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Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HCV-RELATED CIRRHOSIS PREVALENCE INCREASES OVER TIME

A new study from Stanford University shows that the rate of cirrhosis found among patients with hepatitis C virus infection increased over time, including those individuals who were unaware they had hepatitis C.

"The number of Americans who have cirrhosis from chronic HCV infection has increased over time, due to aging of the baby boomers with hepatitis C. These data emphasize that healthcare providers should practice the CDC recommendation to screen individuals born between 1945 [and] 1965," W. Ray Kim, MD, professor of medicine, division of gastroenterology and hepatology, Stanford University School of Medicine, told Healio.com/Hepatology.

"Most patients with chronic hepatitis C infection are asymptomatic," Kim said. "Importantly, the proportion of people with cirrhosis was the same between hepatitis C-positive individuals who were aware of their infection and those who were not," adding that chronic HCV is now curable, therefore improved outcome can be expected from a prompt screening and appropriate treatments.

<http://goo.gl/LLknOY>

CT SCANS: ANOTHER TRANSMISSION ROUTE

Israeli health officials say they are investigating a possible link between an outbreak of hepatitis C in Jerusalem and a CT scanner at a small hospital in the city.

Five people have been diagnosed with hepatitis C in recent weeks, all of whom went through a CT scan at the Misgav Ladach hospital on March 17 and who were given a contrast medium fluid.

The CT scanner at the hospital has been shut down, according to Channel 10 news, which notes that 38 people were checked by the device on March 17, including 12 who were given contrast mediums.

<http://goo.gl/FKNXnD>

STUDIES SHOW THAT CURING ADVANCED HEPATITIS C REVERSES THE NEED FOR TRANSPLANT

Two recent studies have demonstrated that curing hepatitis C in people on transplant lists who have decompensated cirrhosis can reverse liver disease to the extent that many patients can be taken off the list.

In the first study, from Canada, researchers with the Multi-Organ Transplant Program at London Health Sciences Centre and the Lawson Health Research Institute have been able to remove one-third (33 per cent) of patients from the active liver transplant waiting list by "curing" them of their hepatitis C disease. This is the first Canadian data that demonstrates the benefit of treating and curing patients with the hepatitis C virus (HCV) in advanced stages of liver disease who have also been assessed for, and would otherwise have received, radical and life-saving liver transplantation.

In this clinical study, 23 patients with advanced liver disease from HCV were identified as candidates for liver transplantation. All patients were prescribed oral antiviral (sofosbuvir-based) treatment regimens. At the time of the interim results, 13 patients had completed HCV treatment and

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HEPCBC PARTICIPATES IN REVIEW OF BC CENTRE FOR EXCELLENCE IN HIV/AIDS

On May 17, 2016, HepCBC participated in an "External Review" of the BC CfE (BC Centre for Excellence in HIV/AIDS – which also covers hepatitis C) in Vancouver. Before going to this panel, we prepared a "wish list" of things HepCBC would love for BC CfE to do. Please read it and let us know if you have anything to add – or if you think we got it wrong.

HepCBC has often publicly called out the BC CfE for focusing on the needs of current users of IV or inhaled drugs (less than 20% of those with HCV), men who have sex with men (MSM), and those co-infected with HIV (less than 5% of those with HCV) while ignoring the great majority of people with HCV who either never used these drugs – or no longer do so, are not MSM, and do not have HIV. BC CfE is known as the centre for the Treatment as Prevention (TasP) model in which people who are currently engaging in "risky behaviours" are cured of hepatitis C in order to prevent transmission to others, a key component of the "public health" model which is focused on prevention rather than curing disease.

However on April 25, 2016, at a conference and in a press release a week later, Julio Montaner, director of the BC CfE, acknowledged that Baby Boomers are particularly at risk of morbidity and mortality (M&M) from HCV and should be offered a cure, as they are more at risk than younger people of severe morbidity and death from the disease. We welcome the acknowledgement of TasP of M&M as well as TasP of Transmission.

As an HCV grassroots patient organization (mostly volunteer-run for over 20 years and un-supported by any government funding whatsoever), HepCBC has been advocating for this very thing since "day one," and will be delighted to work with BC CfE if HCV TasP of M&M is added to BC CfE's "high priority" list.

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

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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.

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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.

(REVERSING NEED FOR TRANSPLANT—from page 1)

10 additional patients were soon to complete HCV treatment.

