

hepc . bulletin

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

STAKEHOLDER SUMMIT: ELIMINATE HEPATITIS C IN CANADA BY 2030

There is a sense of urgency building in the hepatitis C community. Each year, more people are contracting the virus than are being cured of it; more people are dying of HCV than of HIV; liver cancer rates are escalating, as is the need for liver transplants. Demand is growing for Canada to adopt a national "one-time-only" screening program for baby-boomers. Ironically, while several effective cures have been discovered, they remain out of reach to most of the 250,000 or more HCV+ Canadians. However *the elimination of hepatitis C in Canada by 2030 is possible if all stakeholders can find a way to work together towards that goal.* That was the premise of a Sept. 25-26, 2014 Canadian Liver Foundation's "Stakeholder Summit" which brought together twenty key representatives from government, research, the pharmaceutical and private insurance industries, liver-focused physicians' and nurses' groups, public health bodies, a national aboriginal health network, public and government relations agencies, three national and three provincial patient groups (including HepCBC), and one representative from the military. Among these were three people with "lived experience" with hepatitis C including myself. Our task was to answer this question:

"What should we be doing now and over the next 3 years to create a united front and a sense of urgency re: prevention, diagnosis and treatment of people with or at risk for hepatitis C, so that we can collectively drive the elimination of hepatitis C in Canada by 2030?"

Answers to this question were proposed collaboratively at every stage of our meeting, with all present giving feedback and suggestions for the group's consideration. A full and respectful dialogue resulted in many recommendations, including some which patient groups such as HepCBC will probably be supporting actively over the next sev-

eral years. Many of the stakeholders' ideas and suggestions are already being implemented piecemeal in parts of Canada. We agreed on the need to streamline our efforts, conserve limited funds, and avoid redundancy by copying or building upon what others are already doing which works, and to collaborate with other groups instead of competing with them for funding for the same project. We also agreed that garnering the essential broad support we'll need from the public and decision-makers to meet our 2030 goal will frequently mean "letting go of our own agendas" and "speaking with one voice". Below is a sampling of some of the steps which could lead to the eventual elimination of HCV in Canada. There were many more; these are the ones I felt were of most interest to HCV+ people and their caregivers.

- Screening and Prevention

Removing barriers to screening by using point of care testing when possible, increasing the number and type of testing places;

Be ready to endorse and support any broader (not based solely on obvious risk factors) **PHAC HCV testing guidelines** as soon as they are announced;

Developing appropriate **post-test counseling** for those who test positive, including

(Cont'd on page 3)

INSIDE THIS ISSUE

Stakeholder Summit / News	1
Order Form / Marathon	2
HepCBC Open House	4
WHD / Allison Crowe Benefit	5
Local Programs / SVR Honour Roll	6
Conferences / Care Programs	6
Compensation	7
Coming Up	8

HEP C IN THE NEWS

HCV SCREENING TEST FOR CANADA

Janssen Inc. produces simeprevir, an NS3 inhibitor proven very effective for genotype 1 patients, usually combined with pegIFN/RBV (pegylated interferon + ribavirin.) The company has found in the US that some patients don't respond as well to the drug, and those patients often have genotype 1a virus with a mutation called Q80K. The company doesn't want people to waste money on a drug that won't help them, so they have developed a screening test, together with our own BC Centre for Excellence in HIV/AIDS (BC-CfE), to be used in Canada. A similar test is already in use with US GT1a patients.

Dr Richard Harrigan, director at the BC-CfE and associate professor at UBC Faculty of Medicine, will lead the analysis of past blood samples to see how the virus has mutated over time in the Canadian population, to help make wise research and budgeting decisions.

Funding is being provided by Genome BC's User Partnership Program (UPP), designed to form partnerships helpful to BC's economy.

