

# hepc . bull

Canada's Hepatitis C News Bulletin  
www.hepcbc.ca

## HEP C IN THE NEWS

### MADRID: TREATMENT FOR ALL

by Jessica Rucker

Thousands marched in Madrid and other Spanish cities this month to protest their government's treatment program for Hep C. The several advocacy groups involved said there is a dire need for improved medical treatments and regulated pricing for drugs because at least 12 people die each day from Hep C in Spain. The group *La Plataforma de Afectados por la Hepatitis C* organized the gathering, which was also attended by many NGOs, trade unions, and political parties.



People supporting those affected by hepatitis C are backlit as they hold a banner during a demonstration in Madrid, Spain, Saturday, Jan. 10, 2015. (Photo by Daniel Ochoa de Olza/AP)

Their chants and signs said "Tratamiento para todos" and "Nosotros muriendo, Vosotros robando" –translated as "Treatment for all" and "We dying, You robbing."

It is estimated that 700,000 people in Spain have Hep C, but only one-third have been diagnosed.

Newly developed Hep C medications are said to have a very high cure rate, but only a fraction of those diagnosed as infected will receive any this year as a result of the public health's exclusionary dispensing plan, which some Spanish doctors call "unprofessional and anti-scientific."

Spanish media reported that the recently allowed new Hep C medication Sovaldi was bringing in profits far beyond its production cost, due to the patent policy of pharmaceuti-

(Continued on page 3)

## URGENT: TWO CALLS FOR PATIENT INPUT

Once again, CADTH (Canadian Agency for Drugs and Technologies in Health) and BC Pharmacare are requesting input from our Patient Group, and we need your help **quickly!** Please do not hesitate. We need your input **now!**

### (1) DETAILS about CADTH submission for daclatasvir and asunaprevir:

CADTH has issued a call for us to submit input into the BMS drug combo daclatasvir (Daklinza™) and asunaprevir (Sunvepra™) PLUS we are to evaluate each of them separately as well. Competition among the top few drug companies making hepatitis C treatments is heating up and should eventually result in lowered pricing. So please help us to get these drugs through the "Canadian drug pipeline" as quickly as possible! We will accept input from patients and caregivers until Tuesday, February 24th, 2015 at midnight, via email. **Details:**

<http://hepcbc.ca/2015/01/request-patient-input-daclatasvir-asunaprevir-combo/>  
**Background info:** <http://hepcbc.ca/bms-daclatasvir-and-asunaprevir-background-info/>

(Cont'd on page 2)

## HepCBC MEMBERSHIP NOW FREE!

Membership in HepCBC is now FREE. To encourage more people to become part of the governance of our society, HepCBC's Board recently decided to waive the \$10 membership fee starting January 1, 2015.\* Membership includes:

- A **SUBSCRIPTION** to once-a-month email with link to our most current hepatitis C news bulletin, the *hepc.bull*.

- A **MEMBER PACKAGE** with pamphlets, yellow/red ribbon pins, information about volunteering opportunities and how to participate in our Annual General Meeting plus other ways to make your voice heard. (If you prefer not to receive anything by mail, there is an option for this choice. Everything mailed from HepCBC has no reference to hepatitis C on the envelope.)

- A **VOTE** at the Annual General Meeting (next meeting September 15, 2015) which will be held online, to encourage participation from people outside the Victoria area.

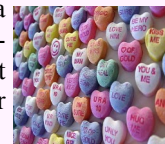
- A **CHANCE TO SERVE** on the Board of Directors. It gives you a voice in the direction the organization is heading, its goals, and its methods. (You must become a Member and indicate your desire to run for the Board at least 30 days prior to the AGM).

Join with others who are trying to make the best hepatitis C treatment and care both affordable and accessible to all who need it, whether in Canada or anywhere else in the world!

### JOIN HERE:

<http://hepcbc.ca/hepcbc-membership-form/>

\*Those who have already paid the fee have a choice of getting a refund or converting any fees paid for 2015 into a charitable tax-free donation. Send us an email at [info@hepcbc.ca](mailto:info@hepcbc.ca) stating your choice, please.



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## ORDER OR DONATION FORM

NOTE: Ordering (or donating) via Credit Card or PayPal is available online at [www.hepcbc.ca/hepcbc-order-form/](http://www.hepcbc.ca/hepcbc-order-form/) OR...

Fill out form below with a cheque made out to "HepCBC" - Send to our NEW address:

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\*Only Name and Email address required for emailed Bulletin.

Membership also requires a postal address.

We will mail you a Member Package with pamphlets, yellow and red ribbon pins, information about volunteering opportunities, and how to participate in our Annual General Meeting, plus other ways to make your voice heard.

(Note: Nothing mailed to you from HepCBC will have ANY reference to hepatitis on the envelope.)

