people living with and affected by epilepsy to be aware of which candidates were informed about the epic failures in the adult epilepsy program in BC by publishing the names, parties and ridings of candidates who took the time to meet with us and hear the issues on the BC Epilepsy Society website and YouTube channel. These candidates also agreed to further inform themselves of BC's adult epilepsy crisis and share out information to their constituents and other members of their party.

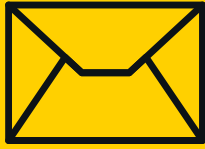
- **51% of candidates who met with us were from the BC Green Party**
- **27% of candidates who met with us were from the BC Liberal Party**
- **22% of candidates who met with us were from the BC Libertarian Party**

0% of candidates from the BC NDP met with BC Epilepsy Society

During our Roll Call campaign, the BC NDP sent us a letter informing us that our message had been heard “loud and clear”. BC NDP Leader, John Horgan decided that 0 BC NDP MLA candidates would meet with BC Epilepsy Society during the BC Provincial Election. Instead, the BC NDP assured us that they would reach out after the election to meet with us.

It has now been 9 months since the BC Provincial Election took place and, true to form, we still have not heard back from any elected officials at the BC NDP.

WHAT CAN YOU DO TO HELP?



WRITE TO YOUR MLA OR YOUR MP AND FOLLOW UP TO ENSURE ACTION IS TAKEN BY THEM



MEET WITH YOUR MLA OR YOUR MP TO DISCUSS AN ACTION PLAN TO ADDRESS THE CRISIS



SIGN OUR PETITION



TAKE OUR SURVEYS



EDUCATE YOUR FAMILY, FRIENDS AND LOVED ONES ABOUT EPILEPSY AND SEIZURES



LEARN SEIZURE FIRST AID AND TEACH IT TO OTHERS



BECOME A MEMBER OF BC EPILEPSY SOCIETY

WHAT CAN YOU DO TO HELP?



DONATE TO THE BC EPILEPSY SOCIETY



DONATE TO EPILEPSY RESEARCH THROUGH BC EPILEPSY SOCIETY OR CURE EPILEPSY



PARTICIPATE IN THIRD-PARTY FUNDRAISING IN SUPPORT OF BC EPILEPSY SOCIETY



POST ON SOCIAL MEDIA ABOUT EPILEPSY AND SEIZURES



TAKE PART IN BC EPILEPSY SOCIETY COMMUNITY EVENTS



SUPPORT FAMILY MEMBERS, FRIENDS, PEERS, CLASSMATES, STUDENTS, COWORKERS, EMPLOYEES AND LOVED ONES WITH EPILEPSY



TAKE PART IN INTERNATIONAL PURPLE DAY® FOR EPILEPSY AWARENESS ON MARCH 26TH

Appendix 1: Detailed Chart about Adult Epilepsy Beds Across the Province

Province	Population *	Epilepsy Age adjusted Prevalence	Adult Epilepsy Monitoring Beds
Alberta	4,350,901	NPHS 4.4 (3.7, 5.3) CHS 5.7 (4.9, 6.6)	10
British Columbia	5,046,780	NPHS 5.2 (4.4, 6.1) CHS 3.6 (3.0, 4.3)	4
Manitoba	1,364,400	NPHS 4.4 (3.7, 5.3) CHS 3.0 (2.5, 3.7)	4
Nova Scotia	966,709	NPHS 6.1 (5.2, 7.1) CHS 6.7 (5.8, 7.6)	4
Ontario	14,484,242	NPHS 5.0 (4.2, 5.9) CHS 5.2 (4.5, 6.1)	26
Quebec	8,447,609	NPHS 4.5 (3.7, 5.3) CHS 5.4 (4.6, 6.3)	8
Saskatchewan	1,171,027	NPHS 5.2 (4.4, 6.1) CHS 5.0 (4.2, 5.8)	4

Appendix 2: Epilepsy Medications that are not covered in BC

"No other province in Canada has created barriers for epilepsy patients to access epilepsy medication prescribed by physicians and neurologists. This is unique to BC. I don't understand why other provinces are safer for people with epilepsy to live in." -Kim Davidson

NOT COVERED UNDER BC PHARMACARE OR UNDER BC SPECIAL AUTHORITY:

- Brivaracetam (Brivlera)
- Oxcarbazepine (Trileptal)
- Pregabalin (Lyrica)

These medications are not covered at all, meaning that BC patients must choose between paying for groceries or paying out-of-pocket for these life-saving medications.

