



HepCBC Hepatitis C Education & Prevention Society  
Room #20, 1139 Yates Street - Victoria, British Columbia, V8V 3N2  
[www.hepcbc.ca](http://www.hepcbc.ca)

September 28, 2015

Dear Honourable Ministers,

**Re: Delays in treatment accessibility**

We are writing to you today about our concerns in the length of time it is taking for patients in Canada to get access to a new treatment for those suffering from a devastating condition resulting from liver disease: overt Hepatic Encephalopathy (HE).

HepCBC is a patient-led organization which provides education and support for people with hepatitis C, and submits reviews at the provincial and federal levels for better treatment options for those affected by this disease. We are calling on your governments to make a timely decision on whether to provide Canadian patients access to a widely-recognized treatment for HE, rifaximin. Postponing this decision severely impacts critically ill patients and their families who are unable to afford this vital treatment, which can keep them functioning while they await either a liver transplant or other treatment (such as that for hepatitis C).

Hepatic Encephalopathy is a terrifying complication of cirrhosis. Patients struck by HE will experience progressively worse periods of confusion, anxiety, disorientation, paranoia, nightmares, delusion, fits of rage, and finally coma. It is a progressive condition that severely impacts patients' quality of life, ability to work and contribute to society, and ensure the well-being of their families. With proper and timely treatment, HE is potentially reversible.

Due to the episodic nature of their condition, HE patients are often marginalized by the healthcare system, as they are difficult patients who require repeat hospitalizations to deal with their HE episodes. According to research, HE accounts for 50 per cent of all cirrhosis-related hospitalizations - a significant draw on our health care resources.

Until now, standard of care for HE has been simply lactulose, a drug with powerful laxative properties which helps remove poisons from the body. While this treatment has been the preferred solution for physicians for a number of years, it has its drawbacks. Efficacy is a significant issue, as is lactulose's side-effects and palatability. Therefore, as an organization representing the interests of many patients with (or at risk for) HE, we were delighted to hear about Health Canada's approval of this additional or alternative HE treatment, which as an antibiotic targets HE very differently from lactulose. While rifaximin is still more expensive per

day than lactulose, because of its superior ability to slow the complications of HE and, very significantly, to prevent expensive hospitalizations, it was deemed cost-effective.

Over a year ago, we outlined our position to the Common Drug Review during their patient group input process. In April, we were delighted when informed that rifaximin was recommended for listing under provincial drug plans in all Canadian provinces by the Canadian Drug Expert Committee. HepCBC also completed a Patient Group Submission about rifaximin to BC Pharmacare on January 18 this year, to which we are still keenly awaiting a response.

Given that this treatment represents a potential improved standard of treatment, we understand that it was given a priority review through the Common Drug Review. As this passed this 5 months ago, we are now puzzled about this delay.

It is our understanding that the pan-Canadian Pharmaceutical Alliance makes decisions about drug listings, but we are coming to you as representatives elected by the people, many of whom we also represent. Given that the new treatment is federally approved and required by so many patients, we believe that it is crucial that this issue is resolved as soon as possible to save lives and enable these people to get back to contributing to society and to allow families to get their dear ones back at home.

Patients and their families are calling on your governments to ensure that rifaximin is listed swiftly for all Canadians, so that HE patients will not continue to suffer needlessly from this devastating condition.

Sincerely,

[SIGNATURE REDACTED]

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