

hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

NEWS: HCV ACTIVISTS OCCUPY WHO

ON EVE OF WORLD HEPATITIS DAY, NEW YORKERS WITH HEPATITIS C AND ALLIES BLOCK TRAFFIC AND OCCUPY LOBBY OF WORLD HEALTH ORGANIZATION (WHO) DEMANDING LEADERSHIP TO END THE EPIDEMIC

Protest is part of a global day of action in over a dozen countries calling on WHO's Director General Margaret Chan to fight for access to hepatitis C prevention, diagnostics and treatment.

Photos available online: <http://bit.ly/17G4I8N>

New York, NY - People with hepatitis C and allies protested outside of the World Health Organization's NYC office today to draw attention to the international health agency's failure to address the global hepatitis C epidemic. The activists, many of whom are living with hepatitis C, blocked traffic on Second Avenue at 47th Street after occupying the lobby of WHO's office building. They also held hundreds of balloons that said "Hep C Time Bomb" and a banner outlining their demands.

"We have the tools to end the hepatitis C epidemic, but Dr. Chan can't summon the political will to take this epidemic seriously," said Levele Pointer, a VOCAL-NY Users Union member from the Bronx. "With a range of diagnostic options, proven hepatitis C prevention strategies like methadone and syringe exchange, and medication in the pipeline that may cure 100% of people with hepatitis C, there is zero excuse for inaction from WHO."

WHO has called hepatitis C a "viral time bomb" yet has done little to address the epidemic. There are an estimated 150 million people with chronic hepatitis C infection worldwide, according to WHO, but most of them do not know their status and cannot access prevention or treatment services.

About 350,000 people die from hepatitis C-related liver disease each year. VOCAL-NY,

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HEPCBC'S PLACE WITHIN THE MEDICAL HIERARCHY

Excerpts from an organization profile report by medical student Darrin Wiebe on April 9, 2013

In early 2013, second year medical student Darrin Wiebe researched HepCBC's website and publications (*Peppermint Patti's FAQs*, monthly journal *hepc.bull*, and pamphlets) and titles in our lending library, then interviewed one current and one past Board member. This was for a class assignment for 'Social Competency Training' on the place of patient organizations within the medical hierarchy. Wiebe is with the Island Medical Program based out of the University of Victoria.

Wiebe found that HepCBC is made up of people with "... a vested interest in the dissemination of accurate, helpful knowledge, and the removal of stigma surrounding HCV in the general public. They organized themselves, and have since begun to make some real changes in the approach to HCV-related care...

...HepCBC acts as both an educational source for those affected by a diagnosis of HCV (including those infected, their families, and the providers caring for them) and an advocate in the community. HepCBC is

(Continued on page 3)

WORLD HEPATITIS DAY BECOMES WHD 2013 WEEK IN BC!

World Hepatitis Day (WHD) is officially July 28th every year, to commemorate the birthday of the Australian who discovered the hepatitis B virus, Baruch Blumberg, M.D., Ph.D., and winner of a Nobel Prize. However this is a day for awareness and remembrance for any type of hepatitis including hepatitis C. And in the case of British Columbia 2013, awareness events are occurring over a 9 day period between July 20th and 28th, starting in Nanaimo on July 20th, followed by events in Nelson, Vancouver, Smithers, Campbell River, Grand Forks, Abbotsford, Courtenay, Surrey, and Victoria, ending with Williams Lake!

We hope next year there will be events in even further corners of this province. If you want to add your location to this list, let HepCBC know and we'll give you help getting materials, connections, and other support for your event.

This issue will report on the Nanaimo and Vancouver events, but next issue we'll give you a taste of the diverse ways WHD is commemorated in other parts of the province. HepCBC (with funding from Janssen, Bristol-Myers Squibb, Gilead Sciences, Boehringer-Ingelheim, and Merck Canada) was able to put half-page ads in the *Vancouver Sun*, *The Province*, and the *Times-Colonist* announcing these WHD events, which included an anti-stigma campaign to promote testing among British Columbia's Baby-Boomer, Newcomer (immigrant), and northern/rural/First Nations communities. HepCBC also directly supported and participated in the events in Nanaimo, Surrey, Vancouver, and Victoria.



