

hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

RX&D REBUTTAL TO MOVIE REVIEW

Dear Editor,

I am writing today in response to an article I read recently in the Hep C Bulletin regarding the film 'Fire in the Blood' and in the hope that you may consider publishing the following comment attributable to Russell Williams, President of Rx&D, Canada's Research-Based Pharmaceutical Association:

"Providing medicines to the world's poorest countries requires a thoughtful response from many stakeholders including local governments, international organizations, developed countries and the pharmaceutical industry.

Innovative pharmaceutical companies play an important role in improving health outcomes globally by developing cutting-edge, life-changing medicines after years of rigorous research and staggering investment. Today, it costs more than one billion dollars and more than 10 years of research and development to develop just one new medicine. As such protection for intellectual property through the patent process is essential to ensure that this cycle of investment and innovation continues over and over again across many diseases. There is no contradiction between supporting IP and innovation, and better access to medicines.

That said, the industry believes that alternate models are required to ensure that those living in developing countries have access to care. In 2000, the pharmaceutical industry was instrumental in establishing the Accelerating Access Initiative--a partnership between six global pharmaceutical companies and five multilateral international organizations--to work toward bringing AIDS medicines to African countries at lower prices.

In 2009, The United States President's Emergency Plan for AIDS Relief (PEPFAR) was established. Since then more than 200 pharmaceutical formulations still under patent have been approved for production in the

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REVIEW DRUGS: LOW PLATELETS & H.E.

The Canadian Drug Review (CADTH) has announced two more new drugs for people with hepatitis C. Both need our patient group input! Revolade (Promacta in the USA or "eltrombopag olamine") by Glaxo Smith Kline, and Zaxine (rifaximin) by Salix Pharmaceuticals, are not the "cures" we have all been focusing on recently. Instead, Revolade is used in the treatment of people who are experiencing Thrombocytopenia (low platelets, poor blood clotting), a severe and potentially dangerous side effect of treatment, while Zaxine is a new drug for people who are experiencing hepatic encephalopathy (HE), a common component of end stage liver disease. Revolade is not a new drug, but the application is for a new indication, chronic hepatitis C. If these pass both CADTH and BC PharmaCare reviews, the drugs' costs will be reimbursed. For more info and to SUBMIT your input BEFORE midnight Tuesday, AUGUST 26, 2014 go to <http://hepcbc.ca/2014/07/new-drugs-low-platelets-and-hepatic-encephalopathy/>.

CO-INFECTION WITH HIV: BOB'S STORY

I was diagnosed with non-A/non-B in 1985. I was very sick at the time. The

(Cont'd on page 2)

HEPATITIS C NEWS

OUR EDITORIAL POLICY CLARIFIED

Several recent developments have led us to do some soul-searching here at HepCBC, and we'd like to share them with our readers.

First, we encountered this statement in a July 1, 2014 article by Alan Cassels in the newsmagazine *Common Ground* (<http://commonground.ca/2014/07/the-1000-pill-heist/>): "Here at home in BC, our provincial Drug Benefits Council, whose job is to advise the government on funding decisions, is hearing from physicians, patients, caregivers, patient groups and, of course, the manufacturers. If you have an opinion, maybe you'd like to weigh in (Google: Pharmacare, Your Voice) and you can join the likes of HepC BC, the local hepatitis C advocacy group supported by at least six drug companies, including Gilead, the maker of Sovaldi. We should never be so naïve as to think this is an unbiased process."

Anyone who knows the history of our organization knows that we have always put our members first and have never been in the employ of either government or pharmaceutical companies. This has led to a lot of hardship over the years, but we figured that keeping our integrity intact was worth it.

We are bombarded daily as an organization by requests from both hepatitis C "treatment access" activists and pharmaceutical representatives to publish their information. Over the last few weeks these requests have been increasing noticeably as the "price" debate heats up. We do our utmost to determine the best use of our time and space, both on our website and in the bulletin, to present a balanced view which will enable our readers to make informed decisions.

As an example, we were asked by a representative of another non-profit society last week, "Well, which side are you on?" to which the answer is remarkably clear and easy to state: We are on the side of people with hepatitis C. We support whatever it will

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"I want to volunteer. Please contact me."

"I want to join a support group. Please call."

(Note: The *hepc.bull* is mailed with no reference
to hepatitis on the envelope.)

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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.

RhoGAM

**DID YOU RECEIVE
RHOGAM BEFORE 1992?
DO YOU KNOW OTHERS
WHO DID?**

**GET TESTED!!
UNITE!**

Contact: info@hepcbc.ca

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., L.P.

Please patronize these businesses that have
helped us: Top Shelf Bookkeeping, Merck
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Thrifty Foods.

HEPC CLINIC AT PERCURO



The Hepatology Clinic at PerCuro provides
HCV education and long-term support to pa-
tients and their families undergoing HCV treat-
ment in the Greater Victoria/Southern Vancou-
ver Island region, according to their individual
needs. Specialized nurses help procure finan-
cial coverage for treatment, ensure lab tests are
scheduled, teach self-administration of injecta-
ble medication, help manage side ef-
fects, facilitate a monthly support group, and
liaise with family doctors and specialists re-
garding the patient's treatment and any other
issues of concern.