Registered Canadian charitable organization since 2001. No. 86800-4979-RR00001.

\*\*Download the *hepc.bull* free (since 2001) at [www.hepcbc.ca/hepc-bull-monthly-newsletter/](http://www.hepcbc.ca/hepc-bull-monthly-newsletter/)

**SUBMISSIONS:** The deadline for any contributions to the *hepc.bull*® is the 15<sup>th</sup> of each month. Please contact the editors at [jking2005@shaw.ca](mailto:jking2005@shaw.ca), (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

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## LETTERS TO THE EDITOR

The *hepc.bull* welcomes and encourages letters to the editor. When writing to us, please let us know if you *do not* want your letter and/or name to appear in the bulletin.

# THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, Allison Crowe, Billie Wood and Adrian, Community Living Victoria, Victoria Positive Living Centre, Provincial Employees Community Services Fund, the Victoria Foundation, Dr. C. D. Mazoff, Judith Fry, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Cheryl, Anamaria, S.J., and L.P.

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Bristol-Myers Squibb, Roche Canada, Vertex, Gilead, Janssen, Boehringer-Ingelheim, AbbVie, Rx&D, VanCity, Country Grocer, and Thrifty Foods.

(CALLS FOR INPUT—Cont'd from page 1)

### (2) DETAILS about BC PHARMACARE submission for eltrombopag:

BC Pharmacare has also issued us a call to submit input into the existing Glaxo Smith Kline (GSK) drug eltrombopag (Revolade™) for thrombocytopenia (low platelets causing poor blood clotting and increased risk of bleeding). They are considering reimbursing patients with chronic hepatitis C who use this drug to increase platelet counts, thus allowing those with low platelets to begin treatment, and for those on interferon-based treatments to stay on it. We will accept input from patients and caregivers until Sunday, February 15th, 2015 at midnight via email.

#### Details:

<http://hepcbc.ca/2015/02/request-patient-input-eltrombopag-revolade-low-platelets/>

#### Background info:

<http://hepcbc.ca/revolade-eltrombopag-background-info/>

FYI here is a list of all HepCBC's previous submissions to CADTH and Pharmacare, plus links to their content:

<http://hepcbc.ca/patient-group-submissions-bc-pharmacare-cadth/>



## HEALTHCARE RATIONING IN CANADA

**Treatment delayed is treatment denied.** In the hepatitis C (HCV) world, this was not such an issue when the treatment was based on medicines such as interferon with low efficacy (success) rates and many side effects. With the new direct-acting antiviral (DAA) treatments, infected people are starting to realize the potential of actually curing their HCV successfully, without those terrible side effects. Imagine their shock and anger when the door slams against their dream of being free of this disease, when they discover:

- There is no way they can afford the cost of this treatment.
- Their provincial Pharmacare does not yet cover this treatment.
- They are being required to take and fail an interferon-based treatment before they are eligible to have the treatment covered.
- They are "too healthy"; they do not meet the treatment criteria of proving they have extensive organ (liver) damage.
- They are too sick; with de-compensated cirrhosis, it is too risky to take the new DAAs.
- They have liver cancer or are in need of a transplant, and there's a good chance they could die before becoming eligible for the DAAs.

Our governments and insurance companies continue to place barriers to treatment access such as those above. It is widely accepted by medical professionals that the new DAAs, as with all previous HCV treatments, work better when they are given before significant damage to the body occurs. So **this rationing of drugs (basing treatment eligibility on cost considerations rather than medical criteria) is not based on science, but rather on the bottom line.**

Patients can understand that they may not be treated immediately if there is a limited supply of the drugs, or if the medical system is unprepared to accept a large influx of patients. They can understand that those who are in most need should be treated first, and that those who can afford it should pay proportionally more than those who can't. However, patients and patient groups such as HepCBC would be more willing to accept delays if they could see other HCV stakeholders making sacrifices as well.

Governments and private insurance companies will have to prepare for increased costs associated with HCV testing and treatment. This will involve careful negotiation with pharmaceutical companies, something ongo-

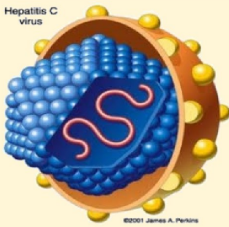
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(HEALTHCARE RATIONING —Cont'd from page 2) ing now which we are watching closely.

The healthcare system will have to prepare a more efficient delivery system to deal with this increased need for HCV services and care. This may involve some re-training of medical personnel, and some beefing up of existing infrastructure such as Telehealth, to provide equitable HCV care to even the most remote communities.

But clearly, pharmaceutical companies will have to accept that they must charge significantly less for the new, more effective treatments, benefitting from economies of scale (making money from quantity sold, not price charged). Now that it is possible to eradicate this scourge, we need to think less of profiting from the few as much as treating the many. Surely there is still great profit to be made by several companies, when they consider treating over 100 million people worldwide.