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

HepCBC
 2642 Quadra Street
 PO Box 46009
 Victoria, BC V8T 5G7

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Please email me a PDF copy, free of charge.

Membership + Subscription (1 year)\$20.00

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 (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 jkling2005@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.

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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.

FAQ version 9.0



Peppermint Patti's **FAQ Version 9.0 is NOW AVAILABLE**. Version 8 is available in FRENCH and SPANISH. The ENGLISH version includes treatment information and research from 2012. Place your orders now. It contains 169 pages of information for only \$15 each. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2012, the FAQ V9.0, the slide presentations developed by Alan Franciscus, and all of HepCBC's pamphlets. The Resource CD costs \$10 including S&H. Please send cheque or money order to the address on the subscription/order form: www.hepcbc.ca/orderform.htm

DISCLAIMER: The *hepc.bull*® cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the editors, of HepCBC or of any other group.

REPRINTS

Past articles are available at a low cost in hard copy and on CD ROM. For a list of articles and prices, write to info@hepcbc.ca.

THANKS!!

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

Please patronize the following businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, VanCity, Shoppers Drug Mart, Market on Yates, Country Grocer, and Safeway.

Special thanks to Thrifty Foods for putting our donation tins at their tills and to Sooke Shoppers Drug Mart, for donating the water for sale at the Christmas concert and for having donated the water for our CASL Forum. Thanks, Allison Crowe and Billie Wood for giving your 110% at the Christmas concert. What a great way to start the most beautiful time of the year. Thanks also to Adrian for his continuous support.



CUPID'S CORNER

This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad, write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send a cheque payable to **HepCBC**, and mail to **HepCBC, Attn. Joan, 2642 Quadra Street, PO Box 46009, Victoria, BC V8T 5G7 (250) 595-3892**. Give us your name, telephone number, and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

Disclaimer: The hepc.bull and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.

AD 31

Old-fashioned lady, 71 yrs old, European background, seeks solvent, faithful, age-appropriate gentleman in Victoria, BC, for companionship: movies, walks, cooking. Let's grow old together happily.

Got Hep C? Single? Visit:

<http://forums.delphiforums.com/hepatitis/en1/chat>
<http://groups.yahoo.com/group/HepCingles2>
www.hcvanonymous.com/singles.html
www.hepc-match.com/

NOTE: Before paying for full service *HepC Match*, be aware that the site is not kept up-to date. We have been advised that there are members there who are no longer active, and at least one who is no longer alive, and his listing remains, even though the owners have been notified.



DIAL-A-DIETITIAN

(604) 732-9191 or
 1 (800) 667-3438

Dietitians of Canada: www.dietitians.ca
 HealthLink: www.dialadietitian.org



NEED A BETTER RESUME?

We need a volunteer Executive Director. Also needed: Board members, summarizing, telephone buddies, translation English to Spanish or French. Please contact us at (250) 595-3892 or info@hepcbc.ca



ANNUAL GENERAL MEETING

**Tuesday September 10, 2013
6:30 PM**

**1947 Cook Street,
Victoria, BC
(Victoria Health Unit, Activity Room)**

Schedule:

6:30-7:30pm Welcome and Main Speaker
7:30-8:30pm Annual General Meeting

AGENDA:

- Approve minutes of AGM 2012
- Set number of directors (We are looking for new directors)
- Election of those directors
- President's Report
- Coordinator and Staff Report
- Financial Report

Main Speaker & Topic: T.B.A.

Refreshments provided. Public welcome. No charge. Must be a member to vote. Hope to see you there.

A member is entitled to one vote at a meeting of members, and must become a member at least 30 days prior to the meeting to be able to vote.

CALENDAR: SAVE THESE IMPORTANT DATES!!