This type of professional support is impera-
tive now that standard of care therapy often
involves three medications.

PerCuro also offers access to cutting edge
clinical trials for both naïve and treatment-
experienced patients.

There is no cost involved.

**Nursing Support improves outcomes.
Contact 250-382-6270**

(BOB'S STORY—Cont'd from p. 1)

most severe and long-lasting effects were
chronic fatigue and depression. These
symptoms were overshadowed by a later
diagnosis of hepatitis/HIV co-infection. I
was diagnosed with HIV in 1987. At that
time, I was given a two year life expectan-
cy, so my main concern became the HIV. I
never realized the devastation of the HCV
until the last few years, when I decided to
stop HIV treatment.

BENEFITS OF PALLIATIVE CARE

Palliative care is much underestimated in
the course and timing of treatment for
chronic life-threatening illness. The sooner
one is able to embrace this type of care, the
better. We need more discussion on the
benefits of it.

Please explore the palliative care options.
People are afraid it's a place to go to
die, but the comfort and support actually
allow you to live longer. I was fortunate to
find a doctor who would accept me into the
palliative care program. I can't explain
enough about the benefits of having this
type of care and level of acceptance and

(Continued on page 3)

MARATHON

Mark this date on your calendar:

October 12, 2014 is the date of the Victo-
ria, BC "Goodlife Fitness Marathon" (8k
Road Race \$40, Half Marathon \$75, Full
Marathon \$100. Remember, running is not
the only option! You can WALK either the
Half or Full Marathon, and you can use a
WHEELCHAIR for any of the events.

To register, go to
[www.runvictoriamarathon.com/events/
register.php](http://www.runvictoriamarathon.com/events/register.php)

When asked if you want to join a TEAM,
be sure to select our team, the "HepCBC
Liver Warriors" from the dropdown list. If
you don't see the team listed for the 8k or
Full Marathon, you can create it by writing it
in. If you join our team, please let us know
by email to marathon.hepcbc@gmail.com.

Also, we are looking for Race Day, Info
Booth, and Fundraising Volunteers! This is a
great way to fight stigma, educate the public
about hepatitis C, meet
new friends, get in
shape, demonstrate the
benefits of exercise for
the liver, raise money
for HepCBC's hepatitis
C outreach programs, and have fun!



(BOB'S STORY - Cont'd from page 2)

understanding.

Palliative care allowed me the comfort to reconsider, and with this type of open support and dialog, my small-town G.P. allowed me to enjoy a number of years warding off declining platelets caused by HIV, with Prednisone treatment, which of course could not be maintained for much longer. He gave me the heads up, but when they reached a certain level, he told me that if I ever wanted to reconsider HIV treatment, it had to be now. He cautioned me that if I went back to explore treatment, there would be a new one, and that would be a change of course in my direction and comfort level. I believe the level of comfort I felt in his care allowed me the courage to explore new options, because I knew where I would wind up if they didn't work.

SUPPORT FOR CO-INFECTED

I have to admit I did attempt to connect on line. I couldn't travel to the island for the meetings, and I wasn't able to connect with anyone else co-infected. I want to make that point again: Co-infected people are treated through the kindness of the John Ruedy Immunodeficiency Clinic (IDC) at St Paul's, or do you know of other co-infected people who are accessing treatment elsewhere? There seems to be a lack of mention of it on your website. [Note from editor: It's true. We don't do much in the way of co-infections, usually preferring to direct our few resources to HCV.]

In the February edition of *hepc.bull*, I found the Guided Autobiography and Body Mapping Project. Check it out here: <http://tinyurl.com/BCCPDLifeStories>. I am forever indebted to Shelly Hourston, who was wise enough to see the need and start this project right in the middle of my treatment journey, providing me a connection which was much needed at the time (aimed directly at people co-infected). I think this is an amazing program because of its intention to link people by telephone in a group support setting. I have since spoken to Shelly. She has discovered a lack of response from the co-infected population. Please, if any of you are reading this, we want you to call. Let's start a small group by telephone.



STIGMA: ACTIVITIES ON SALT SPRING

What I can say for sure is I felt zero stigma from anyone--lab techs, doctors, nurses, pharmacy, etc., on Salt Spring. I spent a lot of time in those places! I also advocated for myself, i.e., when an ultrasound was needed, I insisted on having it done in our local hospital. So by the end of the treatment, I felt like I accomplished something which hopefully might make it easier for those coming down the pipes.

During my treatment, I overcame stigma by being open with everyone about my diagnosis. I reached out to our local gay group GLOSSI, and was overwhelmed with support in the form of friendly visitors who spent time with me, listening to my story, and more importantly, sharing their own. There really is no difference if it's cancer, Hep C, dementia... We all have our struggles, and I think this is more evident in small communities where we have to improvise or create support systems.

I had pamphlets installed, both in the community service centre and the hospital lab waiting room. I wanted to see my disease in amongst all the others--my small way of taking the stigma away from the disease. This is an individual action anyone can take in the course of their treatment. Pamphlets are available through CATIE and shipped free of charge. (www.catie.ca) Let's get them out there.