Of the 13 patients who had completed HCV treatment, nine patients had achieved a cure of their chronic hepatitis C (SVR 12), and four more had completed treatment and were pending (sic) a result to confirm a cure (SVR 12). Of the nine cured patients, three (33 per cent) were removed from the liver transplant list due to the vast improvements in their disease severity scores. No significant adverse events were reported. <https://goo.gl/KK6MLA>

The second study, presented at The International Liver Congress 2016 in Barcelona, Spain, demonstrates that patients on the liver transplant list with hepatitis C virus (HCV) and severe liver damage were more likely to be taken off the list or have their need of a liver transplant reduced as a result of direct-acting antiviral therapy.

The study showed that the condition of 35% of these patients improved to such an extent that they were no longer considered in urgent need of a transplant, while 20% of the patients no longer required a liver transplant at all.

Severe liver damage, also known as decompensated cirrhosis, is a life threatening condition in which extensive scarring of the liver results in its inability to function properly. The only treatment currently available for decompensated cirrhosis is a liver transplant. Patients with decompensated HCV cirrhosis comprise 30% of adults on the liver transplant waiting list. There are over 8,500 people in Europe and over 15,000 people in the United States waiting for a liver transplant, with this number expected to increase. Furthermore, in the United States approximately 16% of

(Continued on page 4)

HEPATIC ENCEPHALOPATHY DRUG TO BE COVERED IN ALL PROVINCES EXCEPT BC: A CALL TO ACTION

Anyone who has experienced "brain fog" knows the fear that this debilitating condition could actually get much worse, and what that could mean to our lives, our jobs, and our families. When the liver can no longer process toxins, they have nowhere to go and build up in the blood, finally ending up affecting the brain. The most severe form of this is hepatic encephalopathy (HE): a toxic mix of confusion, irrationality, and forgetfulness which can eventually lead to coma and death. It is associated with end stage liver disease. If caught early enough and controlled through medication, the damage can be stopped and in many cases permanent damage reduced and the condition reversed so that patients can return to their normal lives and jobs. Medication can keep people from suffering permanent brain damage and death while awaiting a liver transplant or while on treatment.

The medication which is most commonly used for HE is lactulose, now covered by PharmaCare. But there is another medication, slightly more expensive, which can be used either in those individuals who cannot tolerate lactulose, or for whom it does not work, or even in combination with lactulose to increase the positive effect. This medication, Zaxine™ (rifaximin) made by Lupin Pharmaceuticals, has been used for several years in the USA, and has been approved for sale in Canada since November 2013. It has completed the negotiation with the Pan-Canadian Pharmaceutical Alliance and is now covered by PharmaCare in Saskatchewan, Newfoundland, Nova Scotia and Quebec; all the other provinces are on track to reimburse Zaxine soon EXCEPT BC! We do not know why this is the case, and urge you to tell your doctor and your MLA that BC patients and their families want this product to be covered by BC PharmaCare as soon as possible for cases of hepatic encephalopathy. If more peo-

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BRITISH COLUMBIA
CENTRE for EXCELLENCE
in HIV/AIDS

Stigma is a huge barrier to testing and treatment, and finding stigma-free ways to reach infected people is a critical issue. Focusing on age-cohort (i.e., 1945–1975) screening is a stigma-free method of engaging into care the 75% of Canada’s HCV+ population most at risk of dying from HCV, no need to question whether they fall into a behavioural risk-group, or a particular cultural group, or whatever. Note that one problem with simply adding the issue of HCV in an age cohort group to the BC CfE mandate is that, due to BC CfE’s history with HCV, it could further reinforce widespread stigmatizing associations between hepatitis C and IV/snorted drugs, addiction, rough sex, and HIV. Perhaps an organizational name change or some sort of sub-division into a dedicated group called “BC CfE in HCV” could prevent such an automatic mental association.