GOODLIFE FITNESS VICTORIA MARATHON



SEPTEMBER 15, 2013: Last Day to Register for Victoria's (October) "Goodlife Fitness" Marathon at Regular Prices

OCTOBER 13, 2013: GOODLIFE FITNESS VICTORIA MARATHON. If you are considering joining the HepCBC Liver Warriors team this year (our THIRD YEAR!) in the Goodlife Fitness Victoria Marathon to be held October 13, 2013, you should register very soon! The last day to register at Regular Pricing is September 15th.

You can WALK, WHEELCHAIR, or RUN 8k (road race), 21k (half marathon) or 42k (full marathon). If you're a serious racer, this is a Boston Marathon Qualifier. Other reasons to participate: Help fight stigma against hepatitis C, help publicize the benefits of exercise for those with liver disease, raise funds to help HepCBC continue its education, prevention, and support programs, and personally have fun, get healthy, and meet some great new friends! Register at <http://www.runvictoriamarathon.com/events/register.php>. Be sure to select us from the dropdown list of teams: "HepCBC Liver Warriors"!

We also need volunteers (to cheer on race day, to help at our info booth October 11/12, or to help with fundraising efforts). If you want to help in any way, or to donate, get information at our site: <http://hepcbc.ca/marathons-walks/>. SEE YOU AT THE RACE!

HEPCBC ANNUAL GENERAL MEETING

AUGUST 10, 2013:

-- DEADLINE TO BECOME A REGULAR MEMBER OF HepCBC (\$10/year) who can vote at our 2013 AGM. To become a member, go to www.hepcbc.ca/hepcbc-order-form/.

-- To become a BOARD MEMBER, you will also have to apply for a free police check (email us ASAP for personalized form to take to your local station) and sign a confidentiality pledge (at AGM). Prospective Board Members can start attending meetings as non-voting members at any time. Members must attend three consecutive meetings (before or after being elected as a Board Member) before being granted full voting rights on the Board.

SEPTEMBER 10, 2013: AGM (See details in the column on the left.)

(HEPCBC'S PLACE—Continued from page 1)

run by individuals currently living with hepatitis C, and is an outreach group providing educational material, media presence, (and) peer support... for those dealing with HCV in the Victoria area and beyond. These services include interaction with government agencies, as well as non-governmental organizations at all levels. HepCBC has interactions in regards to policy review, but also provides a source of information to these organizations regarding personal stories and experiences with HCV."

Wiebe's advice to medical practitioners seeking support for their patients is that "it is in any healthcare provider's best interest to be well acquainted with the resources surrounding them, and to be humble when one's knowledge just isn't sufficient. The opportunity to interact with organizations outside the traditional medical hierarchical "box" should be embraced for this reason, as organizations such as HepCBC can take the weight off many practitioners' shoulders, and in many cases are far more qualified...to do so..."

In addition, Wiebe notes, "the stigma associated with this disease can lead to a diagnosis fraught with uncertainty. Often times there is no knowledge of where the infection came from, and helping to provide information in primary care settings is believed to aid in the uncertainty of diagnosis and ongoing care of affected individuals and their families...The acute and chronic complications of HCV, long-standing public stigma, and lack of public knowledge demand such an approach. While this is the case for many chronic diseases, loud and clear is the stated long term goal of HepCBC: 'we should not have to exist'. ...HepCBC and associated HCV advocacy groups are laying a foundation upon which comprehensive care for infected individuals, their families, and their care providers can build."

Wiebe explained the dynamic process and benefits when infected individuals and 'patient groups' evolve from a patient role to a more powerful and influential consumer/client role:

"HepCBC is unique to me in that (most of) the members are those currently living with an HCV diagnosis... I couldn't imagine a closer connection to your cause than to have seen the path before of those you are helping, or perhaps even more-so, to see the path you will take in the future...Providing education and the tools for critical thinking at the patient level degrades the power differential that has traditionally been associated with the medical profession. Patient literacy has been shown to improve outcome and compliance...I believe critical appraisal of the care one receives places someone in more of a client role than that of a patient, in that they retain the control of their outcome: they feel responsible for not only a poor outcome, but for the good outcome, positive changes, and the small victories that come with chronic disease. This attitude should be fostered; organizations like HepCBC are guiding us in the right direction.