Let's agree to work together, each group of stakeholders taking the actions they can and making the sacrifices they must to address the HCV epidemic head-on, so our children and theirs will no longer have to suffer from this terrible disease.



## MAKE TREATMENT ACCESSIBLE TO ALL

### HepCBC & Action Hepatitis Canada Sign Letter Urging Pharma to Make Affordable Treatment Accessible to All

On January 28, 2015, HepCBC joined Action Hepatitis Canada (AHC), Doctors without Borders (MSF or *médécins sans frontières*), the Global Health Justice Partnership, Treatment Action Group (USA), and about 2500+ other groups and individuals to sign a joint letter to Gilead urging Gilead to change their marketing policies in order to make HCV treatment accessible to all. While the letter was addressed to Gilead, we want to emphasize that these policy changes we are advocating apply equally to all other companies developing and producing the new DAA hepatitis C treatments as well. The letter has been turned into a petition which you can read and sign at:

<http://www.petitionbuzz.com/petitions/hepc>

## STUDY: TREAT EARLY

Progression of fibrosis can start early. Doctors, patients and insurance companies need to know how fast Hep C can progress. Researchers did a study to find out the progression rate from infection to liver failure, and what can change that rate. To do this, they examined data from a database of 610,514 military veterans. They studied those who had an initial negative HCV-antibody test, and a later positive one, plus a positive test for the virus. They matched those 1840 veterans with a similar group (age, race, sex) of 1840 veterans with no Hep C. (Those co-infected with HBV or HIV, and those with liver cancer or cirrhosis at baseline were excluded.) Cirrhosis was scored as anything greater than 3.5 fibrosis on a scale of 4.

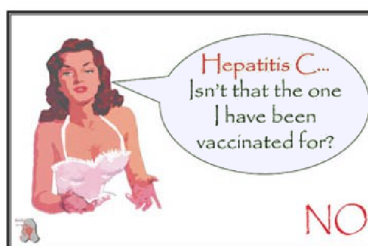
The HCV+ group tended to be younger, with a lower body mass index. They abused drugs and alcohol more and had higher liver enzymes, but had fewer diagnoses of diabetes and blood pressure problems. Fibrosis started early in the HCV+ group, but slowed down after 5 years. At 5 years, 15% of the HCV+ veterans had cirrhosis, compared to 5% of those without HCV. After 10 years, it was found that 18.4% of the HCV+ veterans were cirrhotic, compared to 6.1% of their HCV- counterparts. Liver failure was uncommon in those 10 years after diagnosis of cirrhosis.

The researchers concluded that early treatment should slow or reverse the progression of fibrosis and delay the development of cirrhosis. They suggested that treating those with cirrhosis to avoid liver failure would work, but the number of those "saved" would be small. **"Compared with HCV- persons, HCV+ persons had a significantly faster time to first hepatic decompensation event."** **".....we found that among HCV+ persons the mean FIB-4 scores doubled in the first 4 years after infection and more than 18% of them developed cirrhosis within 10 years after infection."**

Early treatment seems to make more sense than waiting until a patient develops liver damage, according to this study.

Source:

[www.natap.org/2014/HCV/121214\\_01.htm](http://www.natap.org/2014/HCV/121214_01.htm)



(NEWS: MADRID—Continued from page 1) cal company Gilead. La Plataforma has insisted that a generic Sovaldi be offered, in line with WTO policy. One political party, "Podemos", stated they want the government to take control of the patent in order to make a less expensive drug.



People supporting those affected by hepatitis C shout and hold banners raving, 'Less corruption and more medication,' during a demonstration in Madrid, Spain, Saturday, Jan. 10, 2015. (Photo by Daniel Ochoa de Olza/AP)

After much tense public and political-affiliated outpour about these concerns, it is believed that Hep C treatment will be a campaign issue for Spain's elections this year.

"The opposition parties also contrast the billions in public money spent on bailing out Spanish Banks with the inability of the State providing the best treatment for the ill."

"An expensive, market-oriented pharmaceutical model that has clearly failed to provide access to life-saving medicines for the majority of the population of the Global South is now also not working for millions of European citizens." (David Hammerstein article [www.davidhammerstein.com/article-high-priced-hepatitis-c-treatments-spark-massive-public-outcry-and-political-debate-in-spain-125376732.html](http://www.davidhammerstein.com/article-high-priced-hepatitis-c-treatments-spark-massive-public-outcry-and-political-debate-in-spain-125376732.html))



People supporting those affected by hepatitis C raise their hands during a demonstration in Madrid, Spain, Saturday, Jan. 10, 2015. (Photo by Daniel Ochoa de Olza/AP)

"La lucha es la única forma; la alternativa es nuestra muerte". (The fight is the only way; the alternative is our death.) — Chant from the march.

