

We have come a long way. For over 20 years, our only treatment was interferon (IFN), and it is still part of standard treatment, even with its side effects and low response rates. When IFN was used alone, only 5-10% of patients achieved SVR (Sustained Viral Response). That rate increased to almost 20% when taken for 48 instead of 24 weeks. Outcome of treatment improved when ribavirin was added...but the side effects increased. Results improved again when the interferon molecule was combined with PEG (polyethylene glycol), but it sometimes increased the side effects and even the death rates. It became necessary to be able to predict who would be most likely to respond, so as to not expose those who wouldn't, to treatment that might harm them. It became possible to predict which patients might respond to shorter treatment. It was shown that the genotypes-best to worst responders—were 2, 3, 4 and 1. The races responding—best to worst—were Asians, Caucasians, Hispanics, and African-Americans. Younger patients responded better, as well as those with lower viral load, less fibrosis, less fat in the liver, and lower GGT levels. Lately the IL28B gene has been shown to predict response (CC, CT, TT, in the order of best to worst responses). The most accurate predictor, though, was the decrease in viral load by week 12 of treatment. We now know that response can be judged by viral levels at 2 to 4 weeks, saving the patient weeks of possible harm.

SHOULD I BE TREATED?

A long 10 years after pegIFN appeared, the protease inhibitors boceprevir and telaprevir became part of standard treatment, increasing SVR by about 30%. The doctors have lists of people waiting to be treated. Unfortunately there are some undesirable side effects. Very soon after their approval, even easier, more effective DAAs (Direct-Acting Antivirals) were being tested successfully. Some may possibly be approved by next year. Jean Michel Pawlotsky, at the In-

(Continued on page 3)

SOUPAPALOOZA!

www.hepcbc.ca

"Soupa-what?" No, I had never heard of a soupapalooza, either—maybe because the very first one ever was just held this last January 17th, in now-famous Penticton, BC. This brand-new event was generously hosted by the Soupateria, and organized by Pam Rorie of Interior Health and Melanie Gale of Harm Reduction Outreach, who teamed up with several other social service agencies.

So what is the Soupateria? Melanie Gale was able to fill me in: "It is an organization which serves lunch daily to those on a limited budget or living on the street. In this population of people we have a number of people living with Hep C. Many of these people do not know who to turn to for help, so Pam Rorie, along with myself and some volunteers for Harm Reduction, decided to host an event in which many community outreach workers and service providers could all come together to connect with each other and the many people who can benefit from various services. It was an opportunity to bring people together to have a social gathering and learn about various resources in the process."

"Overall, it was a successful event, with about 50 members of the Soupateria community attending. New contacts and appointments were made, as well as some reconnections," reported Pam Rorie. Com-

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A CALL TO ACTION

Urging pharmaceutical giants Gilead and Bristol-Myers Squibb (BMS) to put patients' lives ahead of profits, the HCV Coalition for The Cure launched a White House petition drive on February 19, seeking 100,000 signatures within a month to bring to President Obama's attention an exceptionally promising treatment for a deadly disease being held captive by corporate self-interest.

In 2012, in Phase II trials, a combination of Gilead's drug sofosbuvir and BMS's daclatasvir was found to achieve a 100 percent cure rate for three of the most common genotypes of liver-destroying hepatitis C (HCV), the most widespread blood borne infection in the United States. The combination treatment cured HCV genotype 1 within 12 weeks, and also showed the same promising results with genotypes 2 and 3 (without ribavirin or interferon).

The all-oral combination would represent a great advance in HCV treatment, not only because of its remarkable results but because its side-effects—mild to moderate fatigue, headache and nausea—were welltolerated. It would represent a vast improvement over the traditional chemo-style HCV treatment of interferon and ribavirin. both of which have severe and debilitating side-effects and achieve only about a 40 percent cure rate.

"We had never, ever imagined—even in (Continued on page 4) our wildest dreams—we could treat hepatitis C so quickly, effectively and without serious side effects," said Paul Thuluvath, a physician at Mercy Medical Center in Baltimore, Md., who had six patients on the new treatment. "I think the pharmaceutical companies have a moral responsibility to work together and bring it to market instead of [following] their own vested interests."