It becomes readily apparent with each step in my training that the current medical hierarchy has been born of necessity, and not of ideal design. A system built block upon block, often by those in the trenches, with later modification by government policy leaves a system well suited to the emergent disease, but poorly suited to maintenance of a chronic condition. Organizations that can help guide one towards

(Continued on page 6)

WORLD HEPATITIS DAY 2013 IN NANAIMO...

Congratulations to the Nanaimo Hepatitis C Support Group for such a successful WHD 2013 event, the first in a series of 11 taking place throughout the province during the 9-day period July 20-28! It looks like people not only enjoyed themselves, but that a lot of information was exchanged and new friends made.



*Yum!!
Richard, a Nanaimo volunteer—by all accounts a top chef—tends the BBQ*

The group reported that about 60 people were served. There were hamburgers, hotdogs and veggie burgers, along with salads and munchies. [Editor: But were there any Nanaimo bars?]



Above, a lady learning about the disease at an information table.

The participants shared a lot of info about Hep C with people who didn't know much about it. Many thought there was a vaccine. A lot of people thought that Hep C is in the same class of viruses as Hep A and B. They were given tips and info about treatment. There were a few co-infected people who were happy to come and share their experiences.

One of the organizers noted that a lot of people who came were both hungry and curious. They came, ate, and left with some info about Hep C. How wonderful that they could receive information about this disease!



A World Hepatitis Day 2013 cake greeted friends at awareness event in Nanaimo!

Meet Cindy, co-organizer of Nanaimo awareness event



And there's Fran Falconer, below, in the red cap, long-time Nanaimo hepatology nurse, giving last-minute instructions to volunteers.



This is Rick, running around, making sure everything is perfect.



...AND VANCOUVER

Congratulations, also, to the WHD 2013 event held in Vancouver on July 24th. Here is a nice report from Anita York:

The speakers were fantastic. Elder Gloria Nahanee opened the ceremony with a short talk about traditions of the West Coast Native peoples and gave blessings on our event.



Dr. Mel Krajden

Dr. Mel Krajden gave a talk on new hepatitis treatments.

Nurse Kari Earnshaw followed with a short talk on testing, new

treatments and hope.

Next, Elder Gloria came up again and got us dancing in 4 groups: the Eagles, the Whales, the



Elder Gloria Nahanee's drumming led us in a dance.

Rabbits, and the Deer. It really broke the ice and brought us all together, more focused.

Next was Dr. Edward Tam speaking on the progression of treatment and cures of Hep B&C. He was followed by Karen Stacey who talked on transplants, myself (Anita) speaking on the importance of early testing for Hep C, and lastly was Harley, speaking on Hep B.



Karen Stacey

Elena Murgoci, local representative of the Canadian Liver Foundation and Chair of this event, introduced us.

Dakota Prince had a table for YouthCo.

Karen Stacey had a table about transplants and the Happy Liver Society.



HepCBC Volunteers who manned our info table: Vancouver WHD Co-Chair and speaker Anita York (rt.) and nurse Rosemary Plummer (lt.)

I had a table for HepCBC [Editor: Thank you, Anita!]



S.U.C.C.E.S.S. Society's information table

Elena Murgoci had a table for Canadian Liver Foundation; Jeannine Soltys had a table for BC Centre for Disease Control; and S.U.C.C.E.S.S. Society had a table for hepatitis B.

Next Frank Soda and Rick (camera man and disk jockey) came up and played some short licks for us.

This was the first time all of these diverse organizations worked together to create a joint World Hepatitis Day event in Vancouver. We enjoyed meeting and working with new colleagues and hope it will be an annual event from now on.

Update on July, 2013 article about lack of HCV+ people's representation in organizations which speak in our name.

