



# Common Drug Review *Patient Group Input Submissions*

## **eslicarbazepine acetate (Aptiom) for epilepsy, partial-onset seizures**

**Patient group input submissions were received from the following patient groups. Those with permission to post are included in this document.**

BC Epilepsy Society — permission granted to post.

Epilepsy Newfoundland and Labrador — permission granted to post.

Epilepsy Ontario — permission granted to post.

Epilepsy Association of Nova Scotia — permission not granted to post.

### **CADTH received patient group input for this review on or before September 8, 2014**

CADTH posts all patient input submissions to the Common Drug Review received on or after February 1, 2014 for which permission has been given by the submitter. This includes patient input received from individual patients and caregivers as part of that pilot project.

The views expressed in each submission are those of the submitting organization or individual; not necessarily the views of CADTH or of other organizations. While CADTH formats the patient input submissions for posting, it does not edit the content of the submissions.

CADTH does use reasonable care to prevent disclosure of personal information in posted material; however, it is ultimately the submitter's responsibility to ensure no personal information is included in the submission. The name of the submitting patient group and all conflict of interest information are included in the posted patient group submission; however, the name of the author, including the name of an individual patient or caregiver submitting the patient input, are not posted.

## BC Epilepsy Society

### 1. General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	Eslicarbazepine acetate
<b>Name of the patient group</b>	BC Epilepsy Society
<b>Name of the primary contact for this submission:</b>	[REDACTED]
Position or title with patient group	[REDACTED]
Email	[REDACTED]
Telephone number(s)	[REDACTED]
<b>Name of author (if different)</b>	
<b>Patient group's contact information:</b> Email	
Telephone	604-875-6704
Address	#2500-900 West 8th Avenue Vancouver, BC
Website	<a href="http://www.bcepilepsy.com/">http://www.bcepilepsy.com/</a>
<b>Permission is granted to post this submission</b>	Yes

#### 1.1 Submitting Organization

The BC Epilepsy Society is a non-profit charitable organization providing education, advocacy, and support for those affected by epilepsy. Offers educational events, multi-language information materials, support groups, school outreach, and newsletter. Also provides seizure awareness workshops, funds children to attend accessible camps, awards post-secondary scholarships, and funds research in BC. The BC Epilepsy Society has previously received funding from UCB and Lundbeck. It declares no conflict on interest with Sunovion and no conflict of interest in the preparation of its submission.

#### 1.2 Conflict of Interest Declarations

a) *We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements:*

The BC Epilepsy Society and the author do not have a conflict of interest with Sunovian Pharmaceuticals. The BC Epilepsy Society has previously have received funding from UCB and Lundbeck for post-secondary scholarships and printing costs.

b) *We have the following declaration(s) of conflict of interest in respect of those playing a significant role in compiling this submission:*

The BC Epilepsy Society and the author do not have a conflict of interest with Sunovian Pharmaceuticals.

## 2. Condition and Current Therapy Information

### 2.1 Information Gathering

This information was primarily obtained through one-to-one conversations with people affected by epilepsy and/or their caregivers.

### 2.2 Impact of Condition on Patients

Partial-onset seizures can affect almost every aspect of a person's day-to-day life. This includes, but is not limited to: independence (some individuals may require up to 24 hour supervision by caregivers), the ability to seek or maintain employment, the ability to participate in exercise or educational programs, and social isolation. Financial difficulties caused by unemployment or underemployment and medical costs can lead to a need for financial assistance from government programs. Not knowing when a seizure could occur, can result in excessive anxiety or other mood disorders. Accessing transportation can be a problem, whether it is the ability to drive, to be able to take transit without assistance, or even ride a bike. Teasing, bullying, and social exclusion can also result from having partial-onset seizures.

### 2.3 Patients' Experiences With Current Therapy

The medications currently used for partial-onset seizures may not work for everyone and cause side-effects that are severe enough that require discontinuation of the medication. These side-effects can include: cognitive problems, behavioural problems, excessive hair growth on body, sexual difficulties, gum overgrowth, and thinning of the bones.

Surgery not an option for most people with partial onset seizures due to the risks and limitations of the procedure.

Vagal Nerve Stimulation is not effective for a majority of people with partial-onset seizures as it has shown to have a very low success rate for controlling or even reducing seizure frequency.

