

hepc .bulletin

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

NEWS

ANEMIA DRUGS RECALLED

For years now, it has been suspected that overuse of Amgen's drugs to combat anemia may cause strokes or heart attacks or worsen cancer, but this recall is about tiny, almost invisible flakes of glass found in some vials of their products. Both Amgen and Johnson & Johnson, in coordination with the US FDA, have recalled Epogen and Procrit because of this problem. The drugs are also known as erythropoietin or epoetin alfa. The glass could cause immune system reactions or clots if injected. So far there have been no problems reported that could be blamed on the glass slivers. There should be no shortage, in spite of the recall. An investigation has shown that the drug reacted with the glass vials and produced the flakes. The expiry date will be reduced from 36 months to 12 or 15.

Source: [http://prescriptions.blogs.nytimes.com/September 24, 2010](http://prescriptions.blogs.nytimes.com/September%2024%2C%202010)



MIRACLE MINERAL SOLUTION

Miracle Mineral Solution is sold over the Internet as a health supplement. A watchdog group, the Food Standards Agency (FSA), says the product is very similar to industrial-strength bleach, and, if not diluted as instructed, that the product might cause gastrointestinal problems leading to dehydration and loss of blood pressure, possibly resulting in respiratory failure. The solution contains 28% sodium chlorite. The product's website says the product is the "answer to AIDS, hepatitis A, B and C, malaria, herpes, TB, most cancer and many more of mankind's worst diseases".

Source: <http://news.scotsman.com/health/Internet-39Miracle-Mineral39-similar-to.6550090.jp>

37% SPONTANEOUS CLEARANCE

A Danish study (the DANVIR Cohort Study) published in July 2010 has some interesting results that show a larger rate of spontaneous clearance of the hepatitis C vi-

rus than thought earlier. The study looked back at almost 6300 patients who tested positive for the virus at least once between 1996 and 2005. The real purpose of the study was to compare death rates of those with spontaneous clearances to those who continue to be infected, so the subjects had to be alive at least one year after the test. The researchers took into account age, sex, other illnesses, alcohol and drug use, and income. 37% cleared the virus with no treatment. Survival rates showed 92% of those who cleared the virus and 86% who didn't were alive after 5 years. Liver-related deaths were twice as high in the group who didn't clear the virus, and death rates from liver cancer were 16 times higher. The researchers recommended early antiviral treatment for chronic HCV+ patients.

Source: www.hivandhepatitis.com/hep_c/news/2010/0830_2010_a.html

GENOTYPE 1 SUB-TYPING PROBLEMS

Have you been told you have genotype 1, but the tests don't show if you're a 1a or 1b, or anything other than genotype 1? You're not alone.

Some tests are based only on the analysis of the 5'NCR area of the virus, such as the popular Trugene HCV Genotyping Kit and INNO-LiPA HCV 1.0. These tests are mis-

(Continued on page 5)

INSIDE THIS ISSUE:

News / HepCBC AGM Report	1
Hep C on the Internet	3
Rules of Engagement	3
Hep C Basics: What is a Biopsy?	4
Hep C & Me	5
Conferences	7
PegCARE/PegAssist/Neupogen/Compensation	7
Coming Up	8

(Continued on page 6)



HepCBC Coordinator and Staff Report for our 2010 Annual General Meeting

Cheryl Reitz, Interim Coordinator (volunteer) and Ana Maria Medina, Office Mgr.

It's really a privilege to share with you highlights of HepCBC's education and prevention activities since our last AGM in September, 2009, and tell you about some of our plans for the coming year. HepCBC started out over a decade ago with a focus on hepatitis C patient education, sharing knowledge of research results, treatment and compensation issues, and promoting prevention activities. Over the years, HepCBC has slowly broadened its scope, adding other types of hepatitis C support, and more public awareness activities that publicize risk factors, encourage testing and fight stigma. And we won't stop there. In the future we may focus on such areas as youth prevention activities in local schools which educate students about hepatitis C transmission through tattoos, piercings, or inhaled (as well as IV) drug use. Or at some later time, we may attempt to improve liver disease treatment protocols by providing a forum for all involved including patients and their support systems, medical institutions and personnel, doctors, researchers and others, to make sure everyone's needs are voiced and considered. Ensuring that HCV+ people have critically-important Advanced Directives and appropriate Powers of Attorney in place is another possible future project for HepCBC. Employers will need education on how to support their HCV+ employees. I think it's clear HepCBC has the experience, flexibility, and potential to continue for many years as a powerful voice for the hepatitis C community while enlightening and helping protect the broader community as well.

(Continued on page 6)

SUBSCRIPTION/ORDER FORM

Please fill out & include a cheque made out to **HepCBC** - Send to the following address:

HepCBC
#306-620 View Street
Victoria BC
V8W 1J6

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Address: _____

City: _____ Prov. _____ PC _____

Home(____) _____ Work(____) _____

Email: _____

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Membership + Subscription (1 year)\$20.00

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(Doesn't include the *hepc.bull*)

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

Peppermint Patti's FAQ\$12.00

Resource CD\$10.00

"I enclose a donation of\$ _____
so that others may receive the bulletin."

TOTAL: _____

"I cannot afford to subscribe at this time, but I would like to receive the bulletin."

"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 on line via PayPal at www.hepcbc.ca/orderform.htm

SUBMISSIONS: The deadline for any contributions to the *hepc.bull*® is the 15th of each month. Please contact the editors at jkking2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

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

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

HOW TO REACH US:

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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 8.3

Peppermint Patti's **FAQ Version 8.3** is **NOW AVAILABLE**, Version 8 is available in FRENCH and Version 7.1 is available in SPANISH. The ENGLISH version includes the latest treatment information and research from 2009. Place your orders now. Over 140 pages of information for only \$12 each. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2010; the FAQ V8.3; 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 on this page.

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 HepCBC.

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, A-Channel News, The Ocean, JackFM, Community Living Victoria, Provincial Employees Community Services Fund, Dr. C. D. Mazoff, Lorie FitzGerald, Chris Foster, Judith Fry, United Way, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Judy Klassen, and S. J.

Please patronize the following businesses that have helped us: Top Shelf Bookkeeping, Thrifty Foods, Samuel's Restaurant, Margison Bros. Printers, Roche Canada, VanCity, Schering Canada, Shoppers Drug Mart, and the Victoria Conservatory. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com.

Special thanks to Thrifty Foods for putting our donation tins at their tills in these stores: Greater Victoria: Quadra, Cloverdale, Hillside Mall, Tuscany, Broadmead, Fairfield, James Bay, Admirals Walk, Colwood, Central Saanich, and Sidney. Lower Mainland: Tsawwassen, Coquitlam, Port Moody. Also: Salt Spring and Mill Bay.



CUPID'S CORNER

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

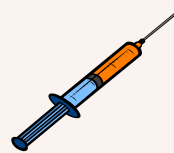
To place an ad, write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send a cheque payable to **HepCBC**, and mail to **HepCBC, Attn. Joan, #306-620 View Street, Victoria, BC V8W 1J6, (250) 595-3892**. Give 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.

TIP OF THE MONTH:

MAKE SURE TO GET YOUR FLU VACCINE!



Got Hep C? Single? Visit:

<http://groups.yahoo.com/group/HepCingles2>

[http://groups.yahoo.com/group/](http://groups.yahoo.com/group/NewHepSingles/)

[NewHepSingles/](http://www.hcvanonymous.com/singles.html)

www.hcvanonymous.com/singles.html

www.hepc-match.com/

www.hepcmatch.com/

CHAT: [http://forums.delphiforums.com/](http://forums.delphiforums.com/hepatitiscen1/chat)
[hepatitiscen1/chat](http://forums.delphiforums.com/hepatitiscen1/chat)

DIAL-A-DIETITIAN

(604) 732-9191 or

1 (800) 667-3438

www.dialadietitian.org

Dietitians of Canada: www.dietitians.ca



MEET NEW FRIENDS!

We need experienced **board members** to occupy key positions. Also needed: summarizing, telephone buddies, translation English to Spanish. Please contact us at (250) 595-3892 or info@hepcbc.ca

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

Hep C Sites on facebook



FIGHT Against Hepatitis C

<http://bit.ly/cvXCGK>



<http://bit.ly/9Nylw3>



Transplant Support Group of British Columbia

You can join the Facebook group by putting "Transplant Support Group of British Columbia" in your browser or using this URL: <http://www.facebook.com/group.php?gid=311699175404&ref=share>

twitter

Hey there! **hepcbc** is using Twitter.
Twitter is a free service that lets you keep in touch with people through the exchange of quick, frequent answers to one simple question: What's happening? Join today to start receiving **hepcbc's** tweets.

<http://twitter.com/hepcbc>



I have been working on my peer support Wendy's Wellness Website and wanted to offer everyone a safe place to get together.

This is the link to my post, offering a secure place to 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 would like a safe place to blog.

<http://wendyswellness.ca/>

RULES OF ENGAGEMENT For Dealing with People with Hepatitis C by Vikki Boddy

1. I am a human being with a point of view. Please respect that.
2. My time is precious to me so please don't waste it.
3. If you have a problem with me, please speak to me. I don't bite. Yet!
4. If you would like me to do something just ask. Don't tell me.
5. If you have an idea please share it. Don't force it on me.
6. You don't have to like me to work with me but you should at least respect my ability to do the job.
7. If something is not working right, let me know (Refer to number 2).
8. Please remember that just because I am sick does not mean I have forgotten everything I have ever learned. I suffer from hepatitis C, not stupidity.
9. It is not necessary to yell because I have a disease. Trust me, my ears work.
10. It is not necessary to talk to me like I am a 2 year old because I have a disease. I have not regressed back to being a toddler so far as I know.
11. I am generally more helpful when I have been included. ESP is not one of my many talents.
12. It will not kill you to be civil to me. There is no need to be rude and unpleasant. (Refer to number 1)

Note: I started these after the Health Ministers meeting in Regina and I have added to them over the years ever since.



www.facebook.com/?ref=home#!/pages/Hepatitis-C-Trust/107063971566?v=info

The Combo Survival Guide from A to Z

<http://www.hepcsurvivalguide.org/comboguide.htm>

PHYSICIANS FOR PATIENTS



An online physician-mediated support group for patients, families, and friends of those with hepatitis C.

<http://hepatitisc.physiciansforpatients.com/>

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COMPETITION!

HepCBC 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

BASICS: WHAT IS A LIVER BIOPSY?

FROM PEPPERMINT PATT'S FAQS VERSION 8.3

BIOPSY

Patients with chronic hepatitis often do not experience symptoms. On the other hand, others complain of excessive fatigue, weakness, and a reduced capacity for exercise.

Since liver damage may occur even in asymptomatic cases (no patient complaints), it is important to perform a biopsy and determine whether there is ongoing liver damage. As chronic hepatitis progresses, damage to liver cells may impair liver function. A biopsy of the damaged liver indicates the degree of cellular necrosis (death of liver cells), inflammation (cellular infiltration and swelling), and scarring (scar tissue beginning to replace functioning liver cells). - "Understanding Chronic Hepatitis" - Schering - 10/92 INH-001/17098403

WHAT IS A LIVER BIOPSY?

A liver biopsy is a diagnostic procedure used to obtain a small amount of liver tissue, which can be examined under a microscope to help identify the cause or stage of liver disease.

The most common way a liver sample is obtained is by inserting a needle into the liver for a fraction of a second. This can be done in the hospital with a local anesthetic, and the patient may be sent home within 3-6 hours if there are no complications.

The physician determines the best site, depth, and angle of the needle puncture by physical examination or ultrasound. The skin and area under the skin is anaesthetized, and a needle is passed quickly into and out of the liver. Approximately half of individuals have no pain afterwards, while another half will experience brief localized pain that may spread to the right shoulder. Some persons, however, have had to be hospitalized afterwards due to extreme pain, shock or puncture of another organ. Many patients have commented that taking Ativan, a tranquilizer, before the procedure helped reduce the pain, since this drug will relax the internal muscles and prevent spasms.

Patients are monitored for several hours after a biopsy to make sure serious bleeding has not occurred. Some patients occasionally have a sudden drop in blood pressure after a biopsy that is caused by a vagal reflex and not by blood loss; this is caused by sudden irritation of the peritoneal membrane. The characteristics that distinguish

this from a bleeding event are: 1) slow pulse rather than rapid, 2) sweating, and 3) nausea.

WHAT ARE THE DANGERS OF LIVER BIOPSY?

The risk of a liver biopsy is minimal. The primary risk is bleeding from the site of needle entry into the liver, although this occurs in less than 1% of patients. Other possible complications include the puncture of other organs, such as the kidney, lung or colon.

Biopsy, by mistake, of the gallbladder rather than the liver may be associated with leakage of bile into the abdominal cavity, causing peritonitis. Fortunately, the risk of death from liver biopsy is extremely low, ranging from 0.01% to 0.1%.

A biopsy should not be done if: 1) you have taken aspirin in the last 5-7 days, 2) the hemoglobin is below 9-10 grams/dl, 3) the platelets are below 50,000-60,000, or 4) the prothrombin time INR is above 1.4.

Those with bleeding disorders such as hemophilia, which can be temporarily corrected with transfused clotting factors, can safely have a biopsy, or they may be able to have a transjugular biopsy.

WILL IT HURT?

Most doctors will not do percutaneous needle liver biopsies under anesthesia. This is because the liver is directly under the diaphragm and moves as you breathe. When the needle is inserted through the skin and body wall, the liver must not be moving or else there is danger of a laceration. To keep the liver from moving, the patient has to stop breathing momentarily. Doctors prefer to have you alert and able to follow directions, but if you are very anxious, you may want to ask for a sedative to help you relax.

The injections of local anesthetic, and the actual puncture of the liver capsule, itself can be a little painful for some people, but it only takes a second and is over very quickly. Other people feel no pain at all, and don't realize it's happened until the doctor tells them they're finished.

Occasionally there will be a small to moderate amount of pain afterwards. If you find that you are uncomfortable, your doctor will generally prescribe a light painkiller immediately after the biopsy. The pain may be far away from the biopsy site, possibly in the pit of your stomach or typically in the right shoulder. Be aware that some doctors are hesitant to give pain killers to those with hepatitis C. It is ad-

visible to discuss this matter with your doctor before hand to avoid unnecessary discomfort.

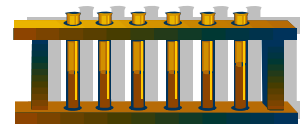
The liver itself has no pain-sensing nerve fibers, but a small amount of blood in the abdominal cavity or up under the diaphragm can be irritating and painful. Very occasionally, small adhesions (scar tissue) may form at or near the biopsy site, and can cause a chronic pain that persists near the liver area after the biopsy.



myehealth

Are you in British Columbia? Are you 16 years old or older? Do you have a BC Care Card? If so, you can now get your lab test results online at a secure internet site at www.myehealth.ca

You must have had a lab test within the last 10 days at a LifeLabs or BC Biomedical laboratory centre in order to register. Have your Care Card number ready. You must use the mailing address that your lab has. Tel. 1-888-522-7758



SURREY, BC ANNOUNCEMENT:

The Fraser North Hepatitis C clinic previously located at the North Surrey Health Unit has moved to the Charles Barham Pavilion on the Surrey Memorial Hospital grounds. The 1 (800) 308-3318 number listed on their pamphlet is not working yet. Try calling (604) 585-5666 extension 77-3095.

(NEWS—Continued from page 1)

typing about 25% of 1a's and 10% of 1b's, according to tests done on 500 treatment-naïve genotype 1 patients.

The new HCV inhibitors are very specific and specialize in different subtypes, so it is extremely important to detect the exact subtype. This study attempts to find the best test to do that. It is heartening to know that the companies Siemens Medical Solutions and Abbott provided kits for the studies. The study was paid for by a grant from the Priority 1 "Life Sciences, Genomics and Biotechnology for Health" program in the European Union. The researchers found that a reverse hybridization test that targets both the 5'NCR and core-coding region accurately identified the subtypes 1a and 1b 99% of the time. Ask for Innogenetics' second-generation Line Probe Assay, INNO-LiPA HCV 2.0), based on reverse-hybridization. According to this study, it is currently the best one. Good luck.

Source: www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0008209?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+plosone%2FPLoSONE+%28PLoS+ONE+Alerts%3A+New+Articles%29

INX-189 PHASE 1a

Inhibitex announced results of its Phase 1a trial of INX-189, an HCV polymerase inhibitor, which used healthy volunteers, who were given a single dose ranging from 3 to 100 mg, or a placebo. The drug produced no serious adverse events. A Phase 1b is planned for later this year.

Source: *Sept. 1, 2010*
www.medicalnewstoday.com/articles/199838.php

ANTIBODIES TO INTERFERON

Doctors from the Netherlands studied a 38-year-old genotype 1 non-responder, cirrhotic HCV+ patient. It was found he had antibodies that neutralized interferon alfa. He had been treated for 16 weeks with standard treatment the year before they re-treated him with 18 months of high-dose peg-IFN (360 µg per week during the first 4 weeks) and weight-based ribavirin. His viral levels were noted on days 1, 2, 4, 7, 14, 21 and 28. He was found to have almost no interferon in his blood, and no response to treatment. Curious, the doctors measured levels of interferon alfa antibodies by ELISA. They were low before starting treatment, and increased after the first week of treatment. He produced antibodies to Roche and Schering (now Merck) products, but not to IFN alfa-C or IFN beta. These doctors advised that patients with no response should be checked for neutralizing antibodies.

Source: www.nejm.org/doi/full/10.1056/NEJMc052880
March 23, 2006



HEP C AND ME: THE INCREDIBLE JOURNEY!

by Petra Hoffmann

Unless you are "well to do," do not get sick in this country! In all of my years, and I had my 50th birthday in June while on treatment, I have always been covered by MSP. I have never in all of these years had a problem with Medical Services Plan...until, that is, I got sick.

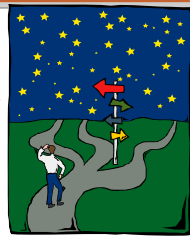
First, I was diagnosed (and have only myself to thank for getting tested), with Hep C. While they were running all the tests, I was also diagnosed with Irritable Bowel Syndrome. When I was finally done with the Pegasys treatment of 6 excruciating months (though I'm grateful it wasn't 12), I remembered, and asked my physician to check what had ever become of the X rays, which by the way, I also had to ask for just prior to my initial Hep C diagnosis. Looking back in the file, he quietly, almost under his breath, told me I have Degenerative Disk Disease. Heck! Two diseases weren't enough for this girl?! I have also been in excruciating pain for years, for I have severe scoliosis of the spine, and have been in a few vehicle accidents. Rather than testing me years ago, I was just put on pain killers and anti-depressants, which doubled as chronic pain relief tablets. My pain has been getting progressively worse for at least the last 10 years now. Needless to say, the X-rays in question are now 2 ½ years old, which actually just dawned on me as I sit and write this article. The now outdated X-rays showed that my neck bones are so jagged, having degenerated so badly, that they pinch off a nerve. I cannot describe to you the pain that I endure, along with the severe stomach pains.

The long and short of why I write this, and I am not sure that I have ever been so frustrated, is that as I mentioned earlier, it was not until I became ill, that I began to have problems with both medical services and Pharmacare. Mostly due to clerical errors on their part, and to not having filed my tax return on time on my part, I was cut

off of medical coverage THREE times during my treatment, and always just before I had to pick up my weekly shot of Interferon. Thank goodness that I was too sick during my treatment to work, because I'm sure I would have lost my job, I spent so much time on the phone with them. I ended up mailing in my last 2 years taxes in their entirety...and lo and behold they just cut me off again today, and mailed me a bill for \$978.00! I am absolutely beside myself. After speaking to a young man who was less than helpful, I accelerated the case today (Sept. 10th) to his supervisor. I spent another exhilarating hour and forty five minutes on hold, and it became apparent that they were not going to answer. I now have to wait 48 hours for them to get back to me, and it is Friday.

Last but not least, I applied for disability and after 14 weeks of waiting for a reply, I was turned down. I had been so sure that I would get coverage, and be able to pay off my looming bills. I have been off of work for about a year now, and after exhausting my Employment Insurance benefits, I have tried to survive on \$610 a month from social services. I now have to go through a "reconsideration" process, and if they turn me down again, I have to go to an "Appeal Tribunal." People...if all this fails, do not be surprised if you see me in the news. I have no intention of laying down. I will fight this all the way!

Please come and follow my journey on:
<http://www.youtube.com/petrabilities>
and visit <http://www.petrabilities.com/> for more information



ADVERSE EVENTS

Report problems with medical products, product use errors, quality problems and serious adverse events.
www.accessdata.fda.gov/scripts/medwatch/medwatch-online.htm

If you are receiving this newsletter by snail mail but have internet access, please consider switching to our pdf version. All you need is Adobe Acrobat Reader, free at this site:

www.adobe.com/products/acrobat/readstep2.html

Just send your email address to info@hepbc.ca and say, "Send me the email version, please," and you, too, can enjoy this newsletter in glorious colour, free of charge.



(HEPCBC Report—Continued from page 1)

Even in these very tough economic times, somehow HepCBC has just kept trucking on, expanding into the Fraser Valley, doing whatever we can to improve the lives of those infected with and affected by hepatitis C, and to prevent others from becoming infected and affected. Whenever possible, we utilize volunteer help—and much of this comes from people with hepatitis C and their families. Our wonderful Office Manager, Ana Maria Medina, has been with us many years and is our only paid employee at the moment; even Ana Maria volunteers much of her time (and her mom's, husband's, and daughter's time!) helping fulfill the goals of HepCBC.

You may have seen our Victoria or Fraser Valley volunteers during World Hepatitis Month (May), giving out information at a community Health Fair, holding a candlelit Memorial service, or on TV, marching with their families in the Victoria Day parade, putting a friendly human face on hepatitis C, fighting society's unfair stigma against this disease—those who are able to be open about their positive status lighting candles and marching for those who must remain anonymous, hiding to protect their jobs and relationships. You can see the pamphlets we put into the offices of doctors who treat our patients, urging them to contact HepCBC for support, especially if they've just been diagnosed, are undergoing treatment, have questions about their symptoms, or simply need companionship and understanding as they struggle with this disease. Perhaps you heard about hepatitis C risk factors at our holiday benefit concert featuring Allison Crowe, or got your yellow & red ribbon at a Thrifty's checkout counter during our annual campaign. Or maybe you accessed our website, www.hepcbc.ca to check out the most recent research or to read our FAQs in English, Spanish, or French. This year Ana Maria has even added Facebook and Twitter networking to our public awareness activities. Meanwhile our amazing Vice President Joan King (now of the Fraser Valley) continues to create and publish the *hepc.bull* bulletin with her friends and colleagues once a month, as she's done continually for many years. Now it's offered online via our website, and many are choosing to access it that way, though Community Living Victoria volunteers continue to mail out the bulletin to anyone who prefers a hard copy delivered via snail mail.

Not so obvious to the public is the confidential live peer-support we offer over the phone, at our monthly support groups, and in hospital and home visits to those in Victoria, Nanaimo, and the Fraser Valley who need it. We have continued to develop and nurture

valuable community partnerships, sharing resources and expertise with other organizations such as Island Sexual Health Society and AIDS Vancouver Island (AVI), even publicizing and participating in one another's activities. Over time we've learned how to more clearly define and differentiate our societies' goals so that we can partner well, not offering overlapping activities nor competing for the same funds. For example, both AVI and HepCBC offer hepatitis C peer-support groups. However, AVI offers theirs once a week, in the daytime, and many of their participants live or work on the street, struggle with mental illness, disability, or addiction, and/or are co-infected with HIV. HepCBC offers a 'clean and sober' group once a month, in the evening. AVI's is run by a trained professional and offers additional counseling and social services. HepCBC's is totally peer-run and offers no "extras". Occasionally there is some crossover of clients and topics, but these two populations generally have different interests and needs. Another example: harm reduction at AVI can mean working directly with addicts and paraphernalia, while at HepCBC it generally involves educating the public about risk factors. Both activities end up protecting the community blood supply from contamination, which can reduce harm to countless others.

We also share our ideas, experience, and advice whenever possible with the media and decision-makers. For example, this year our President Steve Farmer spoke up publicly about his experiences as a liver transplant recipient. Our Nanaimo Board Member (and hepatology nurse) Fran Falconer sent our message throughout North America when she was interviewed by the media about hepatitis C patients intentionally adding poisons to their bodies in hope that their lab tests would show sufficient liver damage to ensure that the BC government's Pharmacare program would cover their astronomical treatment costs. When Triumph Vocational Services wanted guidance in developing career opportunities for HCV+ people, they called on us and were delighted when we offered hepatology nurse Fran Falconer plus another Board Member who is HCV+ as resource people on a couple conference calls. We also cooperate with various 'umbrella' hepatitis organizations—at provincial, federal, and international levels—in sharing information, developing joint activities, and promoting awareness of hepatitis C.

All of this takes time, organization, and money! We've gone without a paid executive since April, 2010. For the interim, I volunteered to use a 'bare bones' approach

to keep the organization running while the Board decided what course to take. It's been six months, and while it has been a real challenge, some positive things are happening. We are developing an interactive, educational awareness project we hope to present in local secondary schools soon, using several enthusiastic UVic pre-med and education student volunteers. Our database structure is being updated by volunteer Gord Warrenchuk to include volunteer information; the database is maintained by longtime volunteer Chris Foster. Office Manager Ana Maria Medina has kept our Main Office in Victoria operating smoothly from approximately 9am to 2pm daily, and our office laptop was recently replaced. We have a couple geeky volunteers who want to update our website in the coming months, making it more attractive and interactive. Our Peer-Support groups in Victoria and Surrey plan to continue into the next year. We are incredibly fortunate to have found a superb volunteer grant writer, Fran Sund, who has applied for several grants during the last few weeks—and she has a few more on the drawing board. Hopefully some of these will bear fruit soon! We've been blessed with many people stepping up to volunteer—too many for me to even process all the application forms, sorry to report.

Obviously, we desperately need a Volunteer Coordinator to process new volunteers; place and train them; and schedule, track and acknowledge their accomplishments. In addition, a true Executive Director's organizational and communication expertise would be a real asset to HepCBC. If you know anyone who can help with these jobs, let us know! As for myself, I will be delighted to hand over my duties to someone else as soon as possible. That's about it! Here's to a truly wonderful year for all of us in the hepatitis C community and our supporters.



NEW: LONDON, ON GROUP

My name is Nicole Elliott, and I am new to the AIDS Committee of London. I am organizing a Hepatitis Peer Support Group for London, Ontario. Our first meeting was held on Tuesday, September 7th, 2010 at 186 King Street, London, Ontario, and will be held the first Tuesday each month, 7-9 p.m. They will be open to those who are infected as well as affected by Hep C.

Contact: Nicole Nelliott@aidslondon.com, aidslondon.com (519) 434-1601 ext. 260, Toll Free: 1(866) 920-1601



CONFERENCES 2010-2011

The Liver Meeting 2010

AASLD's 61st Annual Meeting
October 29-November 2, 2010
John B. Hynes Convention Center
Boston, Massachusetts
Registration: Mid-July
www.aasld.org/thelivermeeting/

"Hepatitis C Virus"

APASL'S 7th Single Topic Conference

December 17-18, 2010
Makuhari Messe
Chiba, Japan
Registration now open
www.k-con.co.jp/apaslstc.html

Enlightening The Future

21st Conference of the APASL
(Asian Pacific Association for
the Study of the Liver)
February 17-20, 2011
Queen Sirikit National Convention Center
Bangkok, Thailand
Early bird registration now open.
[www2.kenes.com/apasl/conference/Pages/
General_Information.aspx](http://www2.kenes.com/apasl/conference/Pages/General_Information.aspx)

1st World Congress on Controversies in the Management of Viral Hepatitis (C-Hep)

19-22 May, 2011
Barcelona, Spain
<http://comtecmed.com/chep/2011/>

HCV 2011

18th International Symposium on
Hepatitis C Virus and Related Viruses
September 8 - 12, 2011
Sheraton Seattle Hotel & Towers
Seattle, WA
Registration: Opens 1 February, 2011
www.hcv2011.org/

EPREX ASSISTANCE PROGRAM

Janssen-Ortho Inc, Canada has a program that may provide assistance