Last month we reported on "Action Hepatitis Canada (AHC)," the new Canada-wide 'umbrella' group made up of organizations addressing hepatitis B and C, on which HepCBC serves on the steering committee. We mentioned that we were trying to get the group to address the problem of lack of representation of members of either HBV+ or HCV+ communities within AIDS service organizations (ASOs) which make up the majority of AHC. AHC will be speaking on behalf of "us" to the media, to pharmaceutical companies, and most importantly, to governmental bodies such as Public Health Agency of Canada. Therefore it is of critical importance that we make sure our voice is heard within these ASOs.

HepCBC continued to express this at the July 19, 2013 monthly meeting of AHC in Toronto, and obtained a promise to insert a sentence about the need for this sort of representation in the Memorandum of Understanding, which organizations joining AHC will be signing. As well, AHC has set up a committee to address this problem. Again, any ideas from HCV+ people or their caregivers (or anyone else) on this issue will be much appreciated by HepCBC's AHC representative, Cheryl Reitz.

(OCCUPY WHO—Continued from page 1)

Treatment Action Group (TAG), and thousands of others from 86 countries calling on WHO to show leadership on fighting the hepatitis C epidemic have launched a petition (www.hepcoalition.org) outlining their demands. Demands during the global day of action targeting WHO include:

- Advocating for rights-based harm reduction;
- Establishing a prequalification process for alternative and biosimilar pegylated interferon products;
- Monitoring the quality of, and increasing access to, HCV diagnostics;
- Prioritizing and expediting the addition of HCV direct-acting antivirals to the WHO Essential Medicines List, to create access to affordable, high-quality, safe, and effective HCV treatment;
- Providing technical support to countries to increase their capacity to deliver HCV care and treatment; and
- Creating clear guidance on HCV screening and testing that explicitly recommends screening for people living with HIV, in whom HCV progresses rapidly, and for people who inject drugs.

This article was originally published in the December 2009 hepc.bull and has been updated with the latest information about standard treatment.

Hepatitis C is generally a disease that progresses slowly. You have time to think about what you want to do.

You should get these tests:

1. A liver panel (blood test—measures enzymes such as the ALT and AST, clotting time, etc.)
2. An HCV-antibody test.
3. A PCR test (looks for the virus itself)
4. Genotype test
5. Alpha-fetoprotein test or AFP (looks for cancer)
6. Ultrasound (looks for tumours)
7. Biopsy or Fibroscan (non-invasive)

The first 5 are blood tests. They will give you and your doctor some important information. The AFP and ultrasound should be done at least yearly and more often if you have cirrhosis (scarring). The only way to know how much damage has been done to your liver is from a biopsy, although most doctors now recognize results from a Fibroscan, which is not dangerous or painful. You may have a lot of virus, but no damage to your liver, or the other way around. You may have a high ALT, and no damage to your liver, or a low ALT and quite a bit of damage. If your liver is not damaged, you may wish to wait before being treated. On the other hand, if your liver is damaged, and you have signs of rapid progression, you may wish to be treated as soon as possible.

Remember:

1. The sooner you start treatment, the more likely you are to respond.
2. The younger you are, the more likely you will respond.
3. The disease generally progresses faster in men than in women, but faster in women after menopause than in women before menopause.
4. The genotype test will tell your doctor what sort of treatment you should take, and for how long. Genotypes 1 generally don't respond so well as other genotypes to interferon treatment. People with genotype 1, depending on their initial response, *may* have to take longer treatment, enter a clinical trial, or wait for new drugs to be approved.

What is treatment like?

The standard treatment is pegylated interferon plus ribavirin (plus a protease inhibitor for genotype 1). The patient injects the interferon under the skin, usually in the abdomen or thighs, once a week, and takes 5 to 6 capsules of ribavirin each day. There are two brands of interferon treatment approved in Canada:

Pegatron and Pegasys. The side effects of either treatment can be much like having a bad case of the flu. The flu-like side effects last about 2 weeks, and then ease off. Some side effects can be permanent, like thyroid disease or eye problems. Some people lose weight and have hair loss. Both the weight and the hair return.