### 2.4 Impact on Caregivers

Partial-onset seizures negatively affect the day-to-day life of the patient's family. The demands of caregiving can result in family dysfunction due to excessive anxiety and stress. The financial burden on the family can also be immense.

## 3. Information about the Drug Being Reviewed

### 3.1 Information Gathering

This information was primarily obtained through print materials from a variety of sources. This included published medical journal studies that did not have a conflict of interest with a pharmaceutical company.

### 3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

a) *Based on no experience using the drug:*

This medication could stop or reduce the amount of partial onset seizures that a person with epilepsy may have. [REDACTED]

[REDACTED] This would also greatly improve their overall day-to-day functioning and their ability to participate in employment and educational opportunities.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

A statistically significant decrease in median seizure frequency versus placebo was observed at the 800 mg dose and at the 1200 mg dose. The efficacy of Aptiom was also consistent regardless of the type of AED that was used in conjunction with Aptiom.

## Epilepsy Newfoundland and Labrador

### 1. General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	Aptiom Epilepsy, Partial onset Seizures (POS)
<b>Name of the patient group</b>	Epilepsy Newfoundland and Labrador
<b>Name of the primary contact for this submission:</b>	██████████
Position or title with patient group	██████████████████
Email	██████████████████████████████████
Telephone number(s)	██████████
<b>Name of author (if different)</b>	██████
<b>Patient group's contact information:</b> Email	<a href="mailto:Info@epilepsynl.com">Info@epilepsynl.com</a>
Telephone	709-722-0502
Address	351 Kenmount Road St. John's, NL A1B 3P9
Website	<a href="http://www.epilepsynl.com">www.epilepsynl.com</a>
<b>Permission is granted to post this submission</b>	Yes

#### 1.1 Submitting Organization

##### a) Geographic Area

Epilepsy Newfoundland & Labrador is the only epilepsy association in Newfoundland & Labrador dedicated to meeting the needs of the more than 10,000 men, women, and children in our Province who are living with epilepsy.

##### b) Our Mission

To share information, and educate the public on the subject of epilepsy; and to adopt any measures necessary to improve the health, strength, and well being of those living with epilepsy, wherever possible, in the province of Newfoundland and Labrador.

##### Programs & Services

Epilepsy Newfoundland and Labrador currently offers a wide range of services and programs concerning all aspects of living with epilepsy. Some of these services include:

**Information** – Extensive access to all sorts of medical and social information regarding such topics as treatment, medication, employment, health matters and social issues.

**News** – Newfoundland and Labrador's own quarterly newsletter *Epilepsy News* as well as the Canadian Epilepsy Alliance Newsletter *Epilepsy Matters* reporting on the very latest happenings in the world of epilepsy.

**Scholarships** – Each year we offer two scholarships for students in Newfoundland and Labrador. Each

scholarship is valued at \$1,000.00 and is open to members of Epilepsy Newfoundland and Labrador who have been diagnosed with epilepsy or seizure disorder.

**Resource Centre** – Providing in-depth information on epilepsy. Borrow books or video's from our Lending Library.

**Alerts** – When we discover something happening that could have a serious impact on people living with epilepsy such as a recall of medication or discovery of new side effects, we make it a priority to let our members know through our Info Alerts. Alerts are also posted on the News and Events section of our website.

**Advocacy** – There is strength in numbers. Need some help with a problem or some direction on an aspect of epilepsy? Let us know, and we will work with you, and in liaison with any other parties involved to try and reach an acceptable outcome.

**Public Presentations** – Have info, will travel. We do a wide variety of presentations and information sessions for groups, organizations, and classrooms of all ages and sizes.

**PAL Programs** – Sometimes it can be lonely living with epilepsy when no one around knows exactly what you're going through. That's where our PAL Programs come in. Members have access to our E-Pal, Pen Pal and Tele-Pal database of other members looking for someone to chat with. We have Pal's of all ages, so there's someone for everyone.

**Thrift Store** - Previously Loved Clothes and Things operates seven days a week to provide quality used goods at very affordable prices. And the best part is that 100% of the profits are used to help fund our programs & services. It's a win-win situation all around.

### 1.2 Conflict of Interest Declarations

Epilepsy Newfoundland and Labrador has NO conflict of interest whatsoever, and no current relationship with Sunovion.