> Gilead withdrew from collaboration with its competitor, pulling its drug from the studies. Dr. Douglas J. Manion, a BMS senior Vice President, said his company is 'keen" to work with Gilead, "but thus far, they have been unwilling to engage in that

(Continued on page 3)

SUBSCRIPTION/ORDER FORM

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

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

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□Donation enclosed		\$_	
TOTAL: \$			
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□"I want to join a su	pport group	p. Please c	all."
(Note: The hepc.bull to hepatitis on the en You may also subsci PayPal at www.hepc	<i>velope</i> .) ribe or don	ate on lin	e via

SUBMISSIONS: The deadline for any contributions to the hepc.bull is the 15th of each SUBMISSIONS: The 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.

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

Download the hepc.bull free at

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

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

HOW TO REACH US:

EDITOR: PHONE: FAX: **EMAIL:** WEBSITE:

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

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

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.

NEW!! FAQ version 9.0



Patti's Peppermint FAQ NOW <u>Version</u> AVAILABLE Version available FRENCH and SPANISH. **ENGLISH** The

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

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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

HepCBC thanks the following for their institutions and individuals generosity: The late John Community Living Victoria, Victoria Centre, Provincial Positive Living 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.

have helped Top Bookkeeping, Merck Canada, Shoppers Drug Mart, Market on Yates, Country Grocer, and Safeway.

Special thanks to Thrifty Foods for have been notified. 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

his 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.

2 AD 30

Youthful, early 50's single Caucasian male. 5'11", 200 lb non-smoker, outdoors, nature walks, camera, musical, science educ. Half life on hold since diagnosed. Time to break-out.

Searching intelligent, young at heart woman to share some time, hobbies, activities, friendship leading to...? Maybe just friends, maybe a family. Life rarely turns out as you wish or imagine.

Tell me about yourself—hobbies, website, photo?

Got Hep C? Single?

http://forums.delphiforums.com/hepatitiscen1/chat http://groups.yahoo.com/group/HepCingles2 www.hcvanonymous.com/singles.html www.hepc-match.com/

Please patronize the following businesses NOTE: Before paying for full service HepC Shelf Match, be aware that the site is not kept up-Roche to date. We have been advised that there are Canada, Vertex, Gilead, Janssen, VanCity, members there who are no longer active, and at least one who is no longer alive, and his listing remains, even though the owners

TIP OF THE MONTH

Taking protease inhibitors? Set the alarm on your phone. Keep the time you take your pills the same each day. It's important!

(SHOULD I BE TREATED?—Cont'd from page 1) ternational Liver Meeting in April 2012, mentioned the "death of interferon" in the near future.

Doctors who have patients with advanced fibrosis must decide whether to treat them now and deal with the side effects or wait for these new treatments. The patient may get sicker and the treatment, more expensive. If the new treatment isn't successful, resistance may develop. Even with IFN, although it is not discussed much, non-responders seem to respond even more poorly to retreatment, possibly indicating resistance to IFN. Some of the DAAs have been affected by resistance, like ABT-450/R + ABT-333 and GS-7977.

The authors think patients with fibrosis stages 0-2, generally speaking, should wait for the newer drugs, and those with stages 3-4 (cirrhosis) should consider treatment as soon as possible. Clinical trials haven't included many later-stage patients, though. They suggest that these patients be given a lead-in treatment with pegIFN/RBV, and those who don't show a 1-log decline in viral load by week 4 should probably not continue with today's standard treatment, but should wait for the new drugs. There may be exceptions for previous partial responders. It may be that those with a 1-log decline should take boceprevir, and those who had poorer results might do better with telaprevir. But there are no studies comparing the two directly. Some of the response rates in previous nonresponders were still very good—about 80%.

Will IL28b tests still be beneficial? Patients with the "best" IL28b results may be able to take shorter treatments, but treatments seem to be giving excellent results even in those hardest-to-treat. A response of more than 1 log at week 4 is still the best predictor of SVR. The hope right now is to develop an all-oral treatment that will produce a SVR in all treatment-naïve patients with only 4 weeks of treatment.