There are two types of protease inhibitors approved in Canada: Boceprevir and Telaprevir. They each have their own side effects.

What else can you do?

Some people can continue working, while others are not able to do so. There can be more serious problems. Some people can't be treated because of heart problems, immune system problems, or serious depression. There are other side effects and reasons people can't be treated. Talk to your doctor.

Other recommendations:

- Stop drinking alcohol.
- Stop smoking.
- Get vaccinated against hepatitis A & B.
- Get a pneumonia vaccine.
- Get a flu shot each year.
- Minimize exposure to toxins like paints, gasoline and insecticides.
- Check out all medications, non-prescription medications, and herbs with your pharmacist; some may hurt your liver.
- Ask a registered dietician about vitamins. Avoid mega-doses.
- The following supplements have been shown to improve IFN treatment results by 30% each: 3 cups of coffee daily, vitamin B12, vitamin D3.
- Exercise regularly, even if you're tired.
- Eat a balanced diet.
- Join a support group.
- Read all you can about Hep C.
- Consider treatment or a clinical trial.
- If you are on treatment, make sure you take your medication on time!!
- Keep copies of all your lab tests and procedures. Make sure you understand them.

www.jhep-elsevier.com/search/results
www.medicalnewstoday.com/articles/247986.php
<http://hepcsupport.org/vitamin-d-may-slow-fibrosis-and-aid-in-hepatitis-c-treatment/>

VOCAL-NY is a grassroots membership organization that works to build a healthy and just New York by fighting to end the war on drugs, the HIV/AIDS and viral hepatitis epidemics, and mass incarceration. www.vocal-ny.org

TRAVEL ASSISTANCE PROGRAM (TAP)

The Travel Assistance Program is sponsored by the BC Ministry of Health and Ministry Responsible for Seniors. TAP was created to help residents of BC to access health care services that they cannot obtain unless they travel. In other words, if you have to travel to get access to specialists in Vancouver, for example, the TAP program will pay for, or give you discounts for your travel costs, such as ferry fares, for you, your vehicle, and for an escort, if one is needed.

Please ask your doctor for a form to complete. You also need to contact MSP to verify your eligibility and to receive a confirmation number before you travel (Phone number below).

You are eligible if you are a BC resident enrolled in the Medical Services Plan, and your travel expenses aren't covered by other insurance policies. There are regulations such as arriving at the ferry, for example, one hour before departure.

This program doesn't include meals, accommodations, car expenses, or local transportation. You must make your own travel and accommodation arrangements. You may obtain more information by calling MSP at 1-800-661-2668 from 8:30 am to 4:30 PM, Monday through Friday. You may also call 250-387-8277 in Victoria.



LOW CAL CRUNCHY CAULIFLOWER

1/2 head of cauliflower florets
2 eggs – beaten
1 t. mustard
2 C. bread crumbs
1 t. taco seasoning
1 T. creamed horseradish
sea salt and black pepper dip
1/2 C. marinara sauce

Break up cauliflower. Beat eggs and add mustard. In a bowl with the breadcrumbs, add taco mix and seasonings. Dip cauliflower into egg, then drop into breadcrumbs and coat. Place on baking sheet covered in parchment paper. Bake at 400F for 15-20 minutes. Turn halfway through. Heat marinara sauce for dipping. Serve immediately.

Source: *It's a Lifestyle...Not a Fad*

(HEPCBC'S PLACE—Continued from page 3)

resources that are of use for shaping a condition into one's life (and not the other way around) can create a more useful environment for the consumer."

Wiebe noted gaps in services:

"HepCBC recognizes...a blaring gap in services to the undiagnosed, given that HCV infection is an ongoing chronic condition, with blatant symptoms noticeable only after many years. Another issue the organization would like to address is some of the stigmatized risk factors (for instance, sexual transmission and IV drug use) and a massive array of non-classical symptoms experienced by its members and the current HCV-positive public. This is partially accomplished by appearances at public events such as World Hepatitis Day and the Victoria Marathon by HepCBC awareness teams such as the Liver Warriors, their marathon walking team, but there is always more to be accomplished."