## 2. Condition and Current Therapy Related Information

Nearly 70% of persons with Epilepsy can have their seizures controlled with current medications. The other 30% can not. It is on behalf of the 30% with intractable seizures that we are writing this submission.

### 2.1 Information Gathering

Information for this submission has been gathered by 30 years experience as Executive Director of Epilepsy Newfoundland and Labrador listening to and advocating for persons with Epilepsy. And as well, by personal experience, as a caregiver of a son who had over 1,400 complex partial seizures. (yes, the number 1,400 is correct)...before finding a combination of medications that has given him back his life and allowed him to be seizure-free.

### 2.2 Impact of Condition on Patients

██████████ male diagnosed 2009 with absence and complex partial seizures. Has been on a drug which seems to be controlling the seizures but is causing side effects to the point where his quality of life is significantly affected. Turbulent mood swings, and sexual dysfunction as a result of the medication are having a substantial impact upon his relationship with his wife, and he fears the deterioration of his marriage.

He has recently found a medication that works more effectively for him. He has taken a job in another Province, and his wife has gone with him.

██████████ female, diagnosed at 17 with multiple types of seizures. Takes two medications but continues to have seizures. Has been unable to keep steady employment due to sick time and suffers from frequent depression as a result. Recently threatened suicide and often feels she will never be able to do all the things other people do. Day to day is an ongoing struggle to keep positive and functional despite her frequent seizure activity.

██████████ female diagnosed in 2006 and was having multiple complex partial seizures daily. Previous to her seizures, was a paramedic and lead a full and active life. Multiple types of medications were tried, but none helped to any great degree. Unable to work, and with any available benefits drained, she was forced to move back in with her parents to live, but was not welcome to stay there long term. She subsequently had brain surgery to remove two spots on her brain, with the hope of regaining a greater quality of life and an eventual return to work. Unfortunately the surgery did not eliminate her seizures, and she still has frequent episodes of epileptic activity. Unable to find suitable housing in her home town, she remains with her elderly parents.

██████████ male and former heavy equipment operator. Diagnosed in 1999 when he started having complex partial seizures on the job. As a result, he had to abandon his career and training. Has been on a variety of medications since then and currently takes two. These medications control his seizures somewhat, but the side effects are severe, causing speech problems, concentration issues, exhaustion, fatigue, and moodiness. He has also begun taking an anti-depressant regimen for the emotional effects brought on by his epilepsy. His days are spent mostly sleeping.

██████████ with seizures since birth. Has been on every medication and combination with various levels of success. Is depressed and very rarely leaves the house because of his frequent seizures. Has never been employed and lives on Social Assistance in poverty. Recently sought help in another Province because he felt that life is not worth living in this condition and that there may be a chance of help somewhere else. There was nothing else to offer him and he was placed back on a previous combination of drugs with no change in his seizure frequency. This man frequently forgets to take his medication (3 x day) and the once a day therapy could be a God-send to him.....**unfortunately, we will never know, as ██████████ passed away two weeks before Christmas.**

██████████ mother of two. Seizures since her teenage years. Has a university degree but could not find work in her field because of her frequent seizures and accompanying memory loss. Has a very rocky marriage. Her husband quite his job to stay home and take care of her and the children when they were young because of her frequent seizures and his fear for their safety. They lived on Social Assistance and in poverty. She was very depressed feeling that she could not care for her own children, complicated by the fact that her husband treated her as a third child. Now that the children are older he has returned to work. She recently found a minimum wage ██████████ job, but was fired because her frequent seizures were 'disturbing to the customers'. **Her young ██████████ was recently admitted to hospital on the psychiatric ward where it is hoped ██████████ will get some help dealing with ██████████ "home life".**

### 2.3 Patients' Experience with Current Therapy

Current therapies work for nearly 70% of persons with Epilepsy. The case history's presented above show the hopelessness felt by the 30% who are still seeking the therapy that will work for them. Treatment must be tailored specifically for each individual in order to be most effective; even individuals with the same type of seizures may require different methods of treatment in order to allow them to have the same quality of life as Canadians living without Epilepsy.

## **2.4 Impact on Caregivers**

We refer to caregivers as ‘people living with epilepsy’ because their lives revolve around the seizures as much as the person having them. We have spouses, parents, and loved ones going to work/school every day full of anxiety and fear about what they will find when they get home. Will the loved one have a seizure and drop the baby? Will the wife have a seizure and burn herself? Will he get a bath alone and drown? She has been suicidal...will this be the day? Who will look after her when we’re gone?