Source: www.hepatitiscnewdrugresearch.com/ hepatitis-c-advanced-fibrosis-treat-or-wait.html



IFN? THINK TWICE

This recent article (2013) says that patients who have not responded or who have relapsed using treatment including interferon (IFN) probably won't respond, and that they may actually die sooner if retreated with interferon. All of us who undergo treatment have as our goal SVR-a sustained viral response, indicating that the virus cannot be detected 6 months after the end of treatment. These authors say that, even though the virus may be gone, it has not been confirmed that SVR improves survival rates. They reviewed data involving 1,976 people who were retreated with IFN alone after previously unsuccessful treatment. The risk of death was the same with IFN, with a placebo, or with no treatment. The researchers didn't stop there. They noticed that one trial, not blinded, was discontinued early, and didn't enrol as many subjects as planned. That data lowered the number of subjects to 1,676, all in two trials. The risk of death then became 9.4% for retreatment with IFN compared to 6.7% for no treatment (including placebo). They concluded that retreatment with IFN alone can be dangerous for previous nonresponders, and this might include IFN even as a part of combination therapy. They believe patients should be informed of the reimburse those costs. possible problems with adverse effects, even though they found that IFN did reduce viral load. The review suggests that SVR may not be the best indicator of successful treatment, and SVR should be re-evaluated as the goal of therapy. IFN definitely reduced occurrences of internal bleeding.

Source: www.eurekalert.org/pub_releases/2013-01/w-chc012813.php

(CALL TO ACTION—Continued from page 1) collaboration."

Instead of collaborating to further research the proven cure, each company instead has tried unsuccessfully to replicate the other's drug.

The HCV Coalition's White House petition follows an earlier petition at *change.org* that was signed by more than 11,000 people. The group also has joined its voice with other consumer advocate organizations, including the Los Angeles-based AIDS Healthcare Foundation, which has long been critical of the pharmaceutical industry.

Margaret Dudley started the petition "Gilead Sciences: Stop Withholding This Cure for Hepatitis C." If you have any questions, please contact her at 210-493-0304 or mdudley@HepC-Cured.org

TRANSMISSION NEWS

ENDOSCOPY

As of September 2011, Dr. Christiane Farazli no longer performs endoscopies at her Ottawa clinic. The clinic failed an inspection because of unsterilized instruments and "gross cross-contamination" involving a scope that wasn't cleaned correctly. Ottawa Public Health says that 6800 letters were sent to former patients treated between April 2002 and June 2011, telling them they should get tested for HIV, HBV and HCV. The doctor was accused of re-using items like snares, destined for just one use. None of the patients tested positive. One of the clinic's registered nurses was accused of failure to monitor vital signs of a patient during a procedure, and of re-inserting un-rinsed forceps into a patient's esophagus after dipping them in formaldehyde.

Inspection reports for Ontario's 280 out-of -hospital clinics can be found online, allowing patients to make informed decisions about their care. Unless there is a complaint, inspections take place every 5 years. A \$10 million class action suit was filed by 1200 former patients. The investigation cost the city \$770,000. The province promised to reimburse those costs.

Source: http://ca.news.yahoo.com/ottawa-endoscopy-clinic-had-gross-cross-contamination-012349873.html 1 Feb, 2013

SHAVE AND A HAIRCUT?

Durham, Ontario made the news because the health department issued a warning. Whitby's Gentleman's Choice Hairstyling on Brock St. South reused single-use razors, and did not clean and disinfect a razor blade and other shaving tools adequately. Clients who were shaved there between November 22, 2011 and January 17, 2013, on any weekday between 9AM-6PM should call the health department as soon as possible (M-F 9-6): 905-666-6241 or 1-800-841-2729. They will give you info about follow-up tests. There is no evidence of transmission of a disease yet. The business did not conform with regulations by keeping a list of clients. The health department reminds everyone to make sure that razors or the blades are disposable and new. Confirm this with the barber/ hairdresser.

Source: www.durham.ca/news.asp? nr=dnews/health/2013/jan3113.htm Jan 31, 2013



SVR HONOUR ROLL

Unfortunately, we 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 6 months 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
- 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. **Daryl Luster** (GT1a) Feb 2011 IFN/ RBV/RO5024048 48 wks



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



J. Lemmon

hcvresearch@rogers.com
Experienced in medical and legal research
Assistance with HCV compensation claims
and appeals

High success rate / Low payment rate References are available



(SOUPAPALOOZA—Continued from page 1) ments were overheard from those attending, expressing their approval and appreciation, and a desire for more such events in

Melanie Gale had the foresight to provide some large blank canvasses and art supplies, with hopes of inspiring a bit of creativity in that low-income community. She and the organizers were amazed and enraptured with what they consider to be "...some truly beautiful pieces of art." Perhaps better yet, one lady was overheard musing, "I wonder if I can teach art."