ACTIVISM

Some of us living with HIV on Salt Spring got together to start a petition with Elizabeth May for a national AIDS strategy. Check it out here: <http://elizabethmaymp.ca/get-involved/national-aids-strategy> Please read and sign this petition. The guidelines for Treatment as Prevention Strategy (TasP) cover co-infection and can easily transfer over to a national approach for hepatitis C.

ACCESS TO TREATMENT

I went to Julio Montaner, world famous for his TasP, and he was very blunt with me. He told me that, in order for him to help lessen my pill burden for HIV, I had to clear the HCV. This made me cry because I had done interferon ten years ago, and because of that failure, I decided to ask for palliative care. But he assured me there was new treatment, and referred me to Dr. Hull. The result was I

just finished one looong year of triple therapy--Incivek/interferon/ribavirin--the hardest treatment I have ever done. This treatment was done by telephone and e-mail from my home in rural B.C., along with my heavy pill burden for HIV. It must be noted that the benefit for me being on palliative care was that the expensive treatment was covered under Pharmacare's palliative formulary. The nurse (my coach) kept up with me in constant contact all the way, and was the reason I was able to accomplish this, including the fact that I was treatment experienced. And my G.P. was so calm and unflappable, it rubbed off on me. I completed full-dose treatment almost 12 weeks ago on Salt Spring. The goal is SVR at week 24 post treatment. I'm waiting for my final results.

As a co-infected person, I experienced discrimination, first from my ASO (AIDS Service Organization), who does not see HCV as part of their mandate, and also from one of the Hep C clinics in Vancouver, because they did not have enough knowledge about HIV. I would not have received treatment if Dr. Montaner did not start the Hep C clinic in his office for us. The Hep C program at I.D.C. uses the same principle as TasP. They want the *virus* to walk through the door. They want to treat it, without discrimination as to which body it presents in. Montaner's goal is to work with HIV, and to do that, he needs to get rid of the HCV. The Hep C doctor uses the same approach, and they accept patients who are mono-infected without HIV. They just want to treat Hep C. I wish more people were aware of this, because they are on the cutting edge of the newest treatments, which can save lives and end suffering. My friend who went to the clinic was approved for treatment, but the cost is prohibitive. They are working on enrolling her in a study which will get her the drug at no cost. She is a long term survivor of chronic Hep C, one of those women who got it from blood transfusion while giving birth some thirty years ago. Her situation is dire. What Pharmacare must consider is the long term costs of people living with this disease, and the expense to them and hospitals for not covering it. It makes economic sense to eradicate this virus as soon as possible, and drug companies must stop being greedy, and have more compassion.

Cheers!
Bob

(REBUTTAL—Cont'd from p. 1)

developing world and distribution in Africa without any objection from pharmaceutical companies. (<http://www.pepfar.gov/>).

And just last week, on the eve of the 20th International AIDS Conference, Medicines Patent Pool announced the signing of a record seven new sub-licensing agreements between innovative pharmaceutical companies and generic manufacturers to speed the availability of more affordable HIV medicines to developing countries. (www.medicinespatentpool.org).

As the association for innovative pharmaceutical companies in Canada, we're proud of the role that the industry is playing to increase access to medicines to less developed nations around the world. Rx&D engages with its member companies and governments on an ongoing basis to enhance access to medicines and improve healthcare both here in Canada and across the developing world. We do this through longstanding partnerships with organizations like Health Partners International Canada and globally through individual company engagement in more than 220 programs and partnerships with governments, NGOs, and others in 160 countries around the world. The projects aim to increase access to medicines, train health professionals, build clinics, fund education, prevent disease and build healthcare capacity.

For more information about this work, please visit <http://www.canadapharma.org/en/making-a-difference/to-the-developing-world>.

(NEWS—Continued from page 1)

take to eliminate this scourge from the face of the earth. We want everyone who has the disease to be treated for it. Plain and simple.

We are given financial support from various pharmaceutical companies, it is true. We would rather be supported by government (impartially) or wealthy donors, but that isn't happening. We tell our funders that we are impartial and transparent, and they tell us that they, too, are bound by strict regulations imposed on them by the government and by RX & D, their umbrella organization. These regulations prevent them from determining our editorial policy—something we would never surrender in any case. Many times in the past, when the government sought to throttle us over the compensation issue, we held firm. We just about went broke, but hey, we're still here. So what can we say but that we will continue to present all sides of this healthy debate without apology in the hopes that honesty and integrity will prove useful tools in the eradication of hepatitis C.

Our financial reports are available by re-

quest at any time. We have one part-time employee. No one else gets paid, except for expenditures pre-approved by the Board and backed up with original receipts. Our reputation is important to us, and yes, we are proud of it!

DEAL WITH IT: Untold Stories of Hepatitis C in Canada

Deal With It, the exciting new one-hour film released by Bang Albino Films, is now available for rental on VIMEO for \$5.99 (24 hour period):

<https://vimeo.com/ondemand/dealwithit>

They'll be giving part of each rental fee to hepatitis C research and to support groups such as ours. Public showings with live forums are being planned in both Vancouver and Victoria—watch the Event Calendar at www.hepcbc.ca for dates/times.