Some caregivers just can’t bring themselves to leave the person with frequent seizures alone, which contributes to low self esteem in the person having the seizure and compassionate fatigue in the caregiver. A large number of caregivers are sleep deprived as they fear what will happen to their loved one if he has a seizure alone at night. So the caregiver either sits vigil all night, or tries to sleep but is too full of anxiety to do so.

In addition, the caregivers have to live with the side effects of various medications along with their loved ones. Mood swings, sexual dysfunction, suicidal thoughts, memory loss, lack of concentration, fatigue, exhaustion, depression, can all play havoc with family life.

## **3. Related Information about the Drug Being Reviewed**

### **3.1 Information Gathering**

Aptiom has not been used yet, by any of our members, so I have no knowledge of the effects of the drug.

### **3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had To Date with the New Drug?**

We do not expect this or any drug to be beneficial to everyone. Our hope, and belief is that it will change the life of someone. Will it stop seizures totally...that is a dream but probably not a reality. But just one less seizure may allow a mother to attend her child’s Christmas concert; may allow a father to attend a baseball game; may allow a young man to go bowling; may allow a young woman to go to the supermarket...alone. Just one less seizure can have a huge impact on a person’s life. They won’t know if it will work for them unless they try it, and they will never get to try it unless you approve it.

It is because we “do not expect this or any drug to be beneficial to everyone” that there are no substantial differences between this submission and the one I made two years ago regarding the new drug, at that time. Various medications have been successful for approximately 70% of Canadians living with Epilepsy. Our hope now is that a few more may find success with Aptiom. This drug, as I understand it, finds its effectiveness through a different mechanism, and therefore may provide hope for another segment of the population still waiting for their seizure-free day.

Persons with intractable epilepsy, are very often unemployed or in part-time positions because of the frequency of their seizures. Because of this, the majority do not have private insurance plans. If these new medications, are not placed on the formulary the majority of our members with intractable epilepsy, the ones who need them the most, will never be given the opportunity to find out if they will work for them.

## Epilepsy Ontario

### 1. General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	Eslicarbazepine acetate (Aptiom™) for adults with partial-onset seizures
<b>Name of the patient group</b>	Epilepsy Ontario
<b>Name of the primary contact for this submission:</b>	[REDACTED]
Position or title with patient group	[REDACTED]
Email	[REDACTED]
Telephone number(s)	[REDACTED]
<b>Name of author (if different)</b>	
<b>Patient group's contact information:</b> Email	[REDACTED]
Telephone	905-474-9696
Address	3100 Steeles Avenue East - Suite 803 Markham, ON L3R 8T3 Canada
Website	<a href="http://epilepsyontario.org">epilepsyontario.org</a>
<b>Permission is granted to post this submission</b>	Yes

#### 1.1 Submitting Organization

Established in 1956, **Epilepsy Ontario** is a registered health charity dedicated to promoting independence and optimal quality of life for those living with seizure disorders. We work to:

- educate, engage and empower people who live with epilepsy by raising public awareness and providing information and education through online and print communications as well as various outreach initiatives.
- advocate for supports and services to improve the quality of life for people living with epilepsy including:
  - equitable access to good quality, evidenced-based health care and community-based supports.
  - equitable access to social services such as ODSP
  - appropriate supports in the school and classroom so children receive meaningful educations. This may include ensuring educators receive appropriate training to help them better understand epilepsy and how to accommodate a child in their learning.
  - ensuring health and safety systems in public spaces that are seizure-friendly.
- provide provincial programs including Summerfest Summer Camp and the OBCL Epilepsy Scholarship.

At the present moment, the membership of Epilepsy Ontario includes 13 community-based epilepsy agencies which provide direct services to children, youth and adults who have epilepsy and their family members. These agencies serve southern Ontario and North Eastern Ontario. However, in areas where there are no agencies, Epilepsy Ontario provides support via phone and email through our Epilepsy Information Specialist. Epilepsy Ontario also provides training to schools, employers, etc. in outlying areas via technology.