See also:

[www.chron.com/news/medical/article/Thousands-protest-in-Spain-for-better-hepatitis-C-6006377.php#photo-7371350](http://www.chron.com/news/medical/article/Thousands-protest-in-Spain-for-better-hepatitis-C-6006377.php#photo-7371350)

Is HCV transmitted sexually? Studies are still being done. We picked two interesting studies, one studying heterosexual couples and another, studying homosexual men.

A 2012 study interviewed 500 HCV+/HIV-long-term, monogamous heterosexual couples, separately, about risk factors for HCV, such as sexual practices and sharing grooming items. Blood was analyzed to see if the couple's viruses matched. It was found that 4% of the partners had HCV. Of those, 9 couples had the same genotype and serotype. It was found that 3 couples among the 500 interviewed had viruses that indicated possible transmission from one partner to the other, so sexual transmission was 0.07% per year. There was no obvious sexual practice that was especially dangerous.

The second report, from England, indicated an increase of STDs among men who have sex with men (MSM), probably due to not using condoms or to unsafe injection practices. Those risky practices may be the reason for the recent spread of HCV among the MSM community there. Most studies have looked at MSMs who are HIV/HCV co-infected. To find out if HCV appears in HIV-negative MSM, they looked for those patients at the clinics and found 44 such patients between 2010 and 2014. Half were classified as having had up to 2 partners. The other half had more than two. The most common risk factor was not using condoms. They also found that the riskiest behavior was receptive, unprotected anal intercourse, About 50% disclosed use of injected or inhaled drugs.

Many seemed to think that when they were screened for HIV, they were also screened for HCV, which usually was not the case. The researchers concluded that "...more research needs to be done to assess the extent of the spread of HCV among HIV-negative MSM not only in London but in other cities and countries."

Health Canada says, "Long-term monogamous couples should decide for themselves about routine condom/dental dam use."

Practicing safer sex is always a good idea for people with multiple partners. People who engage in high-risk sexual behaviour have a greater risk of contracting STDs which can cause open sores and lesions. Open sores and lesions mean a greater risk of blood-to-blood contact and a higher risk of contracting hepatitis C. If you have herpes, you are at a greater risk of catching hepatitis C. It might be possible that HCV piggybacks on the genital herpes virus through genital lesions. If you have multiple partners, use condoms. People with

acute HCV or with compromised immune systems, should be more careful, as these conditions can raise the level of virus in the bloodstream, and can mean a greater risk of infection. Sex during menstruation should be avoided.

Sources:

[www.ncbi.nlm.nih.gov/pubmed/23175457](http://www.ncbi.nlm.nih.gov/pubmed/23175457)  
[www.medscape.com/viewarticle/775549](http://www.medscape.com/viewarticle/775549)  
[www.phac-aspc.gc.ca/hepc/faq-eng.php#a4](http://www.phac-aspc.gc.ca/hepc/faq-eng.php#a4)

## WHOM SHOULD I TELL?

If you have hepatitis C, you are under no legal obligation to tell others. However, the law may change. Right now, it is up to you to decide whether to tell anyone of your hepatitis C status. Some people (and unfortunately some health care providers, also) may have judgmental attitudes or unnecessarily exaggerated fears of infection. People should carefully consider whom they inform, in the light of possible discrimination. How people might have caught the virus is not important. Those who have the hepatitis C virus should be covered by anti-discrimination laws. If in doubt, ask a lawyer.

Cases where patients have been infected by physicians have raised the ethical issue of whether or not infected physicians should be banned from performing invasive procedures. Some hospitals are now insisting that their surgeons be tested, and that those infected get treatment. Surgeons infected with HCV in Germany are allowed to perform surgery with approval of a committee of experts which takes into account the individual situation, such as viral load.

**DISCLOSURE:** "Under public health law in some provinces and territories, people have a legal obligation to not pass on infections like HCV—in other words, to protect sex partners from becoming infected through sex. That is why Public Health (or physicians and nurses working in cooperation with Public Health) often counsel people living with hepatitis C to disclose their HCV infection to sex partners and to practice safer sex, including using condoms for intercourse."

Sources:

[www.catie.ca/en/search/apachesolr\\_search/required%20to%20tell](http://www.catie.ca/en/search/apachesolr_search/required%20to%20tell)  
[www.macleans.ca/society/health/when-a-doctor-has-hep-c/](http://www.macleans.ca/society/health/when-a-doctor-has-hep-c/)  
[www.ncbi.nlm.nih.gov/pubmed/15205780](http://www.ncbi.nlm.nih.gov/pubmed/15205780)

Don't worry. Just because you've been diagnosed with Hep C doesn't mean you can't have a partner. But how do you tell? It can be scary, so practice first. How much will you say? When will you say it? Practicing can help you get over feeling nervous. Write out a speech. Record yourself. Try your speech out with a trustworthy friend or therapist. Ask how s/he would react. Is there anything that makes him/her feel uncomfortable? What could work better?