HepCBC would like to see **close collaboration** among all of these partner-groups with the **goal of eliminating HCV by 2030, starting in British Columbia:**

- BCCDC’s “BC Hepatitis Services” group in a leadership role (respected for its steady surveillance, research, and educational outreach record)
- BC CfE in an advocacy role (good research and treatment model with HIV, experience with vulnerable populations, loud and charismatic voice)
- All health authorities including the various aboriginal health authorities
- Patient support and patient advocacy groups at local, regional, national, and international levels

- Immigrant service and support organizations
- Aboriginal groups such as CAAN and Pauktuutit
- Prisoner advocacy groups such as PASAN, John Howard, and Elizabeth Frye
- Nurses groups, especially CAHN
- Physician groups, especially CASL, CAG plus Infectious Disease, General (GP) and Family Practice groups
- University researchers
- Co-morbidity groups such as Cancer, Kidney, and Diabetes foundations

We would like to see them **collaborate closely** on these activities in particular:

- Ensuring Treatment as Prevention of BOTH transmission and M&M
- Broader screening to include BOTH cohort-based and risk-based criteria
- Supporting advocacy for BOTH lower HCV treatment criteria (or eliminating criteria entirely) and lower HCV drug prices
- Using 2 different HCV “Cascades of Care”: one for “Prevalent” cases such as most Baby Boomers (emphasizing urgent one-time screening at population level, engagement in care and treatment), and the other for “Incident” cases such as “Core Transmitters” (emphasizing engagement in lifestyle changes to prevent re-infection and transmission—as well as treatment followed by regular testing).
- Fostering greater HCV Treatment Equity between Rural/Remote and Urban areas through use of teams of rural/remote GPs, Nurses, and even Community Health Representatives (CHRs) working with Urban HCV Specialists through Telehealth in implementing Professional Development (education),

Patient Diagnosis, and Consultation technologies.

NO MORE STUDIES; we can do this now! Lives are at stake.

The 2-day review was led by Dr. Robert Sindelar of Providence Health Care Research Institute. The 35-minute hepatitis C-themed panel on which we participated was led by Mark Wainberg, Head of HIV/AIDS Research Axis and McGill University’s AIDS Centre; it also included Perry Kendall, BC’s Provincial Health Officer; Research Consultant Don Avison; and Martin Gleave, Executive Director of Vancouver Prostate Centre (by phone). Other organizations participating in the hepatitis C part of the panel included Pacific Hepatitis C Network, Canadian Liver Foundation, GI Society, Pacific AIDS Network, and S.U.C.C.E.S.S.

(HEPATIC ENCEPHALOPATHY)—from page 2)



ple are aware of this new drug and asking why it is not covered, it is more likely that decision-makers in BC’s government will realize the importance of approving new HE medications for people’s lives.

More information about Zaxine™ (rifaximin) and HE:

- <https://www.costcopharmacy.ca/HealthInformationDrug.aspx?id=6540>
- https://www.cadth.ca/sites/default/files/cdr/complete/cdr_complete_SR0388_Zaxine-Apr-20-15.pdf
- <http://hepcbc.ca/2015/10/01/decision-new-hepatic-encephalopathy-drug/>

THANKS!!

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



HepCBC has had “Hepatitis C Info Tables” at an average of 2-3 events every month recently. Check out our “Upcoming Events” calendar on our website for a Canadian Assn. of Retired People (CARP) booth in Richmond on June 25, an all-day booth at Vancouver’s Metrotown Mall on June 30th, and in July, booths at the end of both Victoria and Vancouver Pride Parades! If you’d like to VOLUNTEER at an event, that would be great! Just let us know through the www.hepcbc.ca



Board Member Andrew Pugh distributing “Baby Boomer testing” information at Zoomer Show

www.hepcbc.ca CONTACT US page



HepCBC Volunteer Kathy Wainwright handing out pamphlets and great advice at the Vancouver “Zoomer” Show March 19/20, 2016

NEW NCCIH CLINICAL DIGEST: HEPATITIS C AND DIETARY SUPPLEMENTS

The National Center for Complementary and Integrative Health (NCCIH) has just released the latest information on hepatitis C and dietary supplements.



Milk Thistle

Some people with hepatitis C try complementary health approaches, especially dietary supplements. Several herbal supplements have been studied for hepatitis C; however, no dietary supplement has yet been shown to be effective for hepatitis C or its complications.

- For Consumers: [Hepatitis C: A Focus on Dietary Supplements](#)
- For Health Professionals: [Hepatitis C and Dietary Supplements](#). This issue provides information on the evidence base of several dietary supplements studied for hepatitis C.

(REVERSING NEED FOR TRANSPLANT—from page 2)

patients will die while awaiting a liver transplant.

“The results of the study are very encouraging, but a word of caution is to be mentioned since it is presently unknown how long the clinical improvement will last,” said Dr Luca Belli, Gastroenterology and Hepatology Liver Unit, Niguarda Hospital, Milan, Italy and lead author of the study. “In this respect we encourage multinational observational studies on patients who have been listed for decompensated HCV cirrhosis and subsequently de-listed because of clinical improvement. It is in fact critical to assess the long-term risks of death, further re-deterioration and development of liver cancer more specifically, as all these factors still need to be verified.”