#### 1.2 Conflict of Interest Declarations

a) We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements:

Epilepsy Ontario has received funding from the following:

- UCB Canada
- Eisai
- Sunovion
- Rx&D
- Bayliss Medical

## 2. Condition and Current Therapy Information

### 2.1 Information Gathering

Information was gathered by Epilepsy Ontario through an online survey promoted on social media (Epilepsy Ontario's Twitter and Facebook accounts), on our website, in a weekly *Voices of Epilepsy* e-news article and through a network of contacts with other epilepsy associations, clinicians and researchers.

Survey data was filtered to remove responses from people living outside Canada. Data pertaining to individuals with epilepsy 17 years or younger was also removed.

The remaining survey data from **72 Canadians** was analyzed for this submission which included responses from 54 adults with epilepsy; 11 caregivers who have an adult family member with epilepsy (18 years or older); 1 individual who no longer has epilepsy; and 6 staff with a patient support group for epilepsy or related disorders.

Ninety percent (90%) of these survey respondents were from Ontario.

### 2.2 Impact of Condition on Patients

Most people with epilepsy who responded to this survey were between 18 - 44 years of age (77.8% of the respondents with epilepsy). 16.7% were 45-64 years of age, and 5.6 % were 65-79 years of age.

Epilepsy can affect all facets of a person's life. One of the frequent impacts that epilepsy, and in particular uncontrolled seizures, had on people's activities and daily lives was a lack of independence.

Seizure control is very important. Without seizure control, the unpredictability can lead to a constant fear of not knowing when the next seizure will occur. One respondent summed it up beautifully:

*I hope someday people will no longer have to live with the uncertainty of tomorrow.*

Some of the other responses from adults living with epilepsy included:

*Epilepsy has made me realize how much I took independence for granted, and how is ok to admit you need help from others. The latter is a lot harder than it sounds. Epilepsy took simple things from me: being able to cook, drive, breast feed my children, carry my babies around the house. But it taught me how to adapt although I still need to nap every day I can be a great mother living with epilepsy.*

*At diagnosis, lost job, lost driver's licence, had to move to a city so I could get to work. Had major issues with drug side effects. After 2 years though, I am seizure free and working and driving.*

*Epilepsy has totally devastated my day to day life. I am never certain when I might have another seizure. I can not drive so I have to rely on family or friends for transportation. I have no independence. I suffer from depression.*

*I have been living with epilepsy for 37 years. It has always been challenging, but I have always managed to function fully as a member of society, <and> hold a job*

*I cannot go out alone, the chance of having a seizure is very high. I have 2-5 a day and at night they are worse in my sleep. I have next to no childhood memories, memory is my biggest issue. I put my infant son in harms way during a seizure, thankfully my spouse was home and heard the fall.*

*I don't like being looked upon as a 'damaged' person. When your colleagues or family see you have a seizure they all start to treat you like you are fragile and not the same person you were before the seizure. I am still as capable as I was before the seizure. I can still talk, walk and carry out the same task. I have not physically changed post seizure but I am now treated differently.*

*Because I don't drive it has restricted where I can live, where I can shop (getting purchases home), where I can work. Even though my sz <seizures> are well controlled by a med I live alone and still worry about what would happen if I had a tonic clonic sz <seizure> at home, alone.*

*I started having seizures when I was 19. My adult life has been significantly affected. Careers I was interested in are beyond my reach because I have seizures, primarily due to the significant limitations of not being able to drive, but also due to the inherent vulnerability of uncontrolled seizures, even "just a few" a month.*

*Diagnosed in 3rd year university with no previous issues prior to that, epilepsy came out of nowhere and turned my world upside down. I lost my licence and independence...My boyfriend couldn't handle it and broke up with me.*

*Epilepsy has rattled my confidence and self-esteem. I used to be singer, winning many medals at competitions across Ontario with dreams of becoming an opera star. I am now afraid to perform because of the fear of having a seizure on stage. Epilepsy changed the course of my life's path.*

*Due to epilepsy I have no life. I have no warning if or when I will have a seizure. I live on my own and have to be very conscious of my condition regardless of what I am doing. I can not drive so must walk or take a cab. There is no public transport in my area.*

### **2.3 Patients' Experiences With Current Therapy**

All respondents had been prescribed anti-seizure medication at some point, either now or in the past.