Is the Q80K test right for you? Ask your doctor. (Simeprevir is OLYSIO in US and GALEXOS in Canada)

Source: www.bcmj.org/blog/hepatitis-c-virus-screening-test-canada

VERTEX DROPS INCIVEK

Vertex, once a company providing much hope for those of us with Hep C, is no longer providing Incivek, one of the first two protease inhibitors approved in Canada after US and European approval in 2011, soon after the approval of Boceprevir. The drug will no longer be sold as of October 16, 2014, according to Vertex's Charles Johnson, vice president of global medical affairs. Those patients already taking the drug will be able to complete their treatment.

Worldwide, over 100,000 people have tried

(Continued on page 2)

SUBSCRIPTION/ORDER FORM

Please fill out & include a cheque made out to HepCBC - Send to our NEW address:

HepCBC
#20—1139 Yates Street
Victoria, BC V8V 3N2

Name: _____

Address: _____

City: _____ Prov. ____ PC _____

Home (____) _____ Work (____) _____

Email: _____

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Subscription Only\$10.00
(Doesn't include membership privileges)

Peppermint Patti's FAQ\$15.00

Resource CD\$10.00

Donation enclosed.....\$ _____

TOTAL: \$ _____

"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.)

You may also subscribe or donate on line via

PayPal at www.hepcbc.ca/orderform.htm

Download the *hepc.bull* free at

<http://hepcbc.ca/hepc-bull-monthly-newsletter/>

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

ADVERTISING: The deadline for placing advertisements in the *hepc.bull* is the 12th of each month. Rates are as follows:

Newsletter Ads: Maximum 4 per issue, if space allows. \$20 for business card size ad, per issue. Payments will be refunded if the ad is not published.

HOW TO REACH US:

EDITOR: _____
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Joan King
(250) 595-3892
(250) 595-3865
info@hepcbc.ca
www.hepcbc.ca

HepCBC
#20 1139 Yates St., Victoria, BC V8V 3N2

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.

MARATHON

Mark this date on your calendar:

October 12, 2014 is the date of the Victoria, 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

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!



HEPC CLINIC AT PERCURO

The Hepatology Clinic at PerCuro provides HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region, according to their individual needs. Specialized nurses help procure financial coverage for treatment, ensure lab tests are scheduled, teach self-administration of injectable medication, help manage side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding the patient's treatment and any other issues of concern.

This type of professional support is imperative 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

THANKS!!

Thanks to hepc.bull & FAQ sponsor Bristol-Myers Squibb.



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 Canada, Roche Canada, Vertex, Gilead, Janssen, Boehringer-Ingelheim, AbbVie, Rx&D, VanCity, Country Grocer, and Thrifty Foods.

(NEWS—Cont'd from p. 1)

it in the past 3 years, but new drugs with fewer side effects and better results have made it less popular. Patients seem to prefer Sovaldi (sofosbuvir).

Vertex will focus its efforts and expertise on cystic fibrosis. They announced last October that they would lay off about 370 employees. Even then, patients were waiting for the new drugs, simeprevir and sofosbuvir, approved in the US in November and December. In November, Vertex sold its rights to Incivek back to Janssen, and in May, announced it would stop all of its Hep C research and development. Vertex continues to support existing patients.

Source: Aug 12, 2014

http://natap.org/2014/HCV/081514_03.htm

ACH-3102 + SOFOSBUVIR = 100%

In a small Phase II trial, all 12 treatment-naïve GT1 patients taking Achillion's ACH-3102 (a 2nd generation NS5a inhibitor) plus sofosbuvir for only 8 weeks (no IFN or RBV) tested virus-free 4 weeks after finishing treatment (SVR4). "No on-treatment viral breakthrough or post-treatment viral relapse has been observed to date." There were no significant adverse events or abnormalities observed during treatment. The company is going to try for an even shorter treatment of 6 weeks, with 12 more patients. They are also combining ACH-3102 with their uridine-analog nucleotide, ACH-3422, in Phase I trials, paving the way for Phase II trials possibly this year.

