

Section 1 – General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Boceprevir – for Hepatitis C
Name of patient group	HepCBC Hepatitis C Education and Prevention Society
Name of primary contact for this submission	REDACTED
Position or title with patient group	Interim Coordinator (volunteer executive dir.)
Email	REDACTED
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For information regarding patient input to CDR and CEDAC, please see the "[Patient Input](#)" section

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 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 hepccbull. 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) :Received \$1200 grant in last 12 months from Merck towards publishing educational pamphlets. In the past they have occasionally provided us with minor funding for refreshments and publicity for public forums.

b) :None

Section 2 – Condition and Current Therapy Related Information

2.1 Information Gathering

Information was gathered during one very intense peer support group meeting of 10 members. One person read the questions, another took notes, and a third wrote up the results. Here are participants' codes, ages, genders, and treatment status:

- 1 – 63, F – Failed treatment 18 months ago.
- 2 – 62, F – Presently participating in a trial.
- 3 – 58, M – Failed non-pegylated treatment many years ago.
- 4 – 50, F – Successfully cured 5 years ago.
- 5 – 50, F – Failed treatment 4 times.
- 6 – 63, M – Successfully cured in trial (3 months past with good results)
- 7 – 40, F – Treatment naïve.
- 8 – 60, M – Presently participating in a trial.
- 9 – 56, M – Cured after transplant followed by 72 weeks treatment.
- 10 -55, M – Recently failed his 6-month post-treatment test

2.2 Impact of Condition on Patients

I In order of frequency, members reported the condition-related symptoms below. No symptom was universally-reported; some people exhibit more symptoms than others.

(1) Most frequently reported: Fatigue, digestive problems, muscle and joint pain, brain fog, irritability, depression, cognitive failure (concentration/attention span, speed of thought, fluency of speech, learning and memory), insomnia, slower motor reflexes, and general fear of social interaction (coupled with a fear of being stigmatized).

(2) Also reported: Water-retention, acid reflux, gall bladder attack, lack of appetite, inability to digest many common foods, sensitivity to/avoidance of noise or light, sexual dysfunction, rapid eye deterioration, electrolyte imbalance, iron overload/imbalance, detecting chemical odours (in sweat, urine, stool, breath), anxiety, rage, hypothyroidism, Crohn's disease, seizure disorder, metabolic syndromes (fatty liver, pre-diabetes), toxic encephalopathy, ascites, and esophageal bleeds.

II Day-to-day life is affected by all of the above, but in order of frequency and importance: Fatigue, muscle/joint pain, and slower motor reflexes limit both general activity and job productivity/effectiveness.

Cognitive failure, fear of stigma and fear of social interaction limits both job effectiveness and general social interaction.

Pain during movement can lead to either overuse of painkillers (which can damage liver) or to avoidance of movement (which can lead to weight gain and other degenerative problems)

Digestive and iron-overload problems limit how one shops for and cooks food, one's diet vs. the family's diet, and when (how often) one cooks or eats, affecting this important part of family life and social interaction.

Financial difficulties ensue due to limited job possibilities coupled with the cost of controlling the disease: special food, supplements, and treatment drugs.

Feeling one must keep one's HCV status secret, or to lie about it in order to preserve one's job or relationships is debilitating to one's spirit.

III Activities patients report they now avoid or are unable to do at all:

Fulltime work

Work that involves a lot of physical activity

Work that involves speed (either physical or mental)

Work that involves a lot of social interaction

Work that involves possibility of cuts or other blood-to-blood contact

Contact sports

Public speaking

Eating in restaurants

Meeting new people

Job changes

Medical and dental work in which one should disclose one's HCV status

Dating – due to fear of stigma and social interaction along with sexual dysfunction

Travelling – due to fears of digestive upset, inability to communicate about one's condition, to cross borders with one's medications, or to follow the diet one is used to, or possible non-availability of food or medicine one might need.

Active physical play with kids, grandkids

Computer work and reading – due to eye and/or concentration problems

2.3 Patients' Experience with Current Therapy

I. Most of us in our group either failed treatment or are treatment naïve. We tend to deal with our condition through diet, exercise and supplements/alternative treatment which, though they DO make us feel better and probably slow the progression of the disease, are not going to cure us, and our disease continues its deadly progress.

(1) Our diet changes may include limiting amounts of such things as... complex fats, refined grains, dairy products, simple sugars, animal proteins, iron, soy products, and chemical dyes and preservatives.

They may also include using large amounts of such things as... organic fruits and vegetables, whole grains, fibre, protein (often involving legumes, eggs, and fish rather than red meat), simple oils (such as olive or grape-seed), complex sugars (such as molasses or maple syrup), liver-friendly teas and spices (such as turmeric), and sours (such as citrus juices, vinegar, plain yogurt, sauerkraut, kefir, or kimchi).

(2) Exercise members of our group do: Walking, running, bicycling, dancing, golfing, gardening, yoga, tai-chi, and using elliptical trainer. Not being able to afford a car has actually helped some of us develop good walking and bicycling habits.

(3) Supplements and alternative treatment used in our group included: Cod-liver and other fish Oils, Milk-thistle, Co-enzyme Q10, SAME, Chinese herbs, and acupuncture.

II The current Standard of Care we have generally used for our condition, of course is dual therapy, pegylated interferon plus ribavirin. Those of us who have gone through SOC reported the following side-effects:

(1) Those who had been asymptomatic developed symptoms.