Implications for the future:

"...(HepCBC's) focus is shifting to increased media interaction in the coming year, as well as preparing for a presence at the Victoria Marathon and World Hepatitis Day. Public event participation involves both a physical presence of members, as well as raising awareness of the group and distribution of literature.

The... pamphlets, and associated support and information they provide access to, are sorely needed in BC's remote communities. There has been increased interest in many rural communities in HCV awareness... HepCBC has been invited to join in local committees tasked with addressing these issues. Some communities mentioned included Smithers and Terrace, two small communities located in northwestern BC...

...HepCBC exemplifies a grassroots organization doing what they can with what they have. I of course see that there are needs not yet met by this service, but so do they. Unfortunate as it is, money makes the world go round and it is no more true than here...the organization had insufficient funding to continue with an office space, which makes organization more difficult...A significant legacy bequest was left in 2002/2003 (but will be exhausted at the end of this year), and short term funding from the drug industry has been intermittent, but to date no sustainable funding is in place..."

HepCBC wishes to thank Darrin Wiebe for his analysis of our history, goals, and current situation, which we feel are accurate and timely.

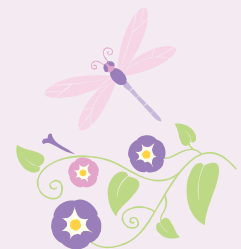
SVR HONOUR ROLL



We often hear only the stories of those who are suffering with Hep C. Our responders go back to "real life" and want to forget about their struggles with Hep C. Have you responded to treatment and remained undetectable for a minimum of 12 weeks* after finishing treatment (i.e., SVR or Sustained Viral Responder)? Let us help you celebrate. You can give others hope. Please take a minute and send us your name, genotype, date of SVR, and type of treatment to post here, and we'll add your name (or initials). Congratulations to our friends:

1. **GJ** - Dec 1998 - IFN/RBV 52 wks—Dr Anderson /Natalie Rock , Vancouver, BC.
2. **Jeanie Villeneuve** - Oct 2000 -Schering IFN/RBV
3. **Kirk Leavesley** (GT1) – 2004 – Roche
4. **Darlene Morrow** (GT1 relapser) Mar 2004 -Hyperthermia/Induction + pegIFN/RBV.
5. **Beverly Atlas** (GT1a) - 2006 - Albuferon/RBV 44 wks
6. **Gloria Adams** (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks -Drs Erb & Yoshida, Vancouver, BC.
7. **Don Crocock** (GT1) Stage II - Dec. 2010 IFN/RBV - 48 weeks [NEW ADDITION]
8. **Daryl Luster** (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
9. **Donna Krause** (GT1 partial responder) SVR -Nov 2011– Pegasys/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks - Dr. Erb, Vancouver. [NEW ADDITION]
10. **Cheryl Reitz** (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
11. **Anita Thompson** (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
12. **Joan King** (GT1b treated 5 times) SVR12 Apr 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC.
13. **Leon Anderson** (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver. [NEW ADDITION]
14. This could be **YOU!**

We know there are many more of you. Please send your name and information to Joan at info@hepcbc.ca and help raise the hope of those still infected.