Source:

http://natap.org/2014/HCV/081514_01.htm

(Continued on page 3)

(NEWS - Cont'd from page 2)

SOVALDI: 90% CURE RATE

Gilead's Sovaldi (sofosbuvir) is now covered by Florida's Medicaid. Treatment cost per patient runs about \$80,000. HMOs (US health maintenance organizations) had signed contracts of up to 5 years last November, with the Health Care Administration, when Sovaldi wasn't yet on the market. It was fast-tracked and approved by the US FDA in December. So the health plans are very worried. If even only 1/3 of the 300,000 infected in Florida got treated, the cost would be close to \$8 billion, some paid by the private sector, and some by taxpayers. The cost is great, but not compared to dealing with cirrhosis, liver cancer, and transplants in untreated patients.

Source: <http://health.wusf.usf.edu/post/medicaid-adds-1000-pill-drug>

HCV INFECTIONS AT 3 TORONTO CLINICS

Three colonoscopy clinics have had outbreaks of Hep C since 2011. The worst part is not that the infections happened, but that they were kept secret by the College of Physicians and Surgeons. Reporters obtained an admission from Toronto Public Health that eleven people were infected, presumably from contaminated vials of sedatives for colonoscopies. MPP France G elinas, health critic, says that these mistakes show that the College of Physicians and Surgeons is failing in its duty to be transparent and to demand quality of care. The critic says that if the first outbreak had been made public, the next two might not have happened. Another MPP wants hospitals to perform such procedures, rather than having them done at community clinics. Eric Hoskins, Health Minister, is looking for ways to improve protocols and inspection programs in those clinics.

Dr. Michael Finkelstein suspects that, since all three clinics were using multi-dose vials for anesthetics, the vials may have been contaminated, thus transmitting the virus between patients. Contamination of the endoscopes was ruled out. "Public Health Ontario, on its website, states 'unsafe injection practices' involving the vials can cause disease transmission. When a patient infected with hepatitis C is injected with medication, backflow of traces of blood can contaminate the syringe. When additional medication is then drawn from the vial and given to the same patient, the needle is often replaced, but the same syringe is used. The vial gets contaminated from the syringe, and the next patient to be injected with medication from it is then placed at risk." At least one of the clinics says

it is no longer using multi-dose vials. "Best practices for injection medication dictate use of single-use vials that are discarded after each procedure and in between patients."

Source: <https://twitter.com/theresaboyle/status/515864839848460288>

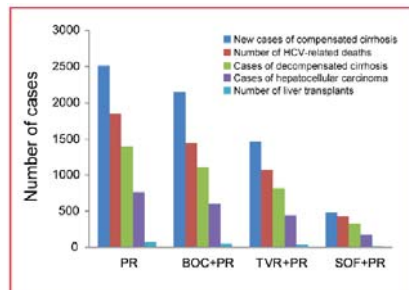
NEW TREATMENT SOF + PR: WORTH IT?

Most of us know how horrendously expensive the new treatments will be. Are they worth it? Investigations have been going on in several centres in the US to decide just that. Here's an example of one, summarized:

The US government worked with four hepatologists to crunch numbers using results from many previous phase III clinical trials and existing health-outcome data using a "Decision-Analytic Markov Model" to predict the actual health benefits of treating a typical group (17% cirrhotic, mean age 52) of Genotype 1 treatment-naïve patients with four different treatments: sofosbuvir (SOF)+PR for 12 weeks, telaprevir+PR for 24-48 weeks, boceprevir+PR for 28-48 weeks, and pegylated interferon + ribavirin (PR) for 48 weeks.

The SOF-based regimen produced the best results with the fewest complications, preventing the most cases of decompensated cirrhosis, liver cancer, liver transplant, and HCV-related death. SOF+PR patients had the greatest life expectancy and the best quality-adjusted life-years (QALYs).

Real-world results may differ from clinical trial results, but this model shows that the high treatment cost is offset by enhanced quality of life and lowered cost of treating advanced disease, making the treatment very cost-effective in a managed health care system.