<http://goo.gl/LEN5Lq>



THE \$1500 CURE

In May 2016 Phillip Smith, editor of the *AlterNet Drug Reporter* and author of the *Drug War Chronicle*, published his account of how he finally got cured for only \$1500 US after running around trying to get his health insurance to pay for his treatment. Even though he is covered by a new Affordable Care Act insurance plan, Phillip was told that he was not sick enough and that he would have to wait. Furthermore because of his deductible, if and when his insurance company decided to treat him it would still cost him “\$6000 in out-of-pocket costs.”

So Phillip turned to the internet and found lots of online vendors of legitimate generic Harvoni in India. He went with a company called *Care Exim*, which offered the pills for \$1,500. The ordering process was complicated and he was really worried that he would be scammed, but it all turned out okay, and as he says:

I paid my money and I took my chances. The package arrived in nine days, untouched by customs. There were indeed three bottles of pills labeled as Hepcinat LP manufactured by Natco, with seals and even a folded paper insert with all the drug information on it. I took the pills for 83 days (saving one for possible testing just in case), waited a couple of weeks, then went to my doctor and had my blood drawn. The following week, he reported that my hepatitis C viral load was now zero. I was cured.

Phillip is really happy that he is cured but is left feeling quite “bilious about the U.S. health-care system in general and the role of privately owned pharmaceutical companies in particular. I had health insurance, yet it proved useless. Hell, I could have flown to India and stayed for three months and taken the pills for less than what it would have cost me to get Harvoni through my insurance company, if it would cover it at all, if I waited for my liver to be damaged first.”

Read more: <http://www.alternet.org/personal-health/84000-hep-c-drug-only-1500>

PHOTOS NOW ONLINE of HepCBC's OUTREACH ROADSHOW to RURAL and REMOTE BC

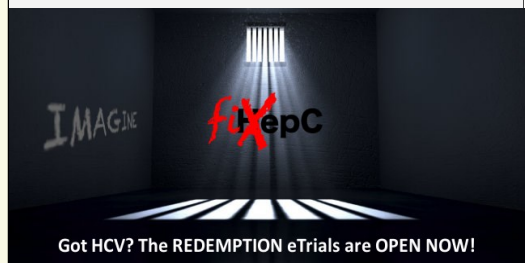
In April-May 2014 HepCBC sent 2 nurses (Fran Falconer and Rosemary Plummer) and 1 hepatitis C survivor (Cheryl Reitz) on a Hepatitis C Outreach ROADSHOW Trip to northern BC. We drove 5600 km in 18 days, making 21 formal presentations in rural and remote locations (plus another 16 informal ones).



Our T-shirts read:

“Williams Lake to Bella Coola...Prince George to Kitimaat Village” and “No Community TOO SMALL or TOO REMOTE for HEPATITIS C – Get tested. There is a cure!”

We have made available an online presentation of our trip with photos at the link below. We invite your comments and questions: <https://goo.gl/TQAxMx>



ARE YOU A POTENTIAL HEPCBC BOARD MEMBER?

HepCBC has some directors that are approaching the age of retirement, and we are hoping to find some dedicated, passionate, (and younger!) people willing to step up and take over their jobs. In particular we hope to find directors who are good at working together on a team to get important stuff done, and who are prepared to make a long-term commitment. Either lived experience with HCV or a medical background involving HCV are "pluses" but not required.

We are also seeking people with experience or background in advocacy at local, provincial or higher levels; grant-writing; public relations; scientific research; and doing outreach into a variety of affected communities including immigrants from various HCV-endemic countries, aboriginal and rural/remote communities, people in recovery, and seniors.

We do our monthly board meetings via Skype, so it is not necessary to live in a particular part of the province to be a board member.

Please let us know if you are interested through www.hepcbc.ca Contact form.

Thanks!