VICTORIA OFFICE RE-OPENING:

HepCBC is re-opening its office in Victoria in August at #20 - 1139 Yates Street, Victoria, BC V8V 3N2. Office hours will be very limited (probably two afternoons per week) since it will be manned only by volunteers. We hope to have a GRAND OPENING sometime in September. Watch our website www.hepcbc.ca for details. If you are interested in becoming a HepCBC volunteer, find out how at <http://hepcbc.ca/volunteer/>. NOTE: this is also our new mailing address, but we will continue to monitor our old PO Box address for mail as well as it is listed on pamphlets, etc.

CHAT ROOM RE-OPENS

HepCBC has had a hepatitis C chat room for over a year at the British-based international HEALTH UNLOCKED portal (<https://healthunlocked.com/hepcbc/>).

However, we've all been too busy to get it going seriously. This is potentially a great way of connecting confidentially with people from all over the world with hepatitis C. There are now 43 members who need to be engaged by one or two really enthusiastic, dedicated leaders.

Are you interested in this sort of challenging volunteer job? If so, join HEALTH UNLOCKED (<https://healthunlocked.com/signup>) and become a member of our group, and start asking/answering/commenting/welcoming, etc. HepCBC has ADMIN privileges and will be monitoring, but if you do a great job, we may consider granting some ADMIN duties to you over time.

HepCBC's ANNUAL GENERAL MEETING Sept. 16, 2014 IN VICTORIA:

Mark September 16th on your calendar! We are delighted to announce this year's guest speaker is Gail Butt, PhD and RN, Associate Director, Hepatitis Services, BCCDC, and Clinical Assistant Professor, School of Nursing, UBC (now in the process of retiring, so we were lucky to talk her into this engagement!) Refreshments provided.

WHERE: Victoria's main Health Unit at 1947 Cook Street, Victoria, BC - Main Meeting Room. Doors are locked at this hour. Entry is at the side door, around the corner of building to the right. Parking on the street.

WHEN: Tuesday, September 16, 2014, 6 pm.

AGM MEMBERSHIP AUGUST 16 DEADLINE:

The AGM meeting is open to the public, but voting is only for members (must join minimum 30 days prior to meeting). Make sure your \$10 annual membership fee is paid by AUGUST 16th. Membership in HepCBC not only allows you to vote; it also makes you eligible to run for the Board of Directors and gives you a voice in the direction the organization is heading, its goals, and its methods. To join, go to: <http://hepcbc.ca/hepcbc-order-form/> You can pay online via credit card or mail a cheque (post by Aug. 16). Thanks!

FUNDING FOR HEP.C.BULL AND PEPPERMINT PATTI'S FAQs

We are pleased to announce that Bristol-Myers Squibb Canada is supporting HepCBC with \$5000 in 2014 specifically earmarked to help publish/distribute this monthly bulletin and to update/publish/distribute Peppermint Patti's FAQs. We have been supported this year as well by general educational grants from BMS, AbbVie, Gilead, Janssen, and Merck. We'd like to take this opportunity to thank everyone for their recognition of the work we do to bring the latest HCV treatment information via mail and the web to our very widespread community.

DALE: STILL IN KAMLOOPS AWAITING TRANSPLANT

Dale's support person says "Dale is back in the hospital with internal bleeding. He required a couple of blood transfusions. There has apparently been more communication

(Continued on page 5)

(NEWS—Continued from page 4)

with the Transplant Centre since this latest turn of events. He may receive a higher priority in the next few months and either start some form of treatment or receive a liver transplant." As you may recall, he was in a hepatic coma a few months back, but fortunately he came out of it though still, like most pre-transplant patients, suffers some hepatic encephalopathy. For a new HE treatment option, see page 1 article...And don't forget, if you live in Vancouver area, Dale and other patients like him from out of Vancouver area, need lots of support in Vancouver during and post-transplant. Karen Stacey and Happy Liver Society do as much as they can, but they really need more volunteers. Contact them via <http://www.happyliversociety.org/>.

WORLD HEPATITIS DAY IN BC...14 IN '14!



Warren Bailey of Vancouver Island Persons Living with HIV/AIDS Society, C.D. Mazoff of HepCBC, and Hermione Jefferis of AIDS Vancouver Island commemorate World Hepatitis Day 2014 in Victoria on steps of the BC Legislature Building

These are the 14 communities we have been told commemorated World Hepatitis Day 2014 - CONGRATULATIONS!

Abbotsford, Campbell River, Castlegar, Courtenay, Dawson Creek, Grand Forks, Kamloops, Kispiox, Nelson, Prince George, Smithers, Surrey, Vancouver, and Victoria. Send us your World Hepatitis Day 2014 photos and stories; we'll select the best ones for our next issue. If you marked the day and aren't on our list, let us know. And if you didn't mark the day, how about next year? It's a really good opportunity to let everyone know hepatitis B and C are international issues, that they are preventable, and that treatment is available (even a CURE for most with hepatitis C!).