Source: http://natap.org/2014/HCV/080814_04.htm

Reported by Jules Levin, NATAP

(SUMMIT —Cont'd from page 1)

providing them with a road-map to treatment, a health monitoring schedule, and ways (besides treatment) to live well with the disease, including referral to peer support. HepCBC would happily participate in such a project;

Using cultural and religious groups to spread the message about risk factors and testing, and to combat stigma and fear. HepCBC has been contemplating setting up a "Hepatitis C Speakers Bureau" for some time to speak at service clubs, refugee centres, and other groups, so it looks like the time is now ripe for this sort of initiative.

• Improving Patient Care

Identifying a **common core of patient needs** across the "HCV continuum of care" - including the burden of stigma, lack of trained medical practitioners, and high cost of treatment - while also identifying **special needs of higher-incidence subgroups** such as baby-boomers (divided into those newly-diagnosed, treatment-naïve, and treatment-experienced), immigrants from certain high-prevalence countries, aboriginal groups, youth, males who have sex with men, those co-infected with HIV, those living in remote, transitory, or Northern communities, persons who inhale or inject drugs, and prisoners;

Creating **culturally-appropriate, respectful, confidential programs and materials** based on the above needs, bearing in mind the wealth of pilot projects, studies, and materials already developed but not yet widely adopted or implemented. HepCBC will definitely look at adopting or adapting existing programs and materials whenever possible.

Organizing a **multi-disciplinary "health navigation program"** open to hepatitis C patients, especially those newly-diagnosed or undergoing treatment - involving medical staff and/or 'peer-to-peer' - via face-to-face, telephone, or online digitally-enabled content and interaction for those living in remote areas or in need of anonymity. Existing hepatitis C peer navigator programs of the Cdn Aboriginal AIDS Network, the Happy Liver Society, and the BC Centre for Excellence in AIDS are models other groups such as HepCBC can build upon. Funding, implementation, and penetration into rural/remote areas could be a challenge; this is a major area in which **collaboration among all the service providing groups would be essential.**

• Making Treatment Accessible

Treatment criteria such as having a minimum ALT score or fibrosis level (or to be

(Continued on page 4)

HepCBC's NEW OFFICE & BOARD

Great news from HepCBC: We opened our new office at 1139 Yates St. in Victoria (Room #20) on Sept. 16, 2014. We are only open one afternoon a week for now (Wednesdays between 1 pm and 5 pm). We hope to offer more extensive office hours in the near future. Hours posted on our website. We also had our 2014 AGM on the same day. Six out of seven of our 2014-2015 Board's Directors have lived experience with hepatitis C (three were successfully treated, while three await a cure). All five members of HepCBC's previous Board (Rosemary Plummer, Joan King, Wally Mutch, Cheryl Reitz, and Chaim-David Mazoff) agreed to stay on, plus we are delighted to warmly welcome two new members who bring fresh energy and ideas from their unique life experiences and talents: Allen McCulloch and Jenine Daubney.



#1. Our office welcomes all age cohorts! A young friend at the Grand (re-) Opening of HepCBC's Victoria Office on Sept. 16, 2014. Address: #20, 1139 Yates Street, Victoria, BC V8V 3N2.



#2. Think Before You Ink poster display at new HepCBC office



#3. There are 3 work stations at HepCBC's new office.



#4. Hepatitis C Awareness pins on top of filing cabinet, new HepCBC office.



#5-6: HepCBC welcomes new 2014-2015 Board members Allen McCulloch and Jenine Daubney! Credit-Photos #1-5: Jenine Daubney



#7. HepCBC Info Booth at the 3rd annual Vancouver Island Refugee Centre Society's (VIRCS) Multicultural Food and Health Fair. We gave out lots of hepatitis C information, much in translated pamphlets from CATIE.



#8. Two political figures visited our booth! From left: Haixia Liu (VIRCS staff person and wife of HepCBC Board Member), Cheryl Reitz (HepCBC Board Member), MLA Rob Fleming (Swan Lake area of Victoria), Victoria Mayor Dean Fortin, and Wally Mutch (HepCBC Board Member). Front, young friend.