(2) Symptoms we had experienced before treatment tended to get worse - particularly fatigue, muscle and joint pain, depression, concentration, irritability and digestive upsets.

(3) These additional problems developed for some of us during treatment, in order of frequency...

Flu symptoms – fever, chills, dizziness

Weakness

Muscle and joint stiffness and slowness

Fatigue

Muscle and joint pain

Anemia (low red cell count)

Shortness of breath

Irritability

Depression

Anorexia and extreme weight loss

Nausea and vomiting

Hair thinning, even loss

Rash

Itchiness

Failure of anti-depressant, need to change type or dose coupled with greater intensity of depression

Inability to concentrate

Susceptibility to infection (low white cell count)

Susceptibility to bleeding (low platelet count)

Lack of interest in outside world

Headache

Detecting strange tastes and smells (in both food and self)

Suicidal thoughts

Constipation/lack of peristalsis

Malabsorption

(4) The side-effects that were severe enough to cause us to go off treatment (or strongly consider it) were...

Severe depression or rage

Suicidal thoughts

Severe anemia

Lack of peristalsis and malabsorption

(5) The treatment side-effects tended to go away after 6 months or so. However, even several years following treatment, several of us still experience these symptoms, whether the treatment was successful or not...

Joint stiffness, swelling, pain (actually worse in those who went through treatment successfully)

Fatigue

Depression

Insomnia

Fear of social interaction

Inability to concentrate

Double vision and general vision deterioration

We all still have to deal with the fear of stigma, whether we are considered 'cured' or not.

III Hardships in Accessing Current Therapy (in British Columbia)

(1) Current treatment criteria disallow treatment for many symptomatic HCV+ people with low ALT counts.

(2) Pharmacare does not pay for EPO and other supplements which may help more people stay on treatment. Strangely, it does pay for transfusion and even transplant, which are far more expensive and could be avoided.

(3) Lack of healthcare worker knowledge about HCV transmission, progression, and treatment. They assume if you have it you are an IVDU.

(4) A multi-disciplinary treatment team is a real plus, but is not available in our city (Victoria) unless one is a 'street person'. The ACCESS/Cool Aid Health Centre has an excellent team and has a great track record for success in supporting street people throughout treatment. Surely our treatment time would be much easier if we could take advantage of Cool Aid's experience and make their great system available to 'the rest of us'!

(5) Due to stigma, those on treatment who need to take time off work may be unable to do so as it would involve disclosing their condition to their employer.

(6) Due to lack of knowledge about the problems HCV+ people can develop over time, British Columbia's rules for granting Temporary Disability and Long-term Disability to HCV+ individuals are very arbitrary and inappropriate. People who are in the middle of treatment and

suddenly find themselves unable to work are faced with a bureaucratic nightmare, and this stress can lead to treatment failure.

2.4 Impact on Caregivers

Most of us are single, so generally we depend for medical care on the medical staff who see us infrequently for a very short time. We depend on friends, hired help (but very rarely – we cannot afford this), and members of our support group for care we cannot provide ourselves. However, some of us live with family-member caregivers. We brainstormed the difficulties our friends and family caregivers face...

- (1) Caregivers may be unfamiliar with or unsuited to this role.
- (2) Caregivers for HCV+ patients are not given the sort of acknowledgement and support available to caregivers of cancer (even HIV+) patients – no respite system is available. Caregivers may feel alienated from the patient, want to escape the situation, and feel guilty for these feelings. So this sort of caregiver support and respite is critical for treatment success.
- (3) HCV+ caregivers are not generally given appropriate health education.
- (4) There is no widely-accepted or accessible end-of-life protocol for HCV.
- (4) Most family-member caregivers suffer from lack of money when their HCV+ spouse or parent can no longer work, and may have to quit or go to part-time work themselves in order to care for their HCV+ spouse or parent.
- (5) Toxic encephalopathy requires 24-hour supervision.
- (6) Lack of knowledge, lack of support, lack of sleep, lack of money – all these cause stress!
- (7) Lack of certainty about their own future and how long they will have to give care – will the patient ever get back to normal? Will they die?
- (8) HCV+ patients often have emotional outbursts, depression, or cognitive problems which their caregivers may not be able to handle. “What happened to the smart, happy person I married?”. Or “Where is the smart, loving, responsible parent who used to take care of ME?”
- (9) Caregivers themselves suffer from social isolation, stigma and inability to discuss their situation with others, and may end up depressed themselves.

Section 3 – Related Information about the Drug Being Reviewed

3.1 Information Gathering

Same format as in Part 2.1

3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had To Date with the New Drug?

a) This was a tough one to answer. Mainly, we want it to eradicate the virus, and to leave us without additional health complications/problems. We hope it will reverse some or all of our symptoms, and reverse at least some of current organ damage. We hope it will take a shorter time to go through. We know it will probably have greater side-effects, so in order to keep on the treatment, we will need AFFORDABLE ways to alleviate these side-effects. We hope our caregivers will be given the support and training they need. We want the criteria to qualify for this treatment, and to have the cost covered by Pharmacare, to be based on a more patient-centred model. We hope the pharmaceutical company that developed this treatment will make this it so affordable that it will be available to anyone who would benefit from it, worldwide.

b) N/A (none of us have had Boceprivir)

Section 4 – Additional Information

No additional information. Questions were clear.