



BC Epilepsy
Society

E-NEWS RELEASE

Improving lives.
Inspiring courage.

June 9, 2016

June 2016

A message from the Executive Director

Hello BC Epilepsy family,

The team at BCES would like to send you well-wishes for a fun and healthy summer.

We will be sending out invitations to attend our "Thriving with Epilepsy" free talk with Olympian Marion Clignet in the upcoming week. Please stay tuned to our [Facebook](#) and [Twitter](#) for details. This is a very rare opportunity to spend time with Marion and learn about her story of resilience and thriving while living with epilepsy. We look forward to seeing you there.

If you would like to suggest content for our upcoming newsletters please email us at info@bcepilepsy.com

Regards,
Lori Eisenhaur
Executive Director

Important **NEW** developments regarding the Clobazam (Frisium) shortage:

Suzanne Nurse, Chair, Canadian Epilepsy Alliance Drug Shortages Committee

Clobazam is in short supply, but is still available at some pharmacies.

If inventories have become low or depleted at your pharmacy, ask your pharmacist to recheck the status of clobazam and Frisium with their suppliers.

The next few days will continue to be challenging for people, due to the depletion of the clobazam inventory at many pharmacies. However, some replenishment of generic clobazam (Apo-clobazam, Apotex Inc.) is expected at the end of this week or early next week. The new stock will be spread across the country with limited amounts to individual pharmacies.

A second replenishment of generic clobazam (Apo-clobazam, Apotex Inc.) is expected to arrive at pharmacies by late June or early July.

It is expected that there will also be periodic shipments of the brand name product, Frisium, over the coming weeks as well.

Health Canada will be working with pharmaceutical manufacturers and other stakeholders to monitor status over the summer.

I take clobazam, what should I do?

- Continue to take clobazam as indicated by your healthcare provider
 - o do not skip doses
 - o do not take less than the prescribed amount
 - o do not make any changes in your treatment without medical advice
- Develop a management plan with your pharmacist and your healthcare provider in case clobazam is not available. You can share the following clinical management suggestions with your healthcare team:
 - If your pharmacy is unable to refill your prescription – ask your pharmacist
 - o have they exhausted all avenues to try and find clobazam for you?
 - o have they searched for generic clobazam and brand name clobazam (Frisium)?
 - If it is necessary to make changes to your treatment plan due to the shortage
 - o ask for a copy of the new treatment instructions in writing
 - o go over the information with your pharmacist
 - o ask your pharmacist to explain the information again if the instructions are not clear

[management suggestions for the clobazam shortage](#)
- Contact your local Canadian Epilepsy Alliance agency if you need help by calling 1-866-EPILEPSY ([1-866-374-5377](tel:1-866-374-5377))

Mental Health and Epilepsy: Stigmas, Lack of Education, and Misunderstandings

Megan Gelmon, Sana Counseling

What is it like to tell someone that you have, or know someone with epilepsy? I don't know about you, but this wasn't something I thought much about until recently.

This question began to grow in my mind after I attended a fundraiser for epilepsy with lots of other people with the condition. The thing I found really odd was that we were all there to support the cause, but a large number of people felt uncomfortable talking about their situations.

At first I thought, "sure, maybe they are just private people and I respect that," but I found myself wondering if that was really the issue. Then, about halfway through the evening I

realized that I had heard the word "stigma" a number of times and this was much to my surprise.

This made me think back into my past and the experiences of telling others that I have epilepsy and I realized that most people *have* responded in such a way that was awkward followed by some timid questioning by those who had the courage to ask.

As I was collecting my intel that night, so many people at the gala talked about others misunderstanding the neurological condition, resulting in confusing seizures and epilepsy with mental illness. It's true and unfortunate that mental illness is still stigmatized in our society (thank goodness we are talking about it more openly in 2016, though we still have a long way to go). We concluded that too many people often confuse epilepsy as a mental illness and this is where the lines begin to blur.

So, this brings me to the age-old question: what should we say when people ask us about epilepsy? How can we help clarify what it is, *really*? Well, obviously say (or don't say) whatever you want. Here are some tips to help you if you're not sure where to begin:

1. Thank the person for asking (for some, that might be difficult).
2. Ask the person if they know what it is, and make sure they're aware of the fact that most people don't really know too much, so you'd be happy to explain epilepsy (if you're comfortable doing so). Education is key!

Note: if you don't know much about the details (or you want to remove the medical jargon) feel free to explain that seizures are ultimately like an electrical storm in your brain, causing us, or a person you know with epilepsy, to convulse or perhaps just zone out into a different state of mental consciousness for a moment or two depending on their kind of epilepsy.

3. If you have epilepsy and you are explaining this to someone, I notice that people might begin to get uncomfortable because they think "oh no, what do I do if that happens while I'm here?" If your seizures are controlled, then you can reassure them that that situation is highly unlikely. If your seizures are not controlled and relatively common in your daily life, simply explain safety protocol and let them know what you would want them to do, or not do.
<http://www.cdc.gov/epilepsy/basics/first-aid.htm>
4. Ask the person if they have any other questions and remember, for those of us who have it- just because we have experienced it, it doesn't mean we know everything, so never be afraid to be honest if you're not sure. Uncertainty could open the door to a really cool learning experience for you and the person who is curious.

If we open up, perhaps in the future, when someone notices our medical alerts, sees a person having a seizure, or meets someone who has epilepsy, they will feel comfortable and empowered because they learned from us! It is true that a little bit goes a long way.

One-third of adults with drug-resistant epilepsy 'can achieve seizure freedom

New research suggests that a significant proportion of adults with epilepsy who fail to respond to two initial antiepileptic drugs (AEDs) can achieve seizure freedom with further drug therapy. The aims of the study, led by Columbia University in New York and *published in the medical journal Epilepsia*, were to examine the seizure response of adults with drug-resistant epilepsy to a third AED, and to identify factors/characteristics that might help doctors to predict a positive outcome.

The data showed that 53% of the cohort never achieved a seizure-free period of a year or

more, and that 16% had a complex, fluctuating seizure course. A further 16%, however, attained seizure freedom within 12 months (early seizure freedom), and 15% had delayed seizure freedom, meaning that seizure control was reached at some point after one year. Factors associated with a more favourable seizure outcome included the length of the follow-up period and the type of epilepsy involved. Specifically, it was shown that people with occipital lobe epilepsy, generalised epilepsy or both focal and generalised epilepsy were more likely to experience a better seizure outcome than those with temporal lobe epilepsy. To read more please click on the link above.

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which provides education, advocacy, and support.*