



Common Drug Review *Patient Group Input Submissions*

perampanel (Fycompa) for epilepsy, primary generalized tonic-clonic seizures

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

Epilepsy Association of Nova Scotia (permission granted to post).

Epilepsy Toronto (permission not granted to post).

CADTH received patient group input for this review on or before November 17, 2015

Disclaimer: 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.

Epilepsy Association of Nova Scotia

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Fycompa (perampanel) Epilepsy, Partial onset Seizures (POS)
Name of the patient group	Epilepsy Association of Nova Scotia
Name of the primary contact for this submission:	[REDACTED]
Position or title with patient group	[REDACTED]
Email	[REDACTED]
Telephone number(s)	[REDACTED]
Name of author (if different)	
Patient group's contact information: Email	[REDACTED]
Telephone	[REDACTED]
Address	306-5880 Spring Garden Road, Hfx, NS B3H 1Y1
Website	www.epilepsyns.org
Permission is granted to post this submission	Yes

1.1 Submitting Organization

Please provide an overview of the organization that is making the submission, including the purpose or aim(s) of the organization and an outline of the type of membership.

Epilepsy Nova Scotia is the only epilepsy association in the Maritimes dedicated to meeting the needs of the men, women and children in Nova Scotia, New Brunswick and PEI living with epilepsy.

Our Mission

To provide education and resources to support persons living with epilepsy, their communities and support ongoing research.

Epilepsy Nova Scotia offers the following Programs and Services:

Purple Day – We participate each year in Purple Day, a Global Epilepsy Awareness Campaign that was started here in Nova Scotia in 2008 by one of our members, a then 9-year-old girl called Cassidy. In June, 2012, The Purple Day Act received Royal Assent and passed into law. This Act officially establishes March 26 as Purple Day, a day for epilepsy awareness in Canada.

Information – We have brochures available on many topics, and can also provide links to websites of interest.

News – Epilepsy news is available on our website (www.epilepsyns.org) and also on the Canadian Epilepsy Alliance website (www.epilepsymatters.com). We also provide links to other relevant sites. Epilepsy Nova Scotia publishes its newsletter, Epicure, three times a year.

Scholarships/Bursaries Each year we offer two scholarships and two bursaries to young people with epilepsy to help them with their post-secondary education. The scholarships are available to students in Nova Scotia,

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New Brunswick and PEI. However, the bursaries are available only to students in Nova Scotia. Each scholarship is worth \$500.

Research Grant – We offer a small research grant every second year when funds are available.

Advocacy and Counseling – When requested, we act as advocates for people with epilepsy. We will advocate on their behalf with government departments such as the Department of Community Services, with landlords, teachers or employers. We also offer informal counseling by phone, in the office or by email. Our Medical or Legal Advisory Boards can be contacted for advice, and referrals to professionals can be facilitated if necessary.

Education – We offer a Classroom Education Program (“Thinking About Epilepsy”) primarily to Grade 5 students. We can also make presentations to older and younger students if requested. The Coordinator of the Epilepsy Program, Capital Health, is also available to give presentations to community groups at our request.

Project H.O.P.E. (health of persons with epilepsy) – Project H.O.P.E. is a four module program targeting a diverse group of persons with epilepsy; art therapy, creative writing therapy, life skills program and physical activity. This program is designed to attract all persons with epilepsy and offers something different for everyone. A social and therapeutic program designed to alleviate, prevent and serve those in recovery from mental health conditions such as depression, commonly a secondary condition for those who live with epilepsy. (Still applying for funding)

Kids Kinetics and Krafts Kamp – A program designed for kids in two phases; age 4-7 is a physical activity and craft components. This phase offers kids in this particular age group a safe environment to enjoy physical and creative play with other children with epilepsy while parents have the opportunity to network over coffee nearby. Phase Two offers children 8-11 day camps that involve discovering different types of berries, plant life, bugs, birds, etc. as well as games of soccer baseball and fitness challenges ending in a barbecue. Parents are invited to participate.

1.2 Conflict of Interest Declarations

Epilepsy Nova Scotia has NO conflict of interest whatsoever, and no current relationship with EISAI. However, we do intend to pursue a relationship with EISAI in an attempt to obtain support for services to our members.

