

1) Conf. of eligibility : YES

2) Patient Group Name & name of representative completing this questionnaire:

HepCBC Hepatitis C Education and Prevention Society.

Representative completing questionnaire: [REDACTED] Volunteer.

3) Organization's Address

#20-1139 Yates St. Victoria, BC

4) Postal code

V8V-3N2

5) Conflict of Interest Y/N - YES

6) Describe conflict of interest

HepCBC Hepatitis C Education & Prevention Society has received funding for hepatitis C-oriented projects such as publishing educational materials, organizing educational forums, attending and presenting at educational conferences, advertising in newspapers (events and hepatitis C patient awareness), and holding awareness activities from the following pharmaceutical companies over the last three years: Merck Pharmaceuticals, Hoffman-LaRoche, Vertex Pharmaceuticals, Gilead Sciences, Janssen Pharmaceuticals, Bristol Myers Squibb, Boehringer-Ingelheim, and AbbVie. In addition, the author of this report has attended several educational conferences and meetings for which registration and travel expenses were funded by the pharmaceutical companies listed above.

7) Read PharmaCare info sheet? YES

8) Describe how the condition or disease for which this drug is used affects the day-to-day life of patients in your group.

As a patient group for those affected by chronic hepatitis C (CHC), we at HepCBC have had extensive experience with people suffering from low platelets as a result of cirrhosis. The best way of dealing with CHC cirrhosis is to cure the hepatitis C with one of the new direct-acting antiviral (DAA) treatments which have 90 – 100% success. Once the virus is gone, the liver damage will stop and - if caught in time - the platelet counts will slowly rise back to a safe level. However, many people with this advanced level of the disease are ineligible for treatment (do not meet treatment criteria) due to low platelets which put them in clear danger of bleeding to death. This is particularly the case if the patient also suffers from bleeding varices.

An additional problem is that patients who are on interferon treatment often develop low platelets as a side-effect of the drug, and if this situation cannot be reversed, they are pulled off treatment. These patients are then condemned to worsening CHC, including likely development of cirrhosis over time as well of increased risk of liver cancer and liver failure.

Often the caregiver must take over raising children and being the sole breadwinner of the family, at the same time that the patient's need for attention is also increasing. This puts incredible strain on the caregiver and frequently leads to family breakdown. This situation can be a drain on the larger society, which in the end, often ends up helping support the patient and the family as well.

That patients are either ineligible for treatment, or must stop treatment, due to low platelets, can be devastating to family, friends, and caregivers as well as the patient. This is particularly frustrating if they know a drug (REVOLADE) is out which could solve this problem, and is in once-a-day oral form, yet it is not covered by Pharmacare, so not accessible to most British Columbians who need it.

Patient Voice (67 year old female with stage 4 cirrhosis of the liver due to hepatitis C, genotype 1a, treated but not successfully: "I have thrombocytopenia due to the cirrhosis. I have to be very careful of everything I do so I don't injure myself. Even having surgery would not be a good thing for me right now as things are."

9) If the patients in your group have tried the drug under review, please tell us about the effects they experienced.

We do not know of anyone who has had experience with REVOLADE.

10) What drugs or other treatments have the patients in your group used, or are currently using, for the condition or disease for which this drug is used?

Please list all of the drugs and tell us about the experience of the patients in your group with each treatment.

HepCBC: CHC patients with low platelets are currently given infusions, injections, and less frequently, transfusions. These are painful, inconvenient, and very expensive. Mostly, they don't seem to get any treatment at all.

Patient Voice: "I did take an injectable drug for low hemoglobin when I was on Interferon and Ribivirin in 2011... And I forgot the name...If this drug (REVOLADE) would raise platelets it should be used even before treatment."

11) Please tell us why your organization believes this drug should be included in the BC PharmaCare program.

- Patients who are ineligible for treatment, or unable to complete treatment, could have these barriers lifted, so more people would be able to access treatment, complete treatment, and clear the virus. These people would have a great chance for a longer, more productive life.
- Patients are generally willing to do almost ANYTHING to get rid of hepatitis C virus, so if this drug enabled them to initiate and complete treatment, those patients whom we at HepCBC deal with every day would be delighted to put up with fairly severe side-effects if that meant they would be cured.
- Unfortunately we know that the potential side-effects of REVOLADE can be quite devastating, and that patients need be carefully prepared and monitored during treatment with this drug. Those with very advanced cirrhosis will likely not even be able to take this drug at risk of hepatic decomposition, ironically due to REVOLADE's high hepato-toxicity. That it also should not be used in elderly patients or those with reduced renal or cardiac problems is not good news for the large aging population of HCV+ Baby Boomers.
- This drug would likely result in fewer deaths, higher rates of treatment starts and completions, fewer hospital visits, and less time off work. This health improvement could result in greater financial stability, greater mental stability, and fewer family breakdowns.

To summarize, HepCBC fully supports listing REVOLADE in Canada for use with any patient with chronic hepatitis C and low platelets, depending on extremely close monitoring of those patients whose condition may potentially contraindicate the drug. Hopefully as new treatments for HCV develop which do not result in low platelets, and as patients are treated before their disease has developed into advanced cirrhosis, drugs such as REVOLADE will no longer be required.

Patient Voice: "This drug should be used in all of Canada not just BC. It should also be covered because of the cost. Most drugs are inaccessible to those who are retired and on a fixed income. We just can't get what we need."