It is so wonderful to hear these kinds of comments in particular," said Melanie, "because if even one individual left inspired for a positive change, that makes it all worthwhile. The expectation of the event was to educate, and in my opinion, the expectations were far exceeded."

HepCBC offers sincere congratulations and thanks go to those presenting this event and for telling us about it. Perhaps other communities will be inspired to sponsor similar events in the near future.



HEP C CLINIC AT PERCURO



Did you know that the Hepatology Clinic at PerCuro provides comprehensive HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region?

Specialized nurses assist with the procurement of financial coverage for treatment, ensure lab tests are scheduled appropriately, provide instruction in the self-administration of injectable medication, assist with the management of side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding the patient's HCV status, treatment and any other issues of concern.

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

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

Every attempt is made to meet the individual needs of all patients. There is no cost involved.

Nursing Support improves outcomes. Contact 250-382-6270

CONFERENCES

Canadian Digestive Diseases Week (CDDW) and Annual Canadian Association for the Study of the Liver (CASL) Winter Meeting 1-4 March 2013 Laurel Point, Victoria, BC www.cag-acg.org/annual-conference-cddw

2nd Canadian Symposium on HepC Virus
National Canadian Research Training
Program in Hepatitis C
4 Mar 2013 Laurel Point, Victoria, BC

www.ncrtp-hepc.ca/
(Registration: \$125; some students free)

23rd Conference APASL (Asia Pacific Assoc. for the Study of the Liver) 7-10 March 2013 Singapore www.apaslconference.org/

21st Annual Conference of Indian
National Assoc. for Study of the Liver
22-24 March 2013
HICC, Near Hitec City, Hyderabad, India
www.inasl.org.in/indexhome.php?
do=menu2&lmid=17

EASL 2013 - 48th Annual Meeting of the European Association for the study of the Liver 24-28 April 2013
Amsterdam, Netherlands
www2.kenes.com/liver-congress/pages/home.aspx

DDW - Digestive Disease Week 18-21 May 2013 Orlando, FL <u>www.ddw.org/</u>

2nd Latin American Meeting on Treatment of Viral Hepatitis 24-25 May 2013 Sheraton Hotel WTC Convention Center

São Paulo, Brazil

www.virology-education.com/index.cfm/
t/2nd Latin American Meeting on Treatment
of Viral Hepatitis/vid/79A8744A-B1E1-0C5845D30F3960DA4D3D

23rd Conference of the Asian Pacific Association for the Study of the Liver (APASL)

6-10 June 2013 Singapore <u>www.apaslconference.org/</u>

8th International Workshop on Hepatitis
C Resistance & New Compounds
27-28 June 2013
Cambridge, MA
www.virtualmedicalcentre.com/
conferences/2013-8th-international-workshopon-hepatitis-c/2540

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CHERYL'S JOURNEY THROUGH BC: Part 1

Statistics show the Northern and Interior areas of British Columbia have aboveaverage HCV incidence (new cases per year) and HCV prevalence (% of people who have it). These isolated areas are also the homelands of many of B.C.'s First Nations. One of HepCBC's HCV+ volunteers, Cheryl Reitz, lived in NW BC (Telegraph Creek) from 1977 through 1986, and wanted to go up to that general area between Feb. 11th and March 1st to visit some old friends, so she decided to take 12 pamphlet holders and lots of current HepCBC, CATIE, and PHAC pamphlets up to as many remote health stations, Friendship Centres, and community groups as she could. She had visited Smithers, Moricetown, and Terrace by this bulletin deadline. In the next bulletin there will be a report of her visits to Prince George, Williams Lake, Kamloops, Vernon, Kelowna, and Merritt. Here is her first instalment:

—I left Victoria February 11th, and took the 18-hour Red Eye Greyhound up to Smithers overnight. The trip up here went surprisingly well, and I'm enjoying touching bases with old friends.

—Feb. 13th I spent with some lovely ladies who are passionately committed to HIV and HCV education and prevention: Genevieve Poirier, Program Director at the Dze L K'ant Friendship Centre, Marilyn Morrison (who works with Positive Living North, Dze L K'ant, and is also a health rep at a remote Gitxsgan reserve), plus Melanie Monds and Meaghan Brady from the Smithers branch of Positive Living North.