CONFERENCES

Strengthening the Pillars of
Treatment Access in Canada
Canadian Treatment Action Coalition CTAC)
16-17 Sept 2013
Toronto, ON, Canada
www.ctac.ca

New Science, New Directions in HIV & HCV
Canada AIDS Treatment Information
Exchange (CATIE)
17-19 Sept 2013.
Toronto, ON, Canada
www.catie.ca

AASLD - the 64th Annual Meeting of the American Association for the Study of Liver Diseases
1-5 Nov 2013
Washington DC
www.aasld.org/Pages/Default.aspx

EASL Masterclass on Hot Topics in Hepatology
14-16 Nov 2013
Bordeaux, France
<http://bit.ly/1447ti1>

EASL Translational Research in
Chronic Viral Hepatitis -
Bridging Basic Science and Clinical Research
29-30 Nov 2013
Lyon, France
www.easl.eu/events

HEP DART 2013
frontiers in drug development for viral hepatitis
8-12 Dec 2013
The Fairmont Orchid -Big Island, Hawaii
www.informedhorizons.com/hepdart2013/

3rd Global Workshop on HCV Therapy Advances
New Antivirals in Clinical Practice
13-14 December 2013
Rome, Italy (t.b.c.)
www.virology-education.com/index.cfm/

DDW 2014
3-6 May, 2014
McCormick Place -Chicago, IL
www.gastro.org/education-meetings/live-meetings/digestive-disease-week-ddw

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.)

MERCK CARE™

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

- assistance with 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.

NEUPOGEN VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependent on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge. Please note that Amgen will only provide Neupogen to patients on a compassionate basis 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.

COMPENSATION

LAW FIRMS

1986-1990

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



Pre-1986/ Post-1990

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

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

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

LOOKBACK/TRACEBACK

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

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

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

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

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

Manitoba Traceback: 1-866-357-0196

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

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

CLASS ACTION/ COMPENSATION

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

CLAIMS ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

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

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

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-2873

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more:
 ♦ **Campbell River:** Drop in, needle exchange, advocacy. 1371 C - Cedar St. Contact leanne.cunningham@avi.org 250-830-0787

♦ **Comox Valley** Harm reduction, 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 Hermione.jeffers@avi.org

Boundary HCV Support and Education Contact Ken 250-442-1280 ksthomson@direct.ca

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

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

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

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

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

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 9 AM-10 PM. 250-595-3891

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

Kamloops ASK Wellness Centre. Chronic illness health navigation/support. info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098 www.askwellness.ca

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

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

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Support Meetings 1st & 3rd Thu 3-5 PM 437 Wesley St. (access off Franklin St) Contact 250-585-3201, hepcxpeersupport@hotmail.com

Nelson Info & support for prevention, testing, treatment and living well with hepatitis C. Women's gathering monthly. Contact Laura 1-800-421-2437, 250-505-5506, ankorshepc@ankors.bc.ca

New Westminster Stride "HepC" Support Group each Fri 10 AM *except* 4th Fri. of the month. Nurse Practitioner, refreshments. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

Positive Wellness North Island-North Island Liver Service Info, support, treatment. 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:** 2nd Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

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 31943 S. Fraser Way Suite 200, 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 Melinda.herceg@vch.ca 604-485-3310

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

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-574-2487, 1-888-557-2487, <http://health.groups.yahoo.com/group/Network-BC/> wendy@wendyswellness.ca www.wendyswellness.ca

Slocan Valley Support Group Contact Ken 250-355-2732, ken.forsythe@gmail.com

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

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

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

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 bloodties@klondiker.com

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 hepcmmcoord@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 www.hars.ca hars@kingston.net

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

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

Niagara Region Hepatitis C Care Clinic Education, Counseling and Support - Individual / Group, Treatment, Community Outreach, harm reduction. Contact 905-378-4647 ext 32554 HCCC@niagarahealth.on.ca www.niagarahealth.on.ca/services/hepatitis-c-care

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

Owen Sound Info, support. Contact Debby Minielly dminielly@publichealthgreybruce.on.ca

a 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, www.publichealthgreybruce.on.ca/

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700 healthline-peel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

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

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

Unified Networkers of Drug Users Nationally undun@sympatico.ca

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

QUEBEC:

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

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@hepns.ca www.hepns.ca

PRAIRIE PROVINCES:

Manitoba Hepatitis C phone and email support and outreach. Info Line: 1-204-779-6464 or contact Kirk at info@mbhepc.org. Direct line: 1-204-389-5814

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!