WHD IN VICTORIA

AIDS Vancouver Island's Victoria office hosted an event with our community partners on Monday July 28th, from 4-5pm on the steps of the Legislature Building in down-

town Victoria, which included speakers, drummers, give-aways, and information about local HCV and HCV/HIV resources. The following day, Tuesday July 29th at 2pm and again at 7pm, AVI showed the new documentary about hepatitis C in Canada, 'Deal With It'.

"INTERFERON-FREE" NEWS

Until July 15th, ribavirin was only approved by Health Canada if it was co-packaged with pegylated interferon. But on July 15th, Health Canada announced its approval and market availability of the first Canadian stand-alone oral ribavirin for the treatment of chronic HCV. The drug, IBAVYR™ is made by Quebec-based Pendopharm, a division of Pharmascience Inc. This means some patients will be able to take an all-oral treatment, without interferon and all its associated complications.

"The approval of IBAVYR transforms the treatment of HCV as some patients will now be able to receive treatment regimens without the use of interferon, thus eliminating the potential side effects associated with interferon that often lead patients not to start, or [not] to complete, treatment," said Dr. Alnoor Ramji, Clinical Associate Professor of Medicine, Division of Gastroenterology, University of British Columbia. "IBAVYR will offer the opportunity for Canadian health care professionals to provide patients ribavirin as part of an all-oral treatment regimen that is well-tolerated, thus allowing more patients to be treated and to achieve viral eradication."

In the US, new guidelines from the AASLD recommend sofosbuvir and ribavirin as the preferred treatment for genotypes 2 and 3. In the near future, we expect that ribavirin plus sofosbuvir (or other similar new HCV drugs from AbbVie, Janssen, BMS, Merck, or others) will be recommended for use with genotype 1 as well. Stay tuned! Remember, however: ribavirin also comes with unpleasant side-effects, and none of these new treatment options are as yet covered by BC PharmaCare. More information:

<http://bit.ly/1qx08Hj>

On another front, on May 1st, Health Canada granted AbbVie "Priority Evaluation" status for its new HCV drugs, and on May 22nd, AbbVie filed a New Drug Submission to them for its all-oral, interferon-free HCV regimen for genotype 1, including those with cirrhosis. AbbVie's all-oral interferon-

free "cocktail" can be used with or without ribavirin, depending on patient factors. Stay tuned!

FREE JOURNAL ACCESS

To celebrate World Hepatitis 28th July 2014 the Expert Collection has provided free access to latest cutting edge review, editorial, original research and drug evaluation papers, from a collection of journals showcasing the latest trends in hepatitis treatment.

http://informahealthcare.com/page/WorldHepatitisDay?utm_source=Twitter&utm_medium=Tweet&utm_campaign=WorldHepatitisDay2014&

DID A HEP C DRUG KILL 15?

Fifteen patients died and over 2500 experienced serious side effects after trying Mitsubishi Tanabe's Teravic, announced news stories on July 26th. Most of those who died had cirrhosis, and the company had instructed doctors that the medicine should not be used by those with cirrhosis or liver cancer. The trial treated 11,135 patients since November 2011, and 23% complained of serious skin inflammation. Mitsubishi Tanabe has reported the side effects to the health ministry.

Source: www.japantimes.co.jp/news/2014/07/27/national/politics-diplomacy/15-die-taking-mitsubishi-tanabe-hepatitis-c-drug/#.U9U2FWPG_UY

HCV BENEFICIAL FOR TRANSPLANT PATIENTS?

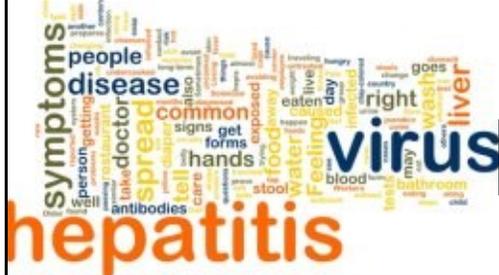
A new study from Munich, Germany, published June 25, found that HCV infection seemed to prevent rejection in half of 34 liver transplant patients. Up to now, transplant patients have used antirejection drugs after a liver transplant, suppressing the immune system and allowing the virus to flourish and damage the new liver. But if these drugs aren't given, the HCV may help the new liver to be accepted even more effectively than the anti-rejection drugs, since the virus itself suppresses the immune system in order to hide. The researchers think that HCV patients may be weaned off the anti-rejection drugs, but that hopefully, with the new all-oral antiviral drugs, liver transplants may no longer be needed. In the same publication, another study found that immune cells produced in a lab setting can treat up to 5 viral infections like herpes and Epstein-Barr, that can cause transplant rejections.

Source: [Hepatitis C Infection May Have 'Silver Lining' for Transplant Patients - WebMD](#) (Thanks, Darlene Morrow, for the link!)

YOUR ONLINE HEPATITIS C TREATMENT INFORMATION TOOLKIT
PACIFICHEPC.ORG/HEPCTIP



WORLD HEPATITIS DAY



WHD: AN OPPORTUNITY TO EDUCATE AND TO FIGHT STIGMA

On July 28th every year, people living with and fighting hepatitis B and C throughout the world joined hands to let others know of their struggles and how others can help them try to eradicate these two terrible diseases from the face of the earth. It was a wonderful opportunity to show the diversity of our faces and stories; nothing dissolves stigma faster than when a real person we can relate to replaces a negative stereotype in our minds, right?