Melanie Monds of Positive Living North in Smithers has been with the organization many decades. She is a strong advocate of HCV prevention, education, testing, treatment, and support -- alongside the organization's very strong HIV/AIDS pro-

At Positive Living North's lunchroom, I recognized a photo of Doreen Stalker on the wall. She was a pioneer in the early days of organizing HCV+ people. Melanie knew her well, and said Doreen is still revered by many local people who appreciated the way she just kept doing everything she could to help HCV+ people and their families, even as she was dying from the disease herself. In

the afternoon I was asked to give an impromptu presentation, along with Genevieve and Marilyn, to a secondary school health class (twelve Grade 8 students), HCV 101 you could call it, and they were very attentive and sweet. They had lots of great ques-



Marilyn Morrison (cent.) of Positive Living North and Genevieve Poirier (rt.) with Cheryl Reitz (lt.), following HCV awareness presentation to class in a Smithers, BC secondary school

Feb. 14th —Valentine's Day! I enjoyed speaking with three Smithers Interior Health Public Health nurses in the morning. They were really pleased to see some of the new CATIE (Canadian Aids Treatment Information Exchange) materials, and enjoyed speaking with someone who has undergone HCV treatment and is open to speaking candidly about a firsthand experience of contracting, living with, and treating HCV. I had a free lunch at Positive Living North, where I talked with several HCV+ people from the area. Then Meaghan was kind enough to drive me to meet with Wanda Nikal, a Community Health Representative at the Health unit on the Moricetown Reserve. She was happy to receive the pamphlets and holder, saying it would be very useful to the people there.

—Feb. 15th—I delivered a pamphlet holder and pamphlets to Genevieve at Dze L K'ant.



Genevieve Poirier (Program Director) accepting pamphlets and holder at Dze L K'ant Friendship Centre in Smithers, BC

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It was good to see they were put in a very visible and accessible spot right in the front foyer of the Friendship Centre. That day as well, Meaghan delivered a pamphlet holder and pamphlets on behalf of HepCBC to the Gitanmaax Health Station on a Gitxsgan Reserve. I had wanted to go up there, and to talk to the nurse at the Hazelton Health Unit as well, but it will have to wait until next time (I am returning in mid-March for a couple of days).

—Feb. 16th-18th was spent with old friends in the Terrace area.

—Feb. 18th —I delivered a holder and pamphlets to the Kermode Friendship Society in Terrace. The receptionist there was very enthusiastic, saying the materials were just what they needed. And now that they know about them, they will be ordering more (all materials I brought were available for free). I also delivered lots of pamphlets and other materials to the Terrace Health Unit and hope to have a chance to talk with the nurses there at a later date.

Even though they were a little heavy, and I needed to bring an extra suitcase, it was worth it because everyone says THANKS; in the North, many people simply haven't seen this stuff, and are so appreciative. They have tons of HIV/AIDS pamphlets, posters, and training, but very little for HCV. They are just starting to grapple with the realization that more people may be dying of hepatitis C complications than from HIV/AIDS (not proven yet for Canada, but definitely shown to be true in the USA). They hope to find the people who are HCV+ but do not know it, and to get them into treatment (or at least to make necessary lifestyle changes) before the disease does its deadly damage, or gets unknowingly passed on to others. My biggest regret: not being able to bring more holders and pamphlets, and not being able to visit all the places along the route such as Houston and Burns Lake.

Feb. 19th—This morning I arrived in Prince George. I will report further in the April bulletin!

Cheryl Reitz

[Editor: We thank Cheryl for the generous donation of her time and effort in bringing information to these communities!]



Hep C Sites facebook.



Hep C, the Silent Killer

facebook.com/pages/Victoria-BC/HepCBC/274985724940



Transplant Support Group of British Columbia

You can join the Facebook group by putting "Transplant Support Group of British Columbia"

in your browser or by using this URL:

www.facebook.com/group.php?gid=311699175404&ref=share



HEPATITIS C CONNECTIONS

www.facebook.com/groups/222751877843182/

I have two groups:

Hepatitis C Connections on Facebook is a group for discussion & support for people living with Hepatitis C and their caregivers.