Don't tell on a first date. Let your prospective partner get to know YOU. If you're asked a personal, direct question, deal with it as such, and say you're not ready to discuss certain topics until you get to know him/her better. Some people suggest telling by the fourth date, so neither of you has invested too much time. Be prepared to be turned down. You may not always be successful. Tell before you get involved enough to be hurt. And if you wait until the other person is emotionally involved, then s/he might feel you were dishonest.

Definitely plan on telling before sleeping with the person, and DON'T leave it until you're in bed or in the hotel room...or in the back seat. If the topic of sex comes up, that might be a perfect time to discuss the matter of both of you getting tested for sexually transmitted diseases. (No, Hep C is not an STD, but there is still the possibility of contracting it through unprotected sex if blood is involved.) Or if you can work it into the conversation somehow, such as talking about your volunteer work, or the movie "Deal With It," it's better than having a talk just about Hep C. Maybe have a pamphlet handy. Give your friend the important facts, but don't overdo it. You will earn "brownie points" by suggesting he or she speak with their doctor. You can truthfully tell the other person that there is less than a 3 percent chance of transmitting Hep C even through unprotected sex in a monogamous relationship.

If you are met with uncertainty, it might be a good thing to say that you understand that he or she needs time to think, and invite your new friend to call you in a day or two. If you haven't heard back after about 3 days, consider calling to say you're still thinking of him/her, but frankly, if the person won't accept you with Hep C, the person is probably not worth your time. Hep C can be a blessing in disguise. A caring person who is interested in you will go to the trouble of investigating the disease, and will be intelligent enough to see it really doesn't matter. It's an excellent way to weed out the duds! But if you really don't want this great opportunity to find a quality mate....get treated. Get cured!

## GIPA & MIPA IN THE HCV (PATIENT RIGHTS) MANIFESTO

What are GIPA and MIPA? These two principles (Greater Involvement of Persons with AIDS and Meaningful Involvement of Persons with AIDS) have guided AIDS organizations over the years, resulting in a high % of HIV+ Board members and HIV+ employees in AIDS organizations. Given that the death rate of HCV has surpassed that of HIV, and that AIDS organizations deal with a high rate of people with HIV/HCV co-infection, and since there are few HCV-dedicated organizations such as ours, the government is asking AIDS organizations to provide HCV services. This could result in a disproportionate % of HIV+ Board members and employees speaking on behalf of, and making decisions affecting, HCV+ people. To help rectify this situation and strengthen the voices of HCV+ people, we have asked AIDS organizations to sign the HCV Manifesto which extends GIPA and MIPA-type rights to HCV+ people. We are very happy to say that besides the 134 individual signers, these 13 Canadian groups, many of them AIDS organizations, have signed the Manifesto as of February 3, 2015:

- AIDS Network Kootenay Outreach and Support Society
- AIDS Vancouver Island
- ASK Wellness Society
- Bloom Clinic of the Bramalea Community Health Centre in the Region of Peel, Ontario
- Canadian AIDS Society
- Canadian AIDS Treatment Information Exchange
- Canadian HIV/AIDS Legal Network
- Canadian Treatment Action Council
- Centre Associatif Polyvalent d'Aide Hépatite C
- HepCBC Hepatitis C Education and Prevention Society
- Prisoners with HIV/AIDS Support Action Network
- Positive Living Fraser Valley Society
- Vancouver Island Persons with AIDS Society

We hope to see you and your organization listed here soon. Go to [www.hepcbc.ca/hcv-manifesto](http://www.hepcbc.ca/hcv-manifesto). READ and SIGN! Translated versions upcoming. French available now at [www.hepcbc.ca/manifeste-vhc](http://www.hepcbc.ca/manifeste-vhc).



## SVR HONOUR ROLL



Have you been undetectable for a minimum of 12 weeks after treatment? Give others hope. Congratulations to our friends:

1. **GJ** - SVR Dec 1998 - IFN/RBV 52 wks - Dr. Anderson/Natalie Rock, Vancouver, BC.
2. **Amberose** - 2000 (GT2a/2c) - Schering IFN/RBV 24 wks
3. **Jeanie Villeneuve** - Oct 2000 - Schering IFN/RBV
4. **Kirk Leavesley** - (GT1) - 2004 - Roche
5. **Darlene Morrow** - (GT1 relapser) - Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.
6. **KG**-Transfused 1987 (GT2a/2c treatment naïve) 2003-4 IFN/RBV 24 wks. Still undetectable in 2014.
7. **Beverly Atlas** - (GT1a) - 2005/2006 - Albuferon/RBV 44 wks
8. **Steve Farmer** - 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
9. **Gloria Adams** - (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks - Drs. Erb & Yoshida, Vancouver, BC.
10. **Don Crocock** - (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 weeks
11. **Daryl Luster** - (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
12. **Donna Krause** - (GT1 partial responder) SVR Nov 2011- Pegasys/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks. Dr. Erb, Vancouver.
13. **Cheryl Reitz** - (GT1b previous partial responder) SVR12 Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquiere, Victoria, BC.
14. **Anita Thompson** - (GT1a treated 3 times) Cirrhosis - Apr 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
15. **Leon Anderson** - (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
16. **Joan King** - (GT1b treated 5 times) June 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
17. **Sandy J.** (GT 1a treatment naïve) Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. Now SVR24.
18. **Andrew P.** - (GT 1a many prev treatment attempts over 10+ years, including Incivek Jan

- 2014.) Sofosbuvir/Ledipasvir + RBV 24 wks
19. **Diane Stoney** - Transfused 3/21/79 (GT 1a treatment naïve) 2/4/2014 - 12 wks placebo, then 12 wks on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC
20. **Coreen Kendrick** - (GT 1a treatment naïve) Mar 10, 2014 MK5172/MK8742 12 weeks Dr. Ramji, Vancouver, BC.
21. **Jack Swartz**—(Treated 3 times) Apr 2014 IFN/RBV/Victrellis, Dr. S. Wong, WHSC.
22. **Del Grimstad** July 2014, 12 weeks Simeprevir/Solvaldi
23. **Linda May** (GT 1b transfused, treatment-naïve) 12 wks Asunaprevir/Daclatasvir . Dr. Tam, LAIR Centre.
24. **Jackie**—(GT1 relapser) - SVR24 June 2013 - IFN/RBV/Boceprevir 48 wks. Dr. Keith Bovell, Guelph, ON.
25. **Bob** (GT1a/HIV relapser) SVR24 Nov 2014 pegIFN/RBV/Incivek 24 wks, Dr. Montaner, Salt Spring Island, BC.

Please send your name and info to Joan at [info@hepcbc.ca](mailto:info@hepcbc.ca)

### Spring Fling

7th Annual Gala  
Friday April 24th 2015

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Showtime: 8 PM

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With all proceeds going to the HLS

## HEPCBC VANCOUVER OFFICE OPENING!

In addition to our Victoria Main Outreach office, HepCBC is delighted to announce we will have an Outreach office in downtown Vancouver soon, as well!

The office will be in #206-A, 938 Howe Street (between Smithe and Nelson Streets). It is not far from Saint Paul's Hospital, the Vancouver City Centre Skytrain Station, and UBC Robson Park – a very convenient location for serving people with hepatitis C. It is small, but includes access to private conference rooms and even a boardroom.

We look forward to having a place to meet with volunteers, people who need information, and others. Plus it will be great to have a place to store educational materials.

Watch our website for information about the Grand Opening (sometime in March) and consider volunteering a few hours a month (or more) at HepCBC's new Vancouver office! Find information about volunteering at HepCBC: <http://hepcbc.ca/volunteer/>.

## HCV MANIFESTO

### Confronting Hepatitis C

#### A Grassroots Initiative

As people with HCV, we claim the right to live lives free of discrimination, to access appropriate health care and to be consulted on policies and programs which affect us. We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness and dependence upon the care of others.

**We are "People with HCV."** *Some of us also have co-infections such as HIV/AIDS, hepatitis B (HBV) or TB. It is up to co-infected people to identify with and seek help from organizations that best meet our needs at a given time.*

**We ask that individuals and groups...**

• **Support people with HCV in our struggle against discrimination** based on our HCV+ status, including such actions as excluding us from our choice of job or residence, denying us insurance, denying us the same standard of medical care given those with other diseases, or segregating us from others.

• **Avoid scapegoating people with HCV**, blaming us for the epidemic or generalizing about our past or current lifestyles. Avoid asking people with HCV how we contracted the disease; it is irrelevant.

• **Support broader testing** of baby boomers, and other groups that are most affected by HCV based on epi-data, to locate people who have HCV but do not know it so that they may be offered life-saving treatment and support.

• **Support a research agenda** committed to delivering cures for HCV and hepatocellular cancer, and for reversing cirrhosis. In order to expedite improvements to their treatments, integrate into the very beginning of clinical trials investigations involving people with cirrhosis, those with co-infections such as HIV/HCV or HBV/HCV, or those who have previously failed treatment.

• **Support greater and meaningful involvement of people with HCV** at all levels of civil society, community organizations, and government (volunteers, staff, spokespeople, and decision-makers).