Section 2 — Condition and Current Therapy Information

2.1 Information Gathering

Information for this submission has been gathered by the Executive Director of Epilepsy Nova Scotia, drawing on the experiences of members of our Association, our Past President, and our Medical Advisory Board.

2.2 Impact of Condition on Patients

Epilepsy affects different people in different ways. Those whose seizures are not controlled are often placed in dangerous situations should a seizure occur while riding a bus, shopping for groceries or crossing a street, to name a few of the activities that most of us take for granted. Persons with uncontrolled seizures are not permitted by law to operate a motor vehicle, leading to a loss of independence that may be insurmountable, particularly for those living in rural areas. Often the medications used to control seizures cause unpleasant side effects that may be completely intolerable to the patient. One side effect of medication often mentioned by patients is impairment of the ability to concentrate or focus. Memory is also often a consequence of seizures or of the underlying cause of epilepsy.

Societal attitudes have a significant impact on persons with epilepsy. Many members of the general public are ill-informed of the true facts about epilepsy, such that people with the condition often face stigma and discrimination. People experiencing seizures, or in the aftermath of seizures, have been “Tazered” or arrested for being “intoxicated” in public. Parents of children with epilepsy are often afraid to let them participate in the normal activities of childhood, for fear that they will have a seizure and be injured. Children with epilepsy may not be invited to sleep-overs because their friends’ parents are afraid that they won’t know what to do if the child had a seizure while away from home.

2.3 Patients' Experiences With Current Therapy

Current therapies work for nearly 70% of persons with Epilepsy. The remaining 30% try to remain hopeful that someday a medication will be found that will help them. New drugs like Fycompa bring hope to many who are close to giving up. While we know that the likelihood of a new drug providing relief to someone who has already failed to achieve success with many, well established therapies, we also know that the potential for success is NEVER 0.

2.4 Impact on Caregivers

When someone has epilepsy, the whole family is affected. Everyone's life revolves around the seizures. There is anxiety around when and where the next seizure will occur, and what impact it will have. A husband is afraid his wife might have a seizure and drop the baby; parents are nervous if their child is invited to a birthday party; a teenager is anxious as he watches his father leave for work. Is today the day that something terrible will happen?

Some caregivers are afraid to leave the person with frequent seizures alone, contributing to a loss of independence and the lack of self-esteem we see so often with this patient population. Compassion fatigue in the care giver is always of concern. Many caregivers are sleep deprived as they either try to stay awake all night in case a seizure happens, or go to bed and find they are too anxious to sleep.

As well, caregivers often have to live with the sometimes highly unpleasant side effects of various medications that their loved ones are taking. Mood swings, sexual dysfunction, suicidal thoughts, memory loss, problems with concentration, fatigue, exhaustion, depression – all can prove devastating to the person involved, and also to those around them.

Section 3 — Information about the Drug Being Reviewed

3.1 Information Gathering

Fycompa has not been approved for general use in this province, but a cursory review of the literature supports the claim that is useful in the treatment of partial onset seizures. The percentage of patients who suffer from uncontrolled seizures is primarily composed of those with this seizure type.

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:*

No drug works for everyone, and each new drug brought to market offers hope to the 30% of epilepsy sufferers whose seizures are not so far controlled. Even a reduction in the absolute number of seizures that these individuals experience can potentially improve overall quality of life. Seizure freedom may become a reality and the person with epilepsy need no longer sit on the sidelines as life passes by. Of course, if this drug is not made available to them, this dream can never come to fruition.

People with intractable epilepsy are very often unemployed or under-employed because of the frequency of their seizures. They usually live on very restricted incomes, and because they are not working, or are only working part-time, the majority does not have private insurance plans. If 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 this new drug will work for them.

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

These are questions we cannot answer at this time. We can say this new drug offers hope and that in itself offers improvement in health and well-being.

Epilepsy Toronto

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Fycompa
Name of the patient group	Epilepsy Toronto
Name of the primary contact for this submission:	[REDACTED]
Position or title with patient group	[REDACTED]
Email	[REDACTED]
Telephone number(s)	[REDACTED]
Name of author (if different)	
Patient group's contact information: Email	[REDACTED]
Telephone	[REDACTED]
Address	[REDACTED]
Website	www.epilepsytoronto.org
Permission is granted to post this submission	No

The patient group has not granted permission to post its patient input submission. As announced in [CDR Update — Issue 99](#), 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*.