14.3 % of people became seizure-free on the first drug, 6.1% became seizure free using a 2<sup>nd</sup> medication, 8.2% became seizure-free on the 3<sup>rd</sup> drug.

Some people achieved seizure freedom with polytherapy, 10.2% became seizure free with a combination of 2 or more anti-seizure medications.

Non-drug therapies worked for some people, 8.2% became seizure-free with a different treatment (e.g. epilepsy surgery, diet therapy, vagal nerve stimulator, etc.).

26.5% had a period of seizure freedom for 6 months or longer but it did not last.

People described living with uncontrolled seizures as follows:

*Living with uncontrolled seizures felt like being trapped in my own body; the lack of control had a big impact on my emotional and psychological well-being and I have also had depression for several years as a teenager.*

*With uncontrolled seizures I have no idea when the next one will occur. I can not take part in any activities. When seizure free I am able to live a normal life and enjoy activities with my family and friends.*

*Living with uncontrolled causes fear. Not knowing when it will happen causes anxiety and stress. Seizure-free causes some relief. But there are moments when you doubt that this will last. It is almost too good to be true. You underestimate the disease and want to stop medications and get back to being a 'normal' person. But unfortunately stopping medications is not an option and eventually the medications stop working and you start the cycle all over again.*

*It's the unknown that is scary - when will it happen?*

### **2.4 Impact on Caregivers**

What challenges do caregivers face in caring for patients with this condition? What impact do treatments have on the caregivers' daily routine or lifestyle? Are there challenges in dealing with adverse effects related to the current therapy?

We heard from **11 Canadian Caregivers** whose family member(s) with epilepsy were 18 years of age or older. Seven of these respondents had an adult child(ren) with epilepsy and 4 had a spouse with epilepsy. The age range of the persons with epilepsy were 18-29 years (N=6 respondents), 30-44 years (N=4 respondents) and 45-64 years (N=1 respondent).

The challenges faced by caregivers were numerous and varied. However, many caregivers made reference to chronic stress and anxiety for the safety of their family member. Uncontrolled epilepsy had an impact on people's ability to work affecting family finances.

Some of the responses included:

*My son who is 21 years old now has epilepsy for the last eight years. Lots, had to change around our family life since then. I quite working for the first three years, we had to be with him all the time for the first few years, and then you realize life has to go on and you don't have a choice, you have to get use to the New Normal.*

*I'm currently having a very difficult time with the disease as my hubby had a horrific seizure almost 2 months ago. He fractured his back and his mind has not yet gone back to normal. I'm back at work and in fear almost every day. I've been looking after him since I was 21 it's been 10 year and I am so very tired.*

*<My> child was diagnosed at 3 years of age and is still not seizure free. The uncertainty of not knowing when the next seizure will be is a source of great stress on us all! Everything is a challenge (school, travel and friendships). Twenty one medications and combinations of medications have been tried and the only success that was enjoyed was with a med that caused vision loss, so that one was discontinued and seizures returned. As a parent, the stress of watching your child go to live in residence for their education is astronomical, constantly being aware of the possibility that a seizure could cause a fall or other injury.*

*Epilepsy has us living constantly at the edge of our seats, never knowing from one day to the next what might happen. Now that we are older I'm so afraid. I worry about him falling and I can't help him or what if he is out alone.*

*With my adult child having uncontrolled seizures for 30 plus years it has been difficult to ensure balance among work, family and especially to ensure that my other children got equal care. With seizures being part of our life from her young age we often had to deal with bullying, others not understanding or knowing how to deal with a seizure occurring. As a nurse and a mother I often faced difficult decisions - even the other medical professionals I work with often did not and still do not understand a lot of the difficulties that are faced by people with epilepsy and their caregivers/family.*