SVR HONOUR ROLL

Have you been undetectable for at least 12 weeks after treatment? Encourage others. Add your name! Congratulations to our friends:

1. **GJ** - SVR Dec 1998 - IFN/RBV 52 wks., Dr. Anderson /Natalie Rock, Vancouver, BC.
2. **Jeanie Villeneuve** - Oct 2000 - Schering IFN/RBV
3. **Amberose** (GT2a/2c) - SVR 2000 - Schering IFN/RBV 24 wks.
4. **KG**-Transfused 1987 (treatment-naïve GT2A/2C) IFN/RBV 24 wks., 2003-2004, Toronto. SVR confirmed 2014
5. **[NEW] Murray Palmer** (GT1a) Transfused. SVR 2003 - Rebetrone 48 wks (cleared at 24 wks.) SVR confirmed 2010.
6. **Darlene Morrow** (GT1 relapser) - Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.
7. **Kirk Leavesley** (GT1) - 2004 - Roche
8. **Beverly Atlas** (GT1a) - 2005/2006 - Albuferon/RBV 44 wks.
9. **Steve Farmer** (Transplant Vancouver 2005) IFN/RBV 72 weeks. SVR 2008
10. **Gloria Adams†** (GT1b relapser) - Fall 2009 IFN/RBV/telaprevir 48 wks., Drs. Erb & Yoshida, Vancouver, BC)
11. **Don Crocock** (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 wks.
12. **Daryl Luster** (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
13. **Donna Krause** (GT1 partial responder) SVR Nov 2011- Pegasys/Copegus, danoprevir/ritonavir/RO5024048 24 wks., Dr. Erb, Vancouver.
14. **Hermione Jefferis** (GT1a) - SVR 2011, PegIFN/RBV, 48 wks., Dr. Partlow, Victoria, BC
15. **Cheryl Reitz** (GT1b previous partial responder) SVR12 Mar 2013 - asunaprevir/daclatasvir 24 wks., Dr. Ghesquiere, Victoria, BC.
16. **Anita Thompson** (GT1a treated 3 times) Cirrhosis - Apr 2013 - Pegasys/boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
17. **Leon Anderson** (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 wks., Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
18. **Joan King** (GT1b treated 5 times) SVR24 June 2013 - asunaprevir/daclatasvir 24 wks., Dr. Ramji, Vancouver, BC
19. **Jackie** (GT1 relapser) SVR24 June 2013 - IFN/RBV/boceprevir 48 wks., Dr. Keith Bovell, Guelph, ON.
20. **Sandy J.** (GT1a treatment-naïve) Oct 31, 2013 - IFN/RBV/Victrelis 28 wks., Fran Faulkner, RN, Vancouver Island. SVR24.

21. **Andrew P.** (GT1a many previous treatment attempts over 10+ years, including Incivek Jan 2014.) Sofosbuvir/ledipasvir + RBV 24 wks.
 22. **Peter A Walker** (GT1a, treatment-naïve) SVR Jan 2014 - PegIFN/RBV +boceprevir (Eprex-for low RBC count from RBV.)
 23. **Diane Stoney** - Transfused 3/21/79 (GT 1a treatment-naïve) Feb 4 2014 - 12 wks. placebo, then 12 wks. on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC
 24. **Coreen Kendrick** (GT1a treatment-naïve) Mar 10, 2014 MK5172/MK8742 12 wks., Dr. Ramji, Vancouver, BC.
 25. **Jack Swartz** (Treated 3 times) Apr 2014 IFN/RBV/Victrelis, Dr. S. Wong, WHSC.
 26. **Del Grimstad** July 2014, 12 weeks simeprevir/Sovaldi
 27. **Linda May** (GT1b transfused, treatment-naïve) asunaprevir/daclatasvir 12 wks., Dr. Tam, LAIR Centre.
 28. **Robin Tomlin** (GT1 treatment-naïve) SVR12 May 4, 2014 - Harvoni 12 wks., Dr. Yoshida VGH.
 29. **Bob** (GT1a/HIV relapser) SVR24 Nov 2014 pegIFN/RBV/Incivek 24 wks., Dr. Montaner, Salt Spring Island, BC.
 30. **Nancy Neel** (GT1a previous relapse IFN/RBV 48 wks.) SVR24 Mar 2015 MK-5172/MK 8742 12 wks., Dr. Ramji, Richmond, BC.
 31. **Catherine Luke** GT3b, treatment-naïve) SVR 12 May 19, 2015 SOF/pegIFN/RBV 24 wks [NEW]
 31. **Sandra Newton** (GT1a treatment-naïve, infected 1984) SVR12 Aug 2015. Harvoni 8 wks., Dr. David Pearson, Victoria, BC
 32. **Wendy Mackay** Transfused 1971 (GT1a prev. 48 wks., Victrelis Triple) Cirrhosis. SVR24 Aug 2015, Harvoni 24 wks., Dr. Tam, LAIR Centre
 33. **Wendy L** (GT1b pegIFN/RBV intolerant) SVR12 Sep 15, 2015, Harvoni 8 wks. Dr. Steve Brien, Peterborough ON.
 34. **Nancy Dunham** Transplant patient. SVR 2015, Harvoni Toronto, ON.
 35. **Chaim David Mazoff** (GT1a treated 5 times) SVR24 Mar 2, 2016 Harvoni 12 wks. Dr. Ghesquiere, Victoria, BC [NEW]
- Please send your name and info to **Joan** info@hepcbc.ca

