

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	REVOLADE for use for Low Platelets in Chronic Hepatitis C
Name of the patient group	HepCBC Hepatitis C Education and Prevention Society
Name of the primary contact for this submission:	REDACTED
Position or title with patient group	HCV+ Volunteer, Board Member
Email	REDACTED
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Name of author (if different)	
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Permission is granted to post this submission	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No

CADTH will post this patient input submission on its website if permission is granted. See [CDR Update — Issue 99](#) for details.

1.1 Submitting Organization

HepCBC is a non-profit society run by and for people infected and affected by hepatitis C. Our mission is to provide education, prevention and support to those living with HCV. Our office with our only paid employee (an office mgr.) is in Victoria, BC. We also have activities and groups in Nanaimo, BC and Surrey, BC. Our representatives attend provincial and federal-level conferences and we give information and support world-wide through our website. We publish a monthly bulletin, the hepcbull. We focus on providing “clean and sober” peer support groups, anti-stigma activities, prevention education to young people, and encourage testing among at-risk groups -- including those who are no longer at risk but may have contracted hepatitis C decades ago. We work alongside local HIV/AIDS organizations in support of co-infected people.

1.2 Conflict of Interest Declarations

a) *We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements:*

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.

b) We have the following declaration(s) of conflict of interest in respect of those playing a significant role in compiling this submission:

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.

Section 2 — Condition and Current Therapy Information

2.1 Information Gathering

This report was developed using data provided by seven (7) individuals:

(1) a patient survey advertised through our website and our email list. No one replied to it, unfortunately.

(2) Input from two (2) HCV+ volunteers who have actively manned HCV+ phone and email support systems for several years, and have extensive knowledge of patient concerns and experiences.

(3) Aggregate input from five (5) HCV+ participants at our August monthly support groups has also been added.

2.2 Impact of Condition on Patients

As a patient group for those affected by hepatitis C, 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 so the liver damage will stop. However, many people with this advanced level of the disease are ineligible to get treatment 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, and if this situation cannot be reversed, they are pulled off treatment. These patients are condemned to worsening CHC, including likely development of cirrhosis over time as well of increased risk of liver cancer and liver failure.

2.3 Patients' Experiences With Current Therapy

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

2.4 Impact on Caregivers

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 is out which could solve this problem, and is in once a day oral form, yet it is not accessible by Canadian CHC patients. 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.

Section 3 — Information about the Drug Being Reviewed

3.1 Information Gathering

Same as in Section 2.1.

3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

a) *Based on no experience using the drug:*

- Patients who are ineligible for treatment, or unable to complete treatment, could have these barriers lifted, so more people would be able to 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 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 this drug 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.

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b) *Based on patients' experiences with the new drug as part of a clinical trial or through a manufacturer's compassionate supply:*

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

Section 4 — Additional Information

(HepCBC): We fully support 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.