(SUMMIT—Continued from page 3)

treatment-naïve or already failed treatment with interferon, etc.) and the long, involved federal and provincial new **treatment regulatory processes** are often considered barriers to treatment. However, this group focused primarily on the **barrier of cost** of the new Direct-Acting Antivirals. A very comprehensive **Disease Management Model** was proposed which could be used to present various cost-benefit analyses to Pharmacare programs and private insurance companies.

A **Treatment Network** of nurse-led clinics supported by industry and the provinces, and a **Provincial Patient Registry** (to collect data, and to keep in touch with untreated patients) was proposed. But of most interest to those seeking treatment was broad consensus among this group that **some form of "triage"** would be necessary over the short term at least – giving treatment first to those with the most severe damage, or most in danger of transmitting to others ("Treatment as Prevention" model). This group likewise stressed the need for all HCV stakeholders, not only pharmaceutical companies, to **compromise** in order to treat everyone in Canada by 2030. This would likely limit, or at least delay, treatment to many of our members. Realizing this assessment was so broadly-held was a bitter pill for me to swallow.

The bright side was that most present endorsed the idea that the most likely way of getting payers to cover treatment for all would be to **frame it as a justice or equity issue**. HepCBC has and will continue to advocate using the argument that denying those who cannot afford it coverage for treatment of a life-threatening disease creates a **two-tier healthcare system**.

- Research and Knowledge Translation (making research results understandable and accessible to Health Care Providers)

Roles of doctors and nurses are changing with the new DAAs, and will change even more, once anticipated widespread testing identifies many more baby-boomers with the disease. **Shorter treatment times and fewer side effects** should reduce the nursing time needed per patient. However new challenges will be the **far greater number of patients**, and the added need for nurses to **help arrange funding** to cover the drugs prescribed. Gastroenterologists acknowledged the need for greater future involvement of **infectious disease specialists and GPs** in the identification and treatment of HCV. Nurses and doctors adopting these new roles will need training and support.

At present, the only factor now showing up

(Continued on page 5)

MORE WHD VANCOUVER PHOTOS!!



Gloria Nahanee of Squamish Nation at Welcoming Ceremony with World Hepatitis Day (WHD) Vancouver 2014 Master of Ceremonies, Sandi Mitchell of BC Centre for Disease Control. July 28, 2014.



Dr. Mel Krajden of BC Centre for Disease Control speaking at WHD Vancouver 2014
Photo credit: ALP.



Dr. Edward Tam of the LAIR Centre speaking at WHD Vancouver 2014.



Anita York, Co-Chair of WHD Vancouver 2013 and Chair of WHD Vancouver 2014 and HepCBC Volunteer: Anita also has organized the Cheering Stations for the Liver Warriors marathon team and delivers pamphlets by handcart to many Vancouver doctors' offices. She starred in the movie DEAL WITH IT: Untold Stories of Hepatitis C in Canada. This lady is totally amazing; THANK YOU, Anita! Photo Credit: ALP.



Deb Schmitz of Pacific Hepatitis C Network and Rosemary Plummer, RN, President of HepCBC relax following WHD Vancouver 2014.



Daryl Luster, President of Pacific Hepatitis C Network and Anita York, Chair of WHD Vancouver 2014 share a laugh at the end of the big day.

ALLISON CROWE TIDINGS BENEFIT CONCERT November 29, 2014 7:30-9:30 pm



Charlie White Theatre,
Mary Winspear Centre
2243 Beacon Avenue
Sidney, BC V8L 1W9

\$25 general - advance
\$20 students/seniors - advance
\$30/\$25 at door
Cheryl: 250-595-3892

TICKETS:

[https://tickets.marywinspear.ca/
TheatreManager/1/login&event=648](https://tickets.marywinspear.ca/TheatreManager/1/login&event=648)

MORE INFO:

[http://hepcbc.ca/event/allison-crowe-tidings-
benefit-concert/](http://hepcbc.ca/event/allison-crowe-tidings-benefit-concert/)

(SUMMIT—Continued from page 4)

in cost-benefit analyses is that of systemic healthcare costs. More research may also be needed into how treatment affects long term non-medical factors such as patients' and their caregivers' **long term productivity and socio-economic status**, mental health, and impact on family life.