This year HepCBC once again worked with other groups to organize and publicize World Hepatitis Day events throughout the province. Let us know what you did in your community. Many of the events were advertised in BC's three major newspapers. Last year 11 communities were on the ad. Of course, we're hoping to include more next year! The best events are educational, friendly, colourful, meaningful, musical, and tasty!

VANCOUVER WHD 2014 was the largest yet, held at the outside Georgia St. entrance to the Vancouver Art Gallery. Tents, tables, speakers, and music in the sun. The Planning Committee this year included representatives from First Nations Health Authority, BC Centre for Disease Control, HepCBC, SUCCESS (the major hepatitis B group in BC), and the Purpose Society.

We hope you will consider hosting a unique and wonderful event in your community next year, and let HepCBC know about it so we can add it to the list in the World Hepatitis Day ads. Start planning now! For ideas, go to <http://whdcanada.org/>

WHD IN WINNIPEG

For World Hepatitis Day, Manitoba MBHEPC planned their meeting at the TD Centre at Portage and Main, marching to the Legislative Building, where they had a podium set up for people to share their stories and to talk about the impact that HCV has had on their lives. WHD t-shirts were worn, and info was handed out along the way and

at the Legislative Building. Bianca Pengelly of the Liver Foundation planned the march and a number of our members participated.

Kirk (*Manitoba mbhepc.org*)

WHAT IS A FIBROSCAN?

FibroScan® is a procedure that can measure scarring (fibrosis) of the liver by testing the stiffness of the tissue. It was approved in April 2013 by the US Food and Drug Administration, stating "FibroScan® is indicated for the measurement of shear wave speed in the liver. The shear wave speed may be used as an aid to clinical management of patients with liver disease."

FibroScan® is painless, and takes only about 15 minutes. It is useful to judge the severity of damage to the liver and is often approved for treatment instead of biopsy. There is no danger of infection or death, and it is not invasive. Having a fibroscan is much like having an ultrasound, but with a "thumpy" feel to it, caused by the "shear waves." They measure how elastic the liver is, by using Vibration-Controlled Transient Elastography (VCTE). The higher the number, the more advanced is the fibrosis (scarring). The significance of the levels varies depending on the type of liver disease. When deciding whether or not the patient has cirrhosis, for example, the maximum level is lower with Hep C than for alcoholic liver disease.

FibroScan® is not as accurate as a biopsy for patients with mid-level liver disease, those with ascites, or those who are morbidly obese. (www.hcvadvocate.org/hcsp/articles/bonacini_2_fibroscan.html) See also: www.hepcbc.ca/fibroscan-alternative-to-biopsy/

FACTS OF THE MONTH

130-150 million people in the world have chronic Hep C.

350-500 thousand die yearly from Hep C-related diseases.

(www.who.int/mediacentre/factsheets/fs164/en/April 2014)

ACT UP BASEL

ACTIVISTS FOR ACCESS TO HCV TREATMENT FOR ALL

www.actupbasel.org/actupbasel/

SVR HONOUR ROLL

Have you responded to treatment and remained undetectable for a minimum of 12 weeks after finishing treatment? Celebrate and give others hope. Please take a minute to send us your info and we'll add your name (or initials). Congratulations to our friends:

1. **GJ** - SVR Dec 1998 - IFN/RBV 52 wks - Dr Anderson/Natalie Rock, Vancouver, BC.
2. **Amberose** - 2000 (GT 2A/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. **Beverly Atlas** - (GT1a) - 2005/2006 - Albuferon/RBV 44 wks
7. **Steve Farmer** - 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
8. **Gloria Adams** - (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks - Drs Erb & Yoshida, Vancouver, BC.
9. **Don Crocock** - (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 weeks
10. **Daryl Luster** - (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
11. **Donna Krause** - (GT1 partial responder) SVR - Nov 2011- Pegasys/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks - Dr. Erb, Vancouver.
12. **Cheryl Reitz** - (GT1b previous partial responder) SVR12 Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquiere, Victoria, BC.
13. **Anita Thompson** - (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
14. **Leon Anderson** - (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
15. **Joan King** - (GT1b treated 5 times) June 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
16. **Sandy J.** (GT 1a treatment naïve) Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. Now SVR24.
17. **Andrew P.** - (GT 1a treatment veteran - multiple previous attempts including Incivek over 10+ years.) Jan 2014. GS-7977/GS-5885 (Sofosbuvir/Ledipasvir) + RBV 24 wks
18. **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
19. **Coreen Kendrick** - (GT 1a treatment naïve) Mar 10, 2014 MK5172/MK8742 12 weeks Dr. Ramji, Vancouver, BC.
20. **Jack Swartz**—(Treated 3 times) Apr 2014 IFN/RBV/Victrellis, Dr. S. Wong, WHSC.