*I am constantly worried, terrified or on edge that my husband will die. I constantly check for his pulse and pray that he won't fall and have yet another concussion. They've greatly impacted our entire life, it's hard for him to keep jobs as he's a liability and once they happen at work he gets forced out. We are currently suing his employer for violating his human rights. The more stress he is under the worse his seizures get. We can no longer afford our home so we are going to have to rent out our condo and move back in with our parents. He never wanted to apply for disability because he was in denial that he was sick now we are in a desperate situation with a <young family to support>. We're both educated and work as professionals but this disease has knocked us flat on our ass. The drugs all seem to have horrific side effects currently he can hardly function and I am left to shoulder everything. I wouldn't wish my life on anyone yet I am thankful for all the wonderful experiences that I am blessed with. I had an expectation of what my life was going to be, we're extremely hard working and my husband is amazing but this disease has seriously ripped a lot of my hopes and dreams and I just pray I won't become a widow with two little mouths to feed. We choose to have children as we have incredible support and I will be able to do it on my own if I need to. Plus he is a fantastic father. However, now I worry about how my babies are going to know fear and worry when they see their father seize... Anyways, I can honestly say I hate epilepsy and hate how it has ravaged our lives, stolen my husband's confidence, his hope and dreams and I seriously just wish it would go away!*

### **3. Information about the Drug Being Reviewed**

#### **3.1 Information Gathering**

Information was gathered through an online survey described in Section 2.1.

#### **3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?**

*a) Based on no experience using the drug:*

Medication can be very successful in treating seizures however the side-effects can be difficult to deal with. One of the most significant problems is that 30% of people with epilepsy do not obtain seizure control with medication. Side-effects of medication, including effects on cognition, can be greater when multiple drugs and/or higher doses are used to try and improve seizure control which adds to the burden of drug-refractory epilepsy.

Some of these individuals may be candidates for other treatments including resective epilepsy surgery, medically-managed dietary therapy, nerve stimulators and deep brain stimulation.

The expectation is that the lives of some patients living with uncontrolled seizures will be improved by this new drug if it can help reduce their seizure frequency and with fewer side-effects as compared to other drug treatments.

There are many different types of epilepsy disorders, and even among the same epilepsy syndromes people's response to treatment varies. Some treatments may work for some but not for others. When a treatment is found that controls seizures there can be significant improvements in quality of life.

People described the change in their life with seizure freedom as follows:

*I don't believe I would have any independence at all if I had to live with uncontrolled seizures. I can drive now, I have a job, I live on my own, and I take care of my children. I think all of that would not be possible with uncontrolled seizures.*

*A breath of fresh air....Living with uncontrolled seizures is stressful, we manage cause we have to but now that I'm seizure free for the past 3 years I can see more how my daily habits I carried to avoid seizure really monopolizes your life. It's stressful to be in crowds to deal with people's reactions, or just your own intimidation of it.. Being without them has really raised my self confidence. I put myself in situations I would normally had avoided. I feel I have less of a limit on myself not cause I ever did but I think having seizures can run you down so you don't always realize you can do it until you've had that window to breath and see things clearly. I can say I had a good life and a happy one even with seizures. It never fully stopped me from being but I can say I'm much happier and feel more in control of my own life then before which is priceless*

*The difference is night and day. It's like a different life, in a way. It's a freedom I only hoped was possible. It's scary how much of my life was determined by my seizures and my epilepsy. I spent a lot of time in bed and on a lot of different medications.*

*b) Based on patients' experiences with the new drug as part of a clinical trial or through a manufacturer's compassionate supply:*

None of the survey respondents had experience with the new drug.

#### **4. Additional Information**

Not applicable.

## Epilepsy Nova Scotia

### 1. General Information

<b>Name of the drug CADTH is reviewing and indication(s) of interest</b>	Aptiom (eslicarbazepine acetate) Epilepsy, Adjunctive Treatment of Partial Onset Seizures (POS) in Adults
<b>Name of the patient group</b>	Epilepsy Nova Scotia
<b>Name of the primary contact for this submission:</b>	██████████
Position or title with patient group	██████████████████
Email	██████████████████
Telephone number(s)	██████████
<b>Name of author (if different)</b>	██████
<b>Patient group's contact information:</b>	Epilepsy Nova Scotia
Email	<a href="mailto:eans@ns.sympatico.ca">eans@ns.sympatico.ca</a>
Telephone	902-429-2633
Address	5880 Spring Garden Road, Suite 306 Halifax, NS B3H 1Y1
Website	<a href="http://epilepsyontario.org">epilepsyontario.org</a>
<b>Permission is granted to post this submission</b>	No

The patient group has not granted permission to post its patient input submission. When permission is not granted, CADTH will post on its website that a patient submission was received, but it was not posted at the request of the submitter.

The patient input that was provided in this submission, along with all other patient input received for this drug, is included in the summary of patient input that is contained in the posted *CDR Clinical Review Report*.