• **Support HCV prevention messaging** which ensures *educational materials do not reinforce stigma.*

• **Support stable and proportionate funding** for HCV organizations and groups which reflects the burden of the disease.

When appropriate, include people who are mono-infected with HCV (95% of all people with HCV) in funded programs for HIV+/HCV+ co-infected people.

• **Support universal access to harm reduction** supplies so that all people can have the option of choosing low risk behaviours.

• **Support the principle that people with HCV be actively and closely involved** in the design and delivery of services we need: *"Nothing about us without us!"*

**We as people with HCV commit to...**

• **Forming groups** to choose our own representatives, deal with the media, select our agenda and plan our own strategies.

• **Being involved at every level of decision-making** and specifically **servicing on the boards of directors** of HCV service-provider organizations.

• **Participating in all HCV forums** with equal credibility as other participants, to share our lived experiences and knowledge.

• **Substituting low-risk behaviours** for those behaviours involving blood-to-blood contact which could endanger others.

**People with HCV claim the right...**

• **To affordable, universal access to the best treatment** available, regardless of where we live or how we contracted the disease, linguistic or cultural barriers, sexual orientation or gender identity, incarceration, level of education, or other non-relevant criteria such as socioeconomic or immigration status.

• **To be treated within our home communities** whenever possible; this includes addressing regional inequities by training and supporting rural and remote HCV treatment teams through technological innovations such as tele-medicine or mobile health.

• **To initiate treatment without requiring clinical proof of substantial liver damage**, since available evidence shows that treatment is more effective before such damage occurs.

• **To affordable, universal access to secondary treatments** which mitigate serious or debilitating conditions associated with either chronic HCV or treatment side-effects.

• **To regular monitoring of internal organ functioning**, especially for those with cirrhosis or extra-hepatic HCV complications.

• **To non-invasive alternatives to biopsy** whenever possible.

• **To access liver transplantation** when medically required; this includes addressing regional inequities by providing supportive care and accommodation for patients coming from outside a transplant centre.

• **To full explanations** of all medical procedures and risks.

• **To privacy, to confidentiality** of testing and medical records, and **to human respect.**

**DISCLAIMER:** Signing this Manifesto in no way signifies support of the organization HepCBC Hepatitis C Education and Prevention Society (HepCBC). This society (HepCBC) is serving as a point for collection and sharing of this Manifesto, but does not claim ownership of it.

**ACKNOWLEDGEMENTS:** While this HCV Manifesto is a "work in progress," the authors wish to acknowledge the previous groundbreaking work of the HIV/AIDS community from which many of the above wordings have been adapted, such as the Denver, GIPA, MIPA, and "Nothing About Us Without Us" principles. Some items also have been adapted from the Canadian Treatment Action Council's (CTAC's) "Treatment Access Bill of Rights" document © 2013 by CTAC.

To support their struggles, hepatitis C (HCV) positive men and women invite you or your organization to sign the "Hepatitis C (HCV) Manifesto" through these webpages:

English: [www.hepcbc.ca/hcv-manifesto/](http://www.hepcbc.ca/hcv-manifesto/)

French: <http://hepcbc.ca/manifeste-vhc/>

HepCBC warmly thanks CAPAHC (Centre Associatif Polyvalent d'Aide Hépatite C) for their cooperation in this project.



This document is being translated in the coming months into Chinese, Farsi, Spanish, and possibly other languages. Challenge your friends and family, your church, mosque, or temple, your service club, your school or university, or your labour or business organization to READ and SIGN the HCV Manifesto.

English: [www.hepcbc.ca/hcv-manifesto/](http://www.hepcbc.ca/hcv-manifesto/) and

French: <http://hepcbc.ca/manifeste-vhc/>

Email: [manifesto@hepcbc.ca](mailto:manifesto@hepcbc.ca) (English) or

[direction@capahc.com](mailto:direction@capahc.com) (French)

Facebook: HCVManifesto (all languages)

Twitter: #HCVManifesto (English) or



## CONFERENCE

27 February 27 2015

4th Canadian Symposium on HCV  
National CIHR Research Training Program  
Banff, AB

[www.ncrtp-hepc.ca/](http://www.ncrtp-hepc.ca/)

## AbbVie CARE

With the approval of HOLKIRA™ PAK, AbbVie is launching AbbVie Care, which is a program that will provide best-in-class solutions to improve outcomes for people living with hepatitis C.

Canadians prescribed HOLKIRA PAK will have the opportunity to request to be enrolled in AbbVie Care. The signature care program is designed to provide a wide range of customized services including reimbursement assistance, education and ongoing disease management support. AbbVie Care will not only support health care professionals but people living with genotype 1 hepatitis C throughout their treatment journey to achieve high cure rates in the real world.

For enquiries: 1-844-471-2273.