We know there are many more of you. Please send your name and info to Joan at info@hepcbc.ca

CONFERENCES

12-13 September 2014
AASLD/EASL Special Conference on Hepatitis C
Sheraton New York Times Square Hotel
New York City, New York
www.aasld.org/additionalmeetings/hcv/Pages/default.aspx

13 September 2014
Latin-American Association for the Study of the Liver (ALEH)
Cancun, Mexico
www.aleh2014.com/

13 September 2014
Prague Hepatology Meeting 2014
Prague, Czech Republic
www.congressprague.cz/en/kongresy/phm2014.html

17-19 September 2014
9th Australasian Viral Hepatitis Conference 2014
Alice Springs, Australia
www.clocate.com/conference/9th-Australasian-Viral-Hepatitis-Conference-2014/31436/

9-11 October 2014
Viral Hepatitis Congress 2014
Frankfurt, Germany
<http://www.viral-hep.org/>

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.

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.

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.

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.

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

LAW FIRMS

1986-1990

Bruce Lemer and Company
Vancouver, BC
Phone: 1-604-609-6699
Fax: 1-604-609-6688
www.lawyers-bc.com/classactions/clalawy.htm



Pre-1986/ Post-1990

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/class/settled/hepc/

Lauzon Belanger S.E.N.C. (Quebec)
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204
<http://lblavocats.ca/en/class-actions/hepatitis-c/active/red-cross.php>

Kolthammer Batchelor & Laidlaw LLP
#208, 11062 - 156 Street,
Edmonton, AB T5P-4M8
Tel: 780-489-5003 Fax: 780-486-2107
<http://www.kbllaw.com/>

LOOKBACK/TRACEBACK

Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056

Lookback Programs, Canada: 1-800-668-2866

Canadian Blood Services, Vancouver, BC
1-888-332-5663 (local 3467) or 604-707-3467

Lookback Programs, BC: 1-888-770-4800

Hema-Quebec Lookback/Traceback & Info Line:
1-888-666-4362

Manitoba Traceback: 1-866-357-0196

Canadian Blood Services, Ontario
1-800-701-7803 ext 4480 (Irene)
Irene.dines@Blood.ca

RCMP Blood Probe Task Force TIPS Hotline
1-888-530-1111 or 1-905-953-7388
Mon-Fri 7 AM-10 PM EST
345 Harry Walker Parkway, South Newmarket, ON L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/ 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
Ontario Compensation: 1-877-222-4977
Quebec Compensation: 1-888-840-5764

CLAIMS ADMINISTRATOR

1986-1990

Administrator 1-877-434-0944
www.hepc8690.com info@hepc8690.com

Pre-86/Post-90

Administrator 1-866-334-3361
preposthepc@crawco.ca
www.pre86post90settlement.ca

Settlement Agreement:
www.pre86post90settlement.ca/PDFs/SA/

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-2873

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more:

• **Campbell River:** Drop in, needle exchange, advocacy. 1371 C - Cedar St.

Contact leanne.cunningham@avi.org 250-830-0787

• **Comox Valley** Harm reduction, counseling, advocacy. 355 6th St., Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400

• **Nanaimo** Counseling, advocacy. 201-55 Victoria Rd. Contact Anita for details. 250-753-2437

anital.rosewall@avi.org

• **Port Hardy** (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shomcliffe Rd. Contact Tom, 250-949-0432 tom.fenton@avi.org

• **Victoria** Access Health Centre, drop in, disability applications, peer training. Support group Tues 12:30 PM, 713 Johnson St., 3rd floor, 250-384-2366 Hemi-one.jeffers@avi.org

ANKORS Hepatitis C Project (Boundary, Nelson, West Kootenay) Hep C Info, support for prevention, testing, treatment and living well with Hep C. Women's gathering monthly. 101 Baker St, Nelson.

Contact Laura 1-800-421-2437 250-505-5506 ankorshepc@ankors.bc.ca

Castlegar Contact Robin 250-365-6137 eor@shaw.ca

Chilliwack PCRS Hep C Prevention, peer support, harm reduction. Meetings 3rd Mon monthly, 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416. lbirdsall@pcrs.ca www.pcrs.ca

Comox Valley Positive Wellness North Island Treatment/Pre & Post-treatment Support Group 2nd & 4th Wed., 615-10th St, Courtenay. Lunch. Contact Cheryl 250-331-8524. Cheryl.taylor@viha.ca

CoolAid Community Health Centre, Victoria. Meetings each Wed 10 AM and Thu 1:30 PM. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz rmilne@coolaid.org for treatment or group info.

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231 dgrimmstad@shaw.ca

Cowichan Valley HCV Support Contact Leah 250-748-3432 r-lattig@shaw.ca

Haida Gwaii support. Contact Wendy wendy@wendyswellness.ca www.wendyswellness.ca

HepCBC info@hepcbc.ca, www.hepcbc.ca

• **Victoria Peer Support:** 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9AM-10PM.