- Formulating/Implementing a coordinated federal/provincial/territorial Action Plan

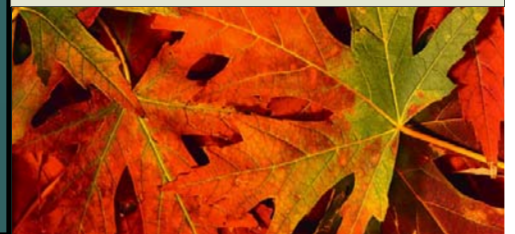
The need for a **hepatitis C political agenda** is clear, as the lack of coordination among the provinces and the federal government is a major barrier to testing and treatment. HepCBC will be challenging politicians at all levels of government to **frame the elimination of HCV from Canada's population by 2030 as a healthcare equity/fairness issue.**

- Public Awareness and Creating a Sense of Urgency

Only if we can gain the support of voters and taxpayers, will hepatitis C stakeholders be able to convince politicians to support all of the above proposed programs. To this end, they suggested a variety of **multimedia public awareness campaigns** using local and national celebrity hosts, and having both celebrities and 'ordinary people' living with hepatitis C tell their compelling stories. Major all-Canada **campaigns should be built around "milestones"** such as World Hepatitis Day 2015 (July 28th), the anticipated announcement of baby-boomer testing, or the approval of a new treatment. HepCBC would like to help out by asking for people with lived experience to step forward to **share their stories**, or to **invite local celebrities to act as emissaries** for hepatitis C testing and treatment.

That's about it. Stay tuned for a report of the November 6-7, 2015 conference I will attend in Toronto on the "**1st International Meeting on Hepatitis Cure and Eradication**"! This will deal with the needs of the entire 180 million or so people now living with hepatitis C. It will definitely be interesting to see if the solutions we've proposed for Canada are considered relevant on the international level.

Author: Cheryl Reitz, Secretary of HepCBC Board and HepCBC's representative on Action Hepatitis Canada's Steering Committee.





VANCOUVER INFECTIOUS DISEASES CENTRE - VIDC

We are the largest centre in Canada for the treatment of HCV in active IDUs, and participate in most of the clinical trials of new antiviral agents. We have developed unique ways of engaging IDUs in care and getting them on trials through our innovative "pop-up" clinics on the Downtown East Side of Vancouver.

Vancouver ID Centre

201-1200 Burrard St
Vancouver, BC V6Z2C7
Telephone: 604-642-6429
(Trials for IDUs, "Pop-up" Clinics)
www.vidc.ca

TORONTO COMMUNITY HEPATITIS C PROGRAM

955 Queen Street East
Toronto, M4M 3P3, ON
(416) 461-1925

This program is for hepatitis C-positive people who have had difficulty accessing treatment and care for their Hep C. Priority is given to people who are uninsured, use substances and/or have mental health issues. The program is centered on group support. People attend a weekly group focused on information about HEP C, treatment and healthy living. TTC and food are offered. The group is a closed group and runs on a 16 to 18-week cycle. The Hep C Clinic runs at the same time.

Hep C Patients can have access to:

- Physicians
- Hep C Treatment Nurse
- Nurses
- Case Manager
- Infectious Disease Specialist
- Psychiatrist
- Hep C Coordinator
- Hep C Community Support Workers.

