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Centre for Epilepsy and Seizure Education in British Columbia

Dedicated to the promotion of independence and quality of life for people with epilepsy and their families across Canada.

Nous travaillons à la promouvoir l'autonomie et la qualité de vie des personnes touché par l'épilépsie.

Charitable Registration Number 88753 6522 RR0001

The Honourable Rona Ambrose, P.C., M.P. Minister of Health Brooke Claxton Building Ottawa, Ontario K1A 0K9

February 13, 2014

RE: Clobazam shortage

Dear Minister:

Clobazam, an anti-seizure medication, is in short supply in Canada.... again. Canadians who rely on this medication for the management of their epilepsy disorder are at risk.

Pround The Wor

Canadian Epilepsy Alliance agencies have received calls and emails from people who have been unable to get their prescriptions of clobazam re-filled. An unanticipated shortage of any anti-seizure drug is extremely serious. Clobazam is from the benzodiazepine family. Epilepsy specialists have indicated this poses an added risk of withdrawal and life-threatening status epilepticus.

No Advance Warning: As of February 12th, there were **no shortages of clobazam posted on**<u>drugshortages.ca</u> even though we have learned that multiple brands are currently in shortage.
Please see the attachment for information about the current status of clobazam.

Obviously, manufacturers were aware of these shortages long before our agencies and individuals in the community had learned about them but they did not provide advance notification. Now that several products are in shortage, notification has either been after the fact (1 manufacturer) or non-existent (3 manufacturers). Plus, an additional manufacturer was recently in a shortage situation which has been resolved, but this information was never posted on drugshortages.ca.

The MSSC Protocol for the Notification and Communication of Drug Shortages outlined clear expectations for manufacturers to "post all shortages on www.drugshortages.ca as soon as they are anticipated or known to occur" and for "all parties to adopt a proactive and precautionary approach to information sharing".

The lack of notification and communication on the clobazam shortages has created a dangerous situation for people who rely on this medication. Patients and their families are left in the dark only finding out about the shortage when their pharmacist cannot re-fill their prescription, leaving people with little time and no tools to seek solutions.

Clearly, voluntary reporting of impending shortages is not happening and we call on the government, once again, to legislate mandatory reporting. We need a better system to anticipate, identify and manage drug shortages. We look to you and your government for leadership on this important issue and the implementation of an effective strategy to protect Canadians.

The immediate concern of our organization is the clobazam supply and the impact these shortages could have have on people living with epilepsy, including a risk of death. There must be an effective strategy to urgently address current supply disruptions and prevent greater supply disruptions from developing over the coming weeks. In addition, patients and health care providers need to be informed and equipped with management information. This issue requires prompt and decisive action.

Yours sincerely,

Hail Dempsey

Gail Dempsey President

Canadian Epilepsy Alliance/l'Alliance canadienne de l'épilepise

Cc: Libby Davies, NDP Health Critic
The Hon. Hedy Fry, Liberal Health Critic

Dr. Nizam Ahmed, President, Canadian League Against Epilepsy