CONFERENCES

2016 APASL Single Topic Conference on Hepatitis C
10-12 June 2016
Kaohsiung, Taiwan
www.apasl-hcv-2016.org/

GEEW 2016
34th Gastroenterology and Endotherapy
European Workshop
22 June 2016
Brussels, Belgium
www.live-endoscopy.com/

EASL - AASLD
Roadmap for Cure
23-24 September 2016
Paris, France
<http://goo.gl/aVGERh>

QUESTIONS ABOUT COMPENSATION?

You can find your answers here:
<http://goo.gl/8hbZ1b>

HepCBC LIVER WARRIORS TEAM AT 2016 VICTORIA MARATHON

Yes, there will be a HepCBC Liver Warriors Team again at the 2016 Victoria Marathon! To register, go to: <http://www.runvictoriamarathon.com/racing-events/registration/> If you

want the Half Marathon, select "HepCBC Liver Warriors" team from the dropdown team list (if you choose a different event, you may have to type in that name in by hand). **July 15th is the deadline** for the less expensive registration rate . Please let HepCBC know if you are joining this year so we can meet up with each other at the race. Hope to see you there!



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WORLD HEPATITIS DAY 2016



One day is simply not enough for viral hepatitis (B and C). There is so much going on, just in the world of hepatitis C, these days that it seems every day is WHD! Keeping up-

dated with the news and passing it on to people who need it is a major challenge. Nevertheless, if you or your organization wants to get involved with this important event, here is where you can get free supplies, posters, ideas, and publicity: <https://whdcanada.org/toolkit/>. Organizations working on raising awareness about hepatitis are welcome to fill in the proposal form here <http://goo.gl/forms/HBTFDxtQ3g>. Please note the submission **deadline is June 3rd, 2016**. This year we particularly encourage getting local landmarks "LIT UP" with red and yellow lights, but be sure to also send out press releases so people will know what the colours mean. The slogan this year is: "Know Your Status? Get Tested – Learn Your Options."

KNOW YOUR STATUS?
Get tested - Learn your options
WORLD HEPATITIS DAY
JULY 28 WWW.WHDCANADA.ORG

There will be WHD events in Vancouver (watch www.hepcbc.ca for details) and in both Nanaimo and Victoria (contact Dawn at HepCBC 250-595-3892). Both Positive Living Fraser Valley (contact Kari through www.plfv.org) and Positive Living North (contact Orlando through www.positivelivingnorth.org) will be having events. If anyone has specific time, place, activity into for any event (anywhere in western Canada or Yukon), let us know through the www.hepcbc.ca **Contact form** and we'll put it on our Event Calendar!



Lighting up of the BC Legislature in Victoria, BC on WHD 2015

ATTEND BLOOD SCANDAL HEARINGS: VANCOUVER, JUNE 20-22

For anyone who opposes the federal government's request that the 1986-1990 Blood Scandal Compensation Fund "surplus" of approximately \$250,000,000 be allocated to "Canada" instead of helping to find and/or compensate its victims as per the original intent: Please consider attending the hearings taking place June 20-22, 2016. While they physically take place in **Toronto**, there will be live video links in **Vancouver** and **Montreal**. We would love to see **all 3 courtrooms** filled with interested members (of BOTH the 1986-1990 and the pre-1986-post-1990 classes) and their family/friends/supporters. We think it will have an impact on the judges. ***This action sets a dangerous precedent that could affect members of both the classes, as well as the many people who could potentially enter either of the classes but are not yet diagnosed.*** The times and locations:

- Vancouver Law Courts—courtroom 52, 800 Smithe Street Vancouver, B.C. 8:30 AM to 2:30 PM local Pacific Time
- Montreal courthouse—courtroom 15.04 1, Notre-Dame East Street Montreal, Qc 11:30 AM to 5:30 PM local Eastern Time
- Toronto Courthouse—courtroom 6-1 361 University Avenue, Toronto, Ontario 11:30 AM to 5:30 PM (Eastern Time)

Please pass this information on to any other interested party. Hope to see you there! It would be great if you could let HepCBC know if you are going to attend as the Canadian Hemophilia Society wants to know the approximate number of attendees in advance if possible. More information available at:

1. <http://goo.gl/r2JOyM>
2. <http://www.hepc8690.ca/home-e.shtml>
3. <http://goo.gl/CtIFkD>

Peppermint Patti's FAQs, V 10.1 !!

Do you have questions about Hep C or about treatment? Do you want to know how to make healthier choices for your liver?

Download for FREE:
<http://wp.me/P7rc49-1T7>

PATIENT INPUT REQUESTED BY BCPHARMACARE FOR BMS'S SUNVEPRA™ (ASUNAPREVIR)



Once again, HepCBC is calling for your patient or caregiver input. BC PharmaCare is reviewing whether to add another Direct Acting-Antiviral (DAA) for hepatitis C to its formulary. This time, Sunvepra™ (asunaprevir) is up for consideration.

This drug will be considered as part of a treatment that is effective for those with Genotype 1 or Genotype 4. It targets the NS3 protease part of the virus, blocking it and making replication of the virus difficult. Its method of action is unique among the current arsenal of DAAs. Although it is not effective on its own, it is paired with Daklinza™ (daclatasvir) or with Daklinza™, peg-interferon plus ribavirin.

Health Canada issued a Notice of Compliance for asunaprevir in March, 2016. You can find links which explain more about this DAA and the patient/caregiver questionnaire up at our site: <http://wp.me/p7rc49-2sq> If you would like to participate in this drug review, please follow the instructions up on our site. You may skip questions and are free to make any other comments you would like to add. You are free to participate if you are affected by hepatitis C in any way: whether you are a patient, a person who has undergone successful or unsuccessful treatment for hepatitis C, or someone who is a friend or caregiver of a person with this disease.

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DEADLINE FOR SUBMISSION TO HepCBC is MIDNIGHT, Monday, June 13, 2016.

DAKLINZA™ (DACLATASVIR) FOR DIFFICULT-TO-TREAT HEPATITIS C PATIENTS

May 24, 2016 /CNW/ – Bristol-Myers Squibb Canada today announced Health Canada's approval of DAKLINZA™ (daclatasvir), in combination with sofosbuvir (with or without ribavirin) for 12 weeks in the treatment of chronic hepatitis C (CHC) in adult patients with hepatitis C virus (HCV) genotypes 1, 2 or 3 in three difficult-to-treat populations, including patients with HIV-1 co-infection, patients with compensated or decompensated cirrhosis and patients with HCV recurrence after liver transplantation

HepCBC applauds the wider use of this excellent treatment option. Further info is available in BMS's [updated product monograph](#).

ABBVIE CARE

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

Canadians prescribed HOKIRA PAK™ will have the opportunity to request to be enrolled in AbbVie Care. The signature care program is designed to provide a wide range of customized services including reimbursement assistance, education and ongoing disease management support. AbbVie Care will not only support health care professionals but people living with genotype 1 hepatitis C throughout their treatment journey to achieve high cure rates in the real world. For enquiries: 1-844-471-2273.

MERCK CARE™

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

- assistance with reimbursement and/or insurance claims.
- financial assistance for co-pay/ deductible for people who qualify.
- multilingual assistance.
- home delivery of medication.

MerckCare™ provides all of these services free of charge.

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

IBAVYR™

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

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

BIOADVANCE®

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

CLAIRE

Bristol-Myers Squibb Canada has created Claire, a patient support program designed to provide patient health information and reimbursement assistance for patients who have been prescribed DAKLINZA™ (daclatasvir). This personalized patient support program is now available, and represents a service offered at no cost to the patient and is fully confidential. It is set up so you will have a single person to take care of you during your treatment. You can call the information line for more details at: 1-844-428-2559. Should you have medical enquiries regarding DAKLINZA™, please contact our Medical Information Department at 1-866-463-6267 or email info@claireprogram.ca

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.

MOMENTUM™ SUPPORT

To learn more about SOVALDI™, HARVONI™ 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 1 855 447 7977. 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™/HARVONI™ 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.

