

# THE EPILEPSY CRISIS IN BC

BUDGET CONSULTATION REPORT



**JUNE 2020**

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# EXECUTIVE SUMMARY

## 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.

According to the International League Against Epilepsy, an individual is considered to have epilepsy when they have at least two unprovoked seizures occurring more than 24 hours apart; or one unprovoked seizure and an increased probability (greater than 60%) of future unprovoked seizures.

## THE PREVALENCE

Epilepsy and seizures are very prevalent. It has been found that 1 in 12 people will experience a seizure during their lifetime and that 1 in 100 people will develop epilepsy during their lifetime.

Epilepsy is one of the most common neurological conditions, affecting approximately 1% of the population. There are 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 BC.

Epilepsy does not discriminate. Epilepsy can be developed by any person of any age, stage of life, gender, race, ethnicity, religion, sexual orientation, socioeconomic status or geographic location.

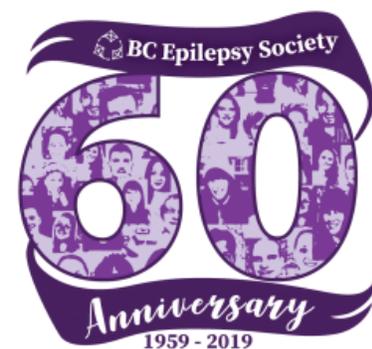
## THE STATISTICS

The World Health Organization found that the risk of premature death is up to three times higher in people living with epilepsy than in the general population.

Additionally, according to the Epilepsy Foundation of the United States of America, it was found that, in the United States of America, more people die from epilepsy than those who die from either breast cancer or traffic accidents annually.

Furthermore, the World Health Organization found that up to 70% of people living with epilepsy could live seizure-free if they were correctly diagnosed and properly treated.

Finally, proving that there is the need for increased awareness of epilepsy worldwide, the World Health Organization, in partnership with the International League Against Epilepsy and the International Bureau for Epilepsy, led a global campaign for epilepsy entitled "Out of the Shadows". This global campaign aims to provide better information about epilepsy and raise the awareness of epilepsy in order to strengthen public and private efforts to improve the care of people living with epilepsy and reduce the impact of epilepsy on the lives of those living with and affected by it.



# THE STORY OF EPILEPSY, THE ORPHANED DISEASE IN BC

Imagine that you are a person living with epilepsy in BC.

Now imagine that you have just been told that the BC government believes that you are only worth \$1.10 per year.

That is how much the BC Government awarded to the BC Epilepsy Society in 2020 for life-saving epilepsy programs and services.

The BC Epilepsy Society only received \$55,000 from the BC Government to provide programs and services for the over 50,000 people living with epilepsy in BC.

This is the story of epilepsy, the orphaned disease in BC.

"I THOUGHT THERE WERE  
*blind spots*  
IN THE BC HEALTH CARE SYSTEM  
BUT THEN I LEARNED THAT  
*epilepsy*  
IS THE BLIND SPOT."

-KIM DAVIDSON, CEO & EXECUTIVE DIRECTOR, BC EPILEPSY SOCIETY

# JARED RICKS STORY

The following story about Jared Ricks will be featured in our What If ... Documentary Series™ which will be released in Fall 2020.

Jared was a 23-year-old young man living with epilepsy and a musician who had just finished recording his second album when he passed away in December 2018 from Sudden Unexpected Death in Epilepsy (SUDEP) after suffering a seizure in his sleep.

SUDEP is the premature death of a person living with epilepsy who was otherwise healthy. They are often found deceased in bed with evidence of a recent seizure occurring while they were asleep. SUDEP is the leading cause of death in people living with epilepsy who have poorly controlled seizures, affecting approximately 1 to 2 of every 1,000 people living with epilepsy annually.

At the time of his passing, Jared was on a 3-year waitlist for epilepsy brain surgery in BC and three other provinces. He had finally gotten a date for his surgery and it was set to take place in March 2019, but he unfortunately passed away three months before his surgery could take place.

Jared's story is just one of many tragic stories that are happening in BC.

Amanda Ricks, Jared's mother, spoke on Shaw TV's *Citizen's Forum* about the epilepsy therapies that could have saved his life that are not available in BC and how BC is a have-not province. You can watch her interview at: <https://bit.ly/2BvhbpE>.