I also have my volunteer website, a safe place to get together and blog about Hep C health. I hope to connect with anyone interested in sharing how we cope and manage our health challenges. Please pass this along to anyone out there who needs this info. www.wendyswellness.ca





AN INVITATION FROM JACQUI

I want to invite all of you to a group I administer on Facebook called Fighting Against Hepatitis C.



(www.facebook.com/groups/fightingagainstHCV/?ref=ts&fref=ts) It is a closed group where no one except the group members can see your posts. If you want an invite, let me know. Also, there is an open group with close to 3,000 members-many of them going through the triple therapy—and there is lots of information there too. It's called FIGHT Against Hepatitis C.

 $(www.facebook. \\ -com/groups/fightagainsthepatitisc/?fref=ts)$



You are welcome to join either one to browse or participate. Apparently, almost all people, no matter what stage of liver disease, are being recommended treatment by their doctors now. I'm not against treatment, but I think a lot of people are not being told the full story of these treatments or the long-term effects of them. I am in favour of a "watch and wait" approach if liver disease is mild, since the newer drugs should be out in a few years, and they promise less toxic drugs with a better SVR and shorter treatment time. That's just my opinion, but I think patients should be given that option.

COMPETITION!

epCBC needs writers for the hepc.bull, and will pay \$50.00 for a featured article. The article should be original, 500 to 800 words, and be about hepatitis C. It may be, for example, about the author's experience with hepatitis C, a study (with references) on some aspect of Hep C, or a call for action. Submissions must be in by the 15th of next month, stating interest in receiving the bonus. If there is more than one submission chosen, the editors reserve the right to print both, or leave one for a future edition.

info@hepcbc.ca

Hepatitis C Research and News



hepatitiscresearchandnewsupdates.blogspot.ca/

http://www.patient-experience.com/index.php/hepatitis-c-a-blogabout-the-signs-and-symptoms-of-hep-c/



Hepatitis C – a blog about the signs and symptoms of Hep C » The Patient Experience

Welcome to our latest informational blog about Hepatitis C (or Hep C as it is often called)



www.pacifichepc.org



PRE-PLANNING YOUR FINAL ARRANGEMENTS?

Please consider arranging for donations to your local hepatitis C organization.

> **COLUMBIA** GASTROENTEROLOGY New Westminster, B.C. 604-525-0155

GLOBAL HEPATITIS C NETWORK IN **CANADA**



www.globalhepc.net



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"At any age, staying strong and flexible helps you do the things you enjoy, and perform day-to-day activities with great ease."

Here, you can find a link to the Move for Life DVD, good eating tips and a series of short "walkabouts," "energy bursts," and lots of great health tips:

www.seniorsbc.ca/features/move for life dvd.html

BINGE DRINKING

Many people drink rarely, but when they do, they go overboard. Binge drinking is becoming more common. (Isn't that better than drinking all the time? Let's see.) This report studies what binge drinking does to the liver.

The liver metabolizes nutrients, drugs, and especially, alcohol. It also produces substances needed by the other organs for their correct functioning. Things that worsen the damage done by binge drinking are habitual heavy drinking, or drinking done on an empty stomach. Drinking after fasting or after starvation makes the damage even worse. About 43% of college students polled responded that they had binged at least once in the previous

These researchers decided to document the results of bingeing. Their studies, both on animals and humans, show not only serious effects on the metabolism of the liver, but also damage to the cells and immunological processes of the liver. Alcohol can affect the epigenetics of the liver-in other words, it can change the genes, causing changes in the DNA. It can change the molecules and kill the cells. These changes can affect other organs, as well. All of this can happen in a normal liver. Imagine if the binge-drinker has hepatitis C. Imagine if the person is also obese. The authors suggest development of strategies to control bingeing and tools to lessen the effects of bingeing.