• **Fraser Valley** Support/Info: 604-576-2022

Kamloops ASK Wellness Centre. Chronic illness health navigation/support.

info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098

www.askwellness.ca

Kamloops Hep C support group, 2nd and 4th Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cheri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support, meeting info. Contact Lisa 1-866-637-5144 ljmortell@shaw.ca

Mid Island Hepatitis C Society Contact mid-islandhepc@hotmail.com

Nanaimo Hepatitis C Support Meetings TBA Contact 250-585-3201 hepcxpeersupport@hotmail.com

New Westminster Stride with Purpose "HepC" Support Group 1st&3rd Fri monthly 10:30-11:30. BBP Nursing Team, refreshments/lunch. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

Positive Wellness North Island-North Island Liver Service Info, support, treatment/pre-post treatment groups. Doctor or self-referral. 1-877-215-7005 250-850-2605.

• **Courtenay:** 2nd Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)

• **Campbell River:** Treatment/pre&post-treatment support group 1st&3rd Thu monthly 10-12pm, Sunshine Wellness Centre, Discovery Room, Campbell River Hospital. Caroline: caroline.miskenack@viha.ca, 250-850-2620

Penticton & District Community Resources Society, Harm Reduction Program, Meetings every 2nd Tues, 12:30-1:30 PM. 330 Ellis Street. Contact Melanie: 250-488-1376 or 250-492-5814

Positive Haven Info, harm reduction, support, drop in, clinic. 10697 135A St. Surrey. Contact Monika 604-589-9004.

Positive Living Fraser Valley (Abbotsford) Hep C support, Drop-in centre #108-32883 S. Fraser Way, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or plfvcentre@plfv.org

Powell River Hepatology Service Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact Melinda 604-485-3310 Melinda.herceg@vch.ca

Prince George Hep C Support Contact Ilse ilse.kuepper@northernhealth.ca

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources Contact Catriona 604-886-5613 catriona.hardwick@vch.ca or Brent 604-740-9042 brent.fitzsimmons@vch.ca

VANDU The Vancouver Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061 vandu@vandu.org www.vandu.org

Vancouver HCV Support Contact Beverly 604-435-3717 batlas@telus.net

Vancouver Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211, or call 604-522-1714 (Shelley), 604-454-1347 (Terry), to talk or meet for coffee.

Vernon telephone buddy, M-F 10-6 Contact Peter pvanbo@gmail.com Tel. 250-309-1358.

YouthCO HIV/Hep C Society of BC. Drop-in T&W 12-3, Fri. 9-12. Call for appts M-F 10-6. 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart stewartc@youthco.org, Briony brionym@youthco.org www.youthco.org

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 ad-min@bloodties.ca

OTHER PROVINCES

ONTARIO:

Barrie Hepatitis Support Contact Jeanie for info/ appointment jeanievilleneuve@hotmail.com

Hamilton Hepatitis C Support Group 1st Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St, Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 mkowalski@hucchc.com

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange. 269 Main St. W, Suite 201, North Bay. Contact 705-497-3560, 1-800-387-3701 or hepccommcoord@gmail.com. www.aidsnorthbay.com

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, Teen Health Centre-Street Health Program Office, 711 Pelissier St., Suite 4, Windsor. Contact Andrea Monkman 519-967-0490 or hepcnetwork@gmail.com. <http://hepcnetwork.net>

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 hars@kingston.net www.hars.ca

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room, 659 King St. East (Enter off King St) Kitchener. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Hep C Support 186 King St, London. For those infected as well as affected by Hep C. Contact: 519-434-1601, 1-866-920-1601, www.hivaidconnection.com

Niagara Region Hepatitis C Care, Port Colborne and St. Catharines Clinics. Education, counseling, individual/group support, treatment, outreach, harm reduction. Contact 905-378-4647 ext 32554 HCCC@niagarahealth.on.ca www.niagarahealth.on.ca/services/hepatitis-c-care

Oshawa Community Health Centre Hepatitis C Team Drop-in, lunch provided each Thurs. 12-1 PM, 79 McMillan St. www.ochc.ca Contact 1-855-808-6242

Owen Sound Info, support. Contact Debby Minielly dminielly@publichealthgreybruce.on.ca 1-800-263-3456 Ext. 1257, 519-

376-9420 Ext. 1257, www.publichealthgreybruce.on.ca/

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700

healthline-peel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

Toronto CLF 1st Mon. monthly Oct.—June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932.

bpotkonjak@liver.ca

www.liver.ca

Thunder Bay Hep C support. Contact Sarah Tycholiz 807-345-1516 (or for 807 area only 1-800-488-5840)

Unified Networkers of Drug Users Nationally undun@sympatico.ca

York Region Hepatitis C Education Group 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 905-940-1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

QUEBEC:

Quebec City Region Contact Renée Daurio 418-836-2307 reneedaurio@hotmail.com

CAPAHC support group meetings 3rd Thurs. monthly 6-8PM, 5055 Rivard St., (Montreal) Contact 514-521-0444 or 1-866-522-0444

ATLANTIC PROVINCES

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767

Online Peer Support:

info@hepnns.ca

www.hepnns.ca

PRAIRIE PROVINCES:

Manitoba Hepatitis C phone and email support and outreach. Contact Kirk at info@mbhepc.org. Direct line: 1-204-231-1437

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E AB Assoc, 550 Allowance Ave. Contact 403-527-7099 bettvc2@hivnetwork.ca

To list Canadian groups here, please send details to info@hepcbc.ca by the 15th of the month. It's free!