## MERCK CARE™

MerckCare™ is a program to help people who have been prescribed PEGETRON™, VICTRELIS™ or VICTRELIS TRIPLE™. The program provides:

- assistance with reimbursement and/or insurance claims.
- financial assistance for co-pay/ deductible for people who qualify.
- 24/7 nursing support by phone.
- multilingual assistance.
- home delivery of medication.

MerckCare™ provides all of these services free of charge.

To enroll in MerckCare™, you can call 1-866-872-5773 or your doctor or nurse can submit an enrollment form for you. Reimbursement specialists are available from 8:00 a.m. to 8:00 p.m. EST Monday to Friday, excluding statutory holidays.

## IBAVYR™

Pendopharm has established the IBAVYR™ Patient Support Program. The program will assist patients who have been prescribed IBAVYR™ (ribavirin tablets) with reimbursement navigation, financial assistance and pharmacy services. Case managers will support patients with insurance-related matters and assess eligibility for financial support. Pharmacy services include adherence support, medication delivery and counseling.

To enquire or to enroll, you may call 1-844-602-6858 Monday–Friday 7am to 11pm EST.

## BIOADVANCE®

JANSSEN's GALEXOS™: BioAdvance® program can assist you in many ways during your treatment. This includes compiling and submitting, on your behalf, all the forms and documents required by your insurance company to request coverage of GALEXOS™, and following up with your insurer to get you the best coverage possible. If you don't have private insurance, the GALEXOS™: BioAdvance® program will investigate public assistance programs that can help pay for your treatment. Whichever type of coverage you have, if your insurance does not fully cover the cost of treatment, the GALEXOS™: BioAdvance® program can usually coordinate and provide financial assistance to help you get treated. Finally, the program can offer many other types of support and your doctor and members of your healthcare team will work with the GALEXOS™: BioAdvance® Program to develop a customized approach to best support you throughout the course of your treatment. Contact: 1-855-512-3740

## MOMENTUM™ SUPPORT

To learn more about SOVALDI™ or the Momentum Program™ in Canada, the patient should speak to his/her doctor or nurse or call the Gilead Sciences Canada medical information line at 1-866-207-4267. Eligible patients may receive an integrated offering of support services for patients and healthcare providers throughout the entire treatment journey, including:

- Access to dedicated case managers/reimbursement navigators to help patients and their providers with insurance-related needs, including identifying alternative coverage options through private, federal and provincially-insured programs.
- The SOVALDI™ Co-pay assistance program, which will provide financial assistance for eligible patients who need help paying for out-of-pocket medication costs.
- Medication delivery services.
- Compliance and adherence programs.

## PEGASSIST

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM - 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or co-payments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

## NEUPOGEN

Amgen has a program for patients who have been prescribed Neupogen. Dependent on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge **as long as it is prescribed and dosed in accordance with the approved product monograph.** This service is accessed through the Victory Program: 1-888-706-4717.

## INCIVEK CARE

Vertex's Incivek Care Patient Assistance Program supports patients with the reimbursement process for Incivek (telaprevir) treatment (Incivek, pegIFN, ribavirin). It will give you an efficient assessment of your options and eligibility. You may qualify to receive co-payment and other financial assistance to supplement your private and provincial drug program coverage. The program also provides dispensing and home delivery options, and expert treatment advice. Call the Support Line at 1-877-574-4298. (Select option 2 for English, then 2 for Incivek Care.)

## COMPENSATION

**Class Action Suit Hotline:** 1-800-229-5323 ext. 8296  
**Health Canada Compensation Line:** 1-888-780-1111  
**Red Cross Compensation pre-86/post-90 Registration:** 1-888-840-5764 [HepatitisC@kpmg.ca](mailto:HepatitisC@kpmg.ca)  
**Ontario Compensation:** 1-877-222-4977  
**Quebec Compensation:** 1-888-840-5764

### CLAIMS ADMINISTRATOR 1986-1990

Claimants may be reimbursed for costs of treatments and accepted hepatitis C medications not covered by public or private healthcare plan while they wait for reimbursement from the 1986-1990 plan.

Administrator 1-877- 434-0944  
[www.hepc8690.com](http://www.hepc8690.com)  
[info@hepc8690.com](mailto:info@hepc8690.com)

### Pre-86/Post-90

Administrator 1-866-334-3361  
[preposthepc@crawco.ca](mailto:preposthepc@crawco.ca)  
[www.pre86post90settlement.ca](http://www.pre86post90settlement.ca)

### Settlement Agreement:

[www.pre86post90settlement.ca/PDFs/SA/](http://www.pre86post90settlement.ca/PDFs/SA/)

**HAVE YOU HAD AN  
ULTRASOUND AND  
ALFA-FETOPROTEIN  
TEST DONE IN THE PAST  
YEAR?**