Source: www.sciencedaily.com/ releases/2013/01/130122162234.htm



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 CARETM

 $\begin{array}{l} MerckCare^{TM} \ is \ a \ program \ to \ help \ people\\ who \ have \ been \ prescribed \ PEGETRON^{TM}\\ VICTRELIS^{TM} \ or \ VICTRELIS \ TRIPLE^{TM}. \end{array}$ The program provides:

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

MerckCareTM provides all of these services free of charge. To enroll in MerckCareTM, 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 RCMP Blood Probe Task Force TIPS Hotline treatment, i.e., deductibles and/or copayments. 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. Dependant 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 Administrator 1-866-334-3361 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/Grant Kovacs Norell Vancouver, BC Phone: 1-604-609-6699 Fax: 1-604-609-6688



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 www.lauzonbelanger.qc.ca/cms/index.php?page=108

Roy Elliott Kim O'Connor LLP.

hepc@reko.ca www.reko.ca/html/hepatitisc.html

Kolthammer Batchelor & Laidlaw LLP #208, 11062 - 156 Street, Edmonton, AB T5P-4M8 Tel: 780-489-5003 Fax: 780-486-2107

kkoltham@telusplanet.net

William Dermody/Dempster, Dermody, Riley & Buntain Hamilton, ON L8N 3Z1 1-905-572-6688

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

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 Registra-

tion: 1-888-840-5764 <u>HepatitisC@kpmg.ca</u> Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764 www.phac-aspc.gc.ca/hepc/comp-indem_e.html

CLAIMS ADMINISTRATOR

1986-1990

Administrator 1-877- 434-0944 www.hepc8690.com info@hepc8690.com www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf

Pre-86/Post-90

preposthepc@crawco.ca www.pre86post90settlement.ca

Settlement Agreement:

www.pre86post90settlement.ca/PDFs/SA/ hepc settleagreement.pdf

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-

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 <u>leanne.cunningham@avi.org</u> 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 Shorncliffe 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 <u>Hermione.jefferis@avi.org</u>

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

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 <u>dggrimstad@shaw.ca</u>

Cowichan Valley HCV Support Contact Leah 250-748-3432 <u>r-l-attig@shaw.ca</u>

HepCBC <u>info@hepcbc.ca</u>, <u>www.hepcbc.ca</u> •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 Chemi 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 Franklyn St) Contact 250-585-3201, hepctxpeersupport@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.

•Courteney: 2nd Fri monthly 1PM, Dropin, 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, 330 Ellis Street, Penticton. Contact: 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 (Abbotsford) Hep C support, Drop-in Health Program Office, 711 Pelissier centre-NEW ADDRESS: 31943 S. Fraser Way Suite 200, M-F 10:30 AM-4:30PM. Info, support worker, rides to hepcnetwork@gmail.com. appointments in surrounding areas. Contact http://hepcnetwork.net 604-854-1101 or plfvcentre@plfv.org

Powell River Hepatology Service Powell River Community Health, 3rd Floor–5000 Ave. Contact Melinda Jovce 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 250-557-1-888-557-2487. 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 <u>catriona.hardwick@vch.ca</u> or Brent, 604-740-9042 <u>brent.fitzsimmons@vch.ca</u>

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 Oshawa Community Health Centre Peter, pvanbo@gmail.com Tel. 250-309-1358. Hepatitis C Team Drop-in, lunch

T&W 12-3, Fri. 9-12. Call for appts M-F 10-6. McMillan St. www.ochc.ca Contact 1 205-568 Seymour St, Vancouver 604-688- -855-808-6242 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 <u>bloodties@klondiker.com</u>

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 705-497-1-800-387-3701 hepccommcoord@gmail.com, www.aidsnorthbay.com

Hepatitis C Network of Windsor & Essex County Last Thurs. month-Valley ly, 7 PM, Teen Health Centre-Street St., Suite 4, Windsor. Contact Andrea Monkman 519-967-0490 or

> 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.hivaidsconnection.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

YouthCO HIV/Hep C Society of BC. Drop-in provided each Thurs. 12-1 PM, 79

Owen Sound Info, support. Contact Debby Minielly

dminiel-

ly@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-

healthlinepeel@peelregion.ca St. Catharines Contact Joe

905-682-6194

Sudbury Circle C Support Group 1st Tues. monthly. Contact Ernie 705-522-5156. hepc.support@persona.ca

or Monique 705-691-4507.

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

bpotkonjak@liver.ca www.liver.ca

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

Unified Networkers of Drug **Users Nationally** undun@sympatico.ca

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

info@hepcyorkregion.org www.hepcyorkregion.org

OUEBEC:

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: <u>info@hepns.ca</u> <u>www.hepns.ca</u>

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 <u>bettyc2@hivnetwork.ca</u>

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