HEALTH BENEFITS 1ST NATIONS AND INUIT

There are a number of health-related goods and services that are not insured by provinces and territories or other private insurance plans. To support First Nations people and Inuit in reaching an overall health status that is comparable with other Canadians, Health Canada's Non-Insured Health Benefits (NIHB) Program found at <http://goo.gl/8K9ODK> provides coverage for a limited range of these goods and services when they are not insured elsewhere. Their number in BC is 604-666-3331 or 1-800-317-7878 (toll-free).

COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296

1986-1990 Compensation Line: 1-877-434-0944

Red Cross Compensation pre-86/post-90 (Federal)

Administrator: 1-866-334-3361

preposthepc@crowco.ca

Ontario Compensation: 1-877-222-4977

Quebec Compensation: 1-800-561-9749

CLAIMS ADMINISTRATOR 1986-1990

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

Administrator 1-877- 434-0944

www.hepc8690.ca

info@hepc8690.ca

Pre-86/Post-90

Administrator 1-866-334-3361

preposthepc@crowco.ca

www.pre86post90settlement.ca

Settlement Agreement:

www.pre86post90settlement.ca/english/eng_home.htm

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:** Positive Wellness program and counseling, harm reduction, needle exchange, advocacy. 1371 C - Cedar St.
Contact leanne.wingert@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 AVI Health Centre.** Counseling, advocacy. **NEW: 102-55 Victoria Rd** Contact Michelle for details. 250-753-2437 michelle.latour@avi.org
- **Victoria Access Health Centre,** Tuesday lunch, disability applications, peer training. Support group Tues 12:30-1:30 PM, 713 Johnson St., 3rd floor, 250-384-2366, ext 3112 leslie.robinson@avi.org.

ANKORS Hepatitis C Project
Hep C Info, support for prevention, testing, treatment and living well with Hep C.

- **Boundary, Nelson, West Kootenay Women's** gathering monthly. 101 Baker St, Nelson. Contact Laura 1-800-421-2437 250-505-5506 ankorshepc@ankors.bc.ca
- **East Kootenay** 209 16th Ave N, Cranbrook, Contact Michelle 250-426-3383 1-800-421-2437 ankorshcv@gmail.com

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

Chilliwack PCRS Hep C Prevention, harm reduction. 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 dgggrimstad@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 Call for office hours. Email support through website form. Peer phone support through:

- **Lower Mainland:** 1-604-259-0501
- **Fraser Valley** Support/Info: 604-576-2022 (9 am-10 pm)
- **The rest of BC:** 1-778-655-8000

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 & counselling 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

Nanaimo - Central Island Hepatitis Service: Nurses & doctors available for info, support, treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-2607,

sarah.hughes@viha.ca or shelby.munk@viha.ca

New Westminster Stride with Purpose "HepC" Support Group 1st & 3rd Wed monthly 1-2:30pm Refreshments.
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&3rdThu monthly 10-12 noon, Discovery Room, Sunshine Wellness Centre, Campbell River Hospital. Jody Crombie at 850-2620, jody.crombie@viha.ca

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 butlas@telus.net

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

Vancouver: YouthCO HIV and Hep C Society of BC. Call for appts or drop in M-F 10-6. 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart info@youthco.org, www.youthco.org

VIDC HCV Support Group 9:30AM-12PM Every Friday 200-1200 Burrard St., Vancouver. Contact 604-642-6429 info@vidc.ca

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

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 admin@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

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 Health System – Hepatitis C Care Clinic (HCCC) Clinics:
New Port Centre-Port Colborne, 4 Adams Street - St Catharines, Niagara Falls Hospital. Education, counseling, individual/group support, treatment, outreach, and harm reduction. Contact 905-378-4647 ext 32554 and 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 healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

Toronto CLF "Living with Liver Disease" group 1st Mon. monthly Oct.—June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932 or 1-800-563-5483 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, 032-2065, rue Parthenais, 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@hepnsc.ca www.hepnsc.ca

PRAIRIE PROVINCES:
Calgary Hep C support group meets 1st & 3rd Wed. monthly, 11:45am-1pm, CUPS 1001-10th Ave, SW. Contact Lynda 403-991-1930 www.cups Calgary.com lyndaw@cups Calgary.com

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 B i a n c a 2 0 4 - 8 3 1 - 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 your details to info@hepcbc.ca It's free!