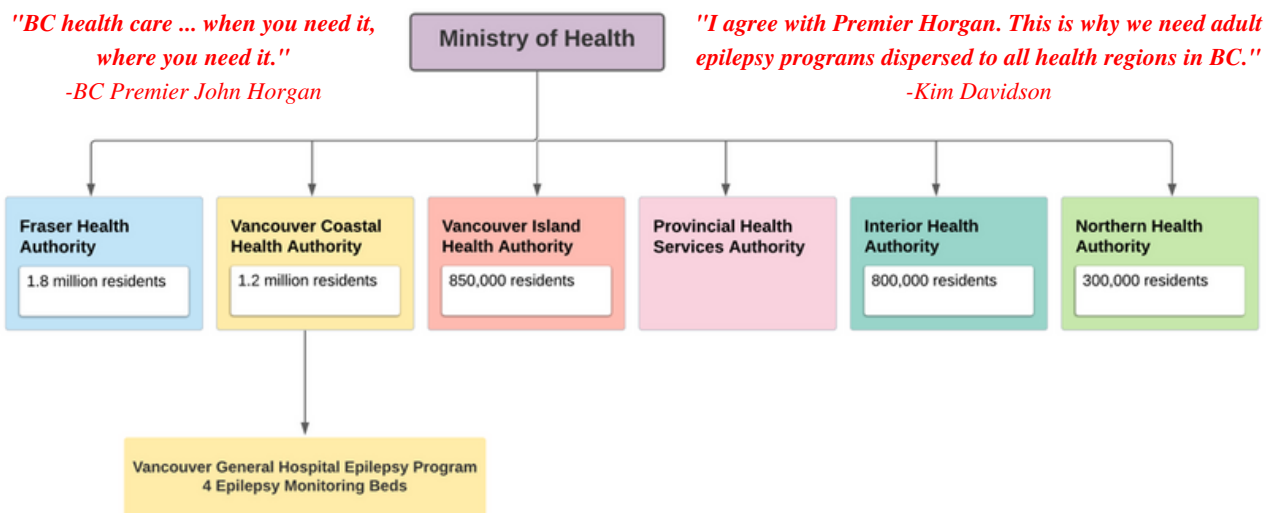
ONLY COVERED UNDER BC SPECIAL AUTHORITY:

- Lacosamide (Vimpat)
- Levetiracetam (Keppra)
- Rufinamide (Banzel)
- Stiripentol (Diacomit)

Special Authority approval must be in place before paying for a prescription and cannot be provided retroactively.

All of these epilepsy medications are covered under provincial drug coverage plans in other provinces across Canada.

Appendix 3: Current Structure of Adult Epilepsy in BC



ABOUT THE BC EPILEPSY SOCIETY

The BC Epilepsy Society is a provincially incorporated non-profit organization and a federally registered charitable organization dedicated to serving the over 50,000 people living with epilepsy in BC and their families, friends and loved ones.

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.

"HOPE IS THE BEGINNING OF ANY MEANINGFUL TRANSFORMATION. THROUGH HOPE, WE CAN BECOME POWERFUL AGENTS OF CHANGE. WE ARE COMMITTED TO BUILDING SYSTEMIC CHANGE TO ESTABLISH A THRIVING ADULT EPILEPSY PROGRAM IN BC FOR THIS GENERATION AND GENERATIONS TO COME."

-Kim Davidson, CEO & Executive Director, BC Epilepsy Society



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