We offer:

- Hep C information and treatment
- Advocacy
- Support
- Informal counseling
- Harm reduction counselling and supplies
- Group support
- Patient accompaniments
- Referrals to doctors, nurses, counselors / case managers, detoxes, housing workers and shelters

Please contact:

Hepatitis C Treatment Nurse
Shannon Taylor
416-461-2493 ext. 846
staylor@srhc.com

HEPATITIS C CIRRHOSIS SUPPORT GROUP

By 2013 my HCV related liver damage had progressed to compensated cirrhosis. I have just completed 48 weeks of interferon, ribavirin and Boceprevir and was undetectable at end of treatment. We still live with liver damage though which motivated me to form a group on Facebook for those dealing with end stage liver disease. The privacy settings are at maximum that FB offers so it is a "secret" group and will not show up on FB search engines and no one outside of group members will see what you post.

Here is the description:

Hepatitis C Cirrhosis Support is a secret group for people living with Hepatitis C stage 4 & 5 compensated and decompensated Cirrhosis, end stage liver disease and liver cancer. Anyone infected with HCV is welcome. Please introduce yourself when you join us and share what you are comfortable with. Ask any questions you may have and we will do our best to help. We are all in this together.

The group link does not show on Facebook unless you are a member. Please e-mail me to be added.

wendy@wendyswellness.ca

Thanks.

Wendy Mackay
Haida Gwaii
B.C.

www.wendyswellness.ca

MANITOBA CLF PRESENTS UPCOMING SPEAKERS:

October 2nd. 1:30 – 3:00pm. *Dr. Reece Malone* speaking. Contact the Canadian Liver Foundation for location.

October 9th. 1:30 – 3:00pm. *Pharmacy Intern* speaking about Liver Disease itchiness and over the counter prescriptions. In the Isabelle Stewart Building.

November 20th. 1:30 – 3:30 pm. *Dr. Wong* speaking. In the Reh-Fit Center (1390 Taylor Ave.)

These are open events!

Bianca Pengelly
Regional Coordinator,
Manitoba

Phone: 204-831-6231
bpengelly@liver.ca
375 York Avenue
Suite 210
Winnipeg, MB R3C 3J3
Website: www.liver.ca



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 send us your info. 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 (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 - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whiteby, 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 treatment veteran - multiple previous attempts including Incivek over 10+ years.) Jan 2014. GS-7977/GS-5885 (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.

Please send your name and info to Joan at info@hepcbc.ca

CONFERENCES

5-6 November 2014

1st INTERNATIONAL MEETING ON
HEPATITIS CURE & ERADICATION
Toronto, Ontario

www.virology-education.com/event/upcoming/1st-international-hepatitis-cure-eradication-meeting-2014/

7-11 November 2014

AASLD - The Liver Meeting
Boston, MA
www.aasld.org

12-13 January 2015

8th Paris Hepatitis Conference
Palais Des Congrès
Paris, France
www.aphc.info/home.php

12-15 March 2015

24th Conference of APASL
2015 Istanbul
www.apasl2015.org/

25-28 June 2015

The Global Viral Hepatitis Summit
15th International Symposium on Viral Hepatitis
and Liver Disease (AASLD Endorsed)
Berlin, Germany
www.isvhld2015.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.)

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 can call 1-844-602-6858 Monday – Friday 7am to 11pm EST.

COMPENSATION

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

URGENT NEWS: SEE PAGE 1 in SEPT 2014 ISSUE

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

Pre-86/Post-90
Administrator 1-866-334-3361
preposthepc@crowco.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, counselling, 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

Central Island Hepatitis Service: Nurses and doctors available to provide info, support and treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-260

Chilliwack PCRS Hep C Prevention, peer support, harm reduction. Meetings 3rd Mon monthly, 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416 birdsall@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 dggrimstad@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 Cherri 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 - Central Island Hepatitis Service: Nurses & doctors available for info, support, treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-260, sarah.hughes@viha.ca or shelby.munk@viha.ca

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 balas@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 stewart@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. E 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 dminiel@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

healthlinepeel@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

Manitoba CLF each Thu 1:30-3. 375 York Avenue, Suite 210, Winnipeg, Contact Bianca 204-831-6231 bpengelly@liver.ca

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 bettyc2@hivnetwork.ca

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