

Inspiring courage.

May 19, 2016

May 2016

A message from the Executive Director

Hello BCES Community,

Spring is moving fast and we have been very busy working on some novel projects. One project we are excited to be working on, is a new and more modern website. Our new website will help us streamline and deliver great content to British Columbians living with epilepsy and their families. While we are in the development phase it would be great to hear from you. Please take our short 5 question survey and let us know about your journey with epilepsy and what you want included in our content. We are looking forward to hearing from you. SURVEY

Regards, Lori Eisenhaur **Executive Director**

Clobazam (Frisium) Shortage Update - May 12, 2016

Suzanne Nurse, Chair, Canadian Epilepsy Alliance Drug Shortages Committee

Over the past few days we have had reports that pharmacies are having difficulty getting clobazam from their suppliers. This suggests that the clobazam shortage is worsening. The best source of information about the supply of your medication is your pharmacist.

The situation will vary from one drug store to another, depending on the amount their supplier has available, whether the pharmacy keeps stock of this drug on-hand or orders it as needed, and other factors.

There are 3 manufacturers of clobazam:

Apotex Inc. (Apo-Clobazam)

- Teva Canada Ltd. (Teva-Clobazam or Novo-Clobazam)
- Lundbeck (Frisium)

See below for estimated resupply dates.

Pharmascience discontinued PMS-Clobazam in April 2015.

What should I do if I take clobazam (Frisium)?

If you or one of your family members take clobazam, we advise that you contact your drug store and ask about the supply of this medication. If your pharmacy is unable to refill your prescription, another pharmacy may be able to.

- Contact your healthcare provider for medical advice if you are unable to get your prescription refilled.
- Clobazam is a benzodiazepine and should not be stopped abruptly.
- If clobazam is unavailable, your healthcare provider may prescribe an alternate drug to prevent benzodiazepine withdrawal and to control your seizures.
- Work closely with your healthcare provider and your pharmacist throughout the shortage.

If you need information or assistance regarding a drug shortage, please contact your local epilepsy agency by calling 1-866-EPILEPSY (1-866-374-5377).

Estimated Resupply Dates:

Apotex Inc. posted a shortage of Apo-Clobazam in early December on <u>drugshortages.ca</u>. No explanation has been provided. The estimated resupply date for Apo-Clobazam has changed multiple times, initially it was April 15, 2016 then it was extended to September 1, 2016. The newest resupply estimate is November 30, 2016.

Teva-Clobazam (also called Novo-Clobazam) from Teva Canada Ltd. is also on back-order and new shipments are not expected to be available until September 30, 2016.

Frisium is on allocation, so pharmacies can only order limited quantities.

There have been no reports, so far, on <u>drugshortages.ca</u> from Teva Canada Ltd. or Lundbeck.

How to Practice Positive Thinking: Positive Thinking and its Affects on People With Epilepsy

Megan Gelmon, Sana Counseling

We've all heard those sayings, about glasses being half-full, how we shouldn't sweat the small stuff, that we should always look on the bright side of life, the list could go on all day. It seems that while, at times, these sayings might be irritating, the idea behind them is something to seriously mull over.

Over the past few years, studies have shown that attitude and gratitude have considerable effects on our emotional, mental and physical health. These studies are important for all of us to take into account,

especially those of us who are already prone to harder times with mental (and possible physical) health due to a brain condition or side effects as a result of our medications.

Research done on positive thinking by the mayo clinic has shown that positive thinking:

- -Increases life span
- -Lowers rates of depression
- -Lowers levels of distress
- -Allows for greater resistance to the common cold
- -Allows for better psychological and physical well-being
- -Reduces risk of death because of cardiovascular disease
- -Allows for better coping skills during hardships or times of stress

Pretty cool, right? For those of us with epilepsy, or families who are trying to cope with someone living with seizures, positive thinking might seem frustrating and somewhat illogical at times, but practice makes perfect. Here are some tips on how to practice positive thinking:

Surround yourself with positive people

Positive people allow for positive energy and that energy transfers.

Express gratitude for the people in your life

Sometimes, we get to choose who we let into our lives (like friends). Expressing gratitude toward those who surround us can never go too far and makes others feel happier.

Breathe

Every so often we can feel overwhelmed, perhaps triggered. Take a breath. Look around. Feel your feet on the floor and see the reality around you. Everything is temporary. Nothing is too hard to overcome.

Find the silver lining

This is hard in devastating situations but if you can't see it then wait, it will appear on it's own. Perhaps there is a lesson to be learned, or a blessing in disguise waiting to be revealed.

Imagine a great future

Close your eyes and let your imagination dream up the life you see for yourself. Now go get it.

New algorithm offers potential for predicting epileptic seizures

A new algorithm developed by computer scientists and mathematicians has shown potential to help predict and warn people with epilepsy against imminent seizures.

Computer scientists and mathematicians at the CEU Cardenal Herrera University, in Valencia, created the prediction model as part of the American Epilepsy Society's Seizure Prediction Challenge in 2014, and they came third place out of 502 submissions. Further analysis of the model, <u>published in the medical journal Brain</u>, has underlined the potential benefits it offers. The team created the algorithm by assessing a large data set of intracranial EEG recordings taken from people and dogs with epilepsy. Please follow the link above to read more.



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