# BC IS A HAVE-NOT PROVINCE

## THERAPIES AVAILABLE IN BC:

35% of the over 50,000 people living with epilepsy in BC (approximately 17,500 people) have drug-resistant epilepsy, meaning that pharmaceuticals alone are not able to control their seizures.

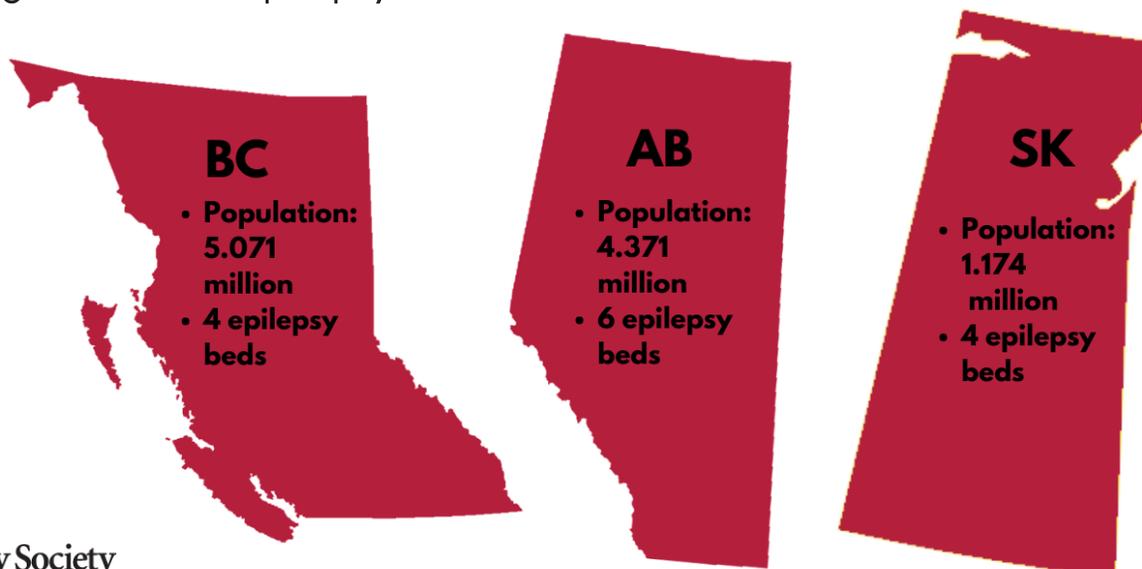
Of this, less than half of them (approximately 8,500 people) are considered to be candidates for epilepsy brain surgery.

The remaining half (approximately 9,000 people) should have access to alternative therapies to help control their seizures, such as the Ketogenic Diet and neuro brain stimulators such as Vagus Nerve Stimulation (VNS).

However, there is currently no Ketogenic Diet Program in the Adult Epilepsy System in BC and the number of VNS neuro brain stimulator procedures done in BC was capped at only 16 procedures in 2019, when in reality, hundreds would have benefited from the procedure and therefore should have been offered the procedure.

## EPILEPSY BEDS IN SEIZURE INVESTIGATION UNITS:

BC only has four epilepsy beds in the Seizure Investigation Unit at the Epilepsy Clinic at Vancouver General Hospital, while other provinces with similar and even less epilepsy populations have twice as many epilepsy beds and twice as many epileptologists in their Epilepsy Clinics.



# BC IS A HAVE-NOT PROVINCE

## NEUROPSYCHOLOGISTS AND NEUROPSYCHIATRISTS:

BC does not have a neuropsychologist or neuropsychiatrist funded or attached to an adult epilepsy clinic, which other provinces in Canada have.

## SYSTEM NAVIGATORS FOR EPILEPSY:

BC does not have system navigators within the health care or social services system to support people living with epilepsy, which other provinces in Canada have.

## EPILEPSY BRAIN SURGERIES:

Epilepsy brain surgeries in the adult epilepsy system in BC are frequently being sent out of province to Alberta and Ontario. There are extremely long waitlists for epilepsy brain surgeries occurring both in and out of province.

## COVERAGE OF EPILEPSY MEDICATION:

BC is the only province in Canada to not provide coverage of Brivlera, a medication used in the treatment of drug-resistant focal epilepsy, despite the fact that, according to a Drug Coverage Decision for B.C. PharmaCare report from the BC Ministry of Health, although the Common Drug Review (CDR) recommended that Brivlera be covered in BC, coverage was not awarded in BC. Pharmacy Compass (a tool from Pacific Blue Cross used to compare prices of medications at pharmacies across BC) outlines the average cost of Brivlera as \$4.88 per pill with a dispensing fee of \$10.43. According UCB Canada Inc., bottles of Brivlera typically contain 60 pills, resulting in an average total cost of \$303.23, which creates an immense financial burden on patients requiring the medication. This causes some people living with epilepsy who require seizure relief through Brivlera, as well as other therapies not currently covered or offered in BC to either spiral into debilitating depression, die by suicide, etc. OR need to move to other provinces, such as Alberta, where it is covered.

## CLINICAL GUIDELINES FOR 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.

# OUR RECOMMENDATIONS

## 1

# SYSTEM NAVIGATORS FOR EPILEPSY

Fund \$500,000 to the BC Epilepsy Society to enable the hiring of six system navigators within our provincial organization.

These system navigators will be based in communities across the province to serve and support people living with and affected by epilepsy in communities across the province and will work within both the health care and social services systems.

# OUR RECOMMENDATIONS

## 2

### EXPAND EXISTING PROGRAMS AND SERVICES

Fund \$500,000 to the BC Epilepsy Society for the expansion of our existing programs and services across the province.

Our programs and services include our Partners in Teaching program delivering free workshops and presentations on epilepsy awareness and seizure first aid and safety to schools for teachers and students. Another important offering is therapeutic support groups for people living with and affected by epilepsy across the province, among many other programs and services.

# OUR RECOMMENDATIONS

## 3

# ADULT KETOGENIC DIET PROGRAM

Create and fund Ketogenic Diet Programs within the Adult Epilepsy System similar to the Ketogenic Diet Program within the Pediatric Epilepsy System at BC Children's Hospital.

These programs should take place at both of BC's Adult Epilepsy Clinics located at Vancouver General Hospital and at the Jim Pattison Outpatient Care and Surgery Centre at Surrey Memorial Hospital.

# OUR RECOMMENDATIONS

## 4

### INCREASE THE CAP FOR VNS PROCEDURES

Increase the current cap of 16 for Vagus Nerve Stimulation (VNS) procedures to at least 40 procedures.

Please note that each VNS procedure costs approximately \$30,000 and is a relatively short procedure, taking less than an hour in length to complete. Additionally, health care professionals in BC already have the training and expertise to do this procedure.

# OUR RECOMMENDATIONS

## 5

# NEUROPSYCHOLOGISTS FOR PEOPLE WITH EPILEPSY

Allocate \$750,000 to create and fund three new epilepsy neuropsychologist positions within the Adult Epilepsy System.

These neuropsychologists should work at both of BC's Adult Epilepsy Clinics in BC located at Vancouver General Hospital and at the Jim Pattison Outpatient Care and Surgery Centre at Surrey Memorial Hospital

# OUR RECOMMENDATIONS

## 6

# MEDICATION COVERAGE OF BRIVLERA

Provide immediate PharmaCare coverage for Brivlera.

Canadians living with epilepsy should have equitable coverage, no matter where they live. BC is the only province that does not cover it.

# OUR RECOMMENDATIONS

## 7

### PUBLIC SERVICE ANNOUNCEMENT

Fund \$250,000 to the BC Epilepsy Society to enable the Society to work with Ministry of Health in the co-creation of public service announcements on epilepsy awareness and seizure first aid and safety, similar to public service announcements currently being televised for stroke to enable more people having an understanding of what a seizure looks like and learning how to help someone having a seizure

# CONCLUSION

Thank you for taking our recommendations for the 2021 Budget into consideration.

Although this is the first opportunity that the BC Epilepsy Society has received to present to the Select Standing Committee on Finance and Government Services, we consider this to be a legacy builder for epilepsy in the province.

We hope that you will help us rewrite the story of epilepsy, the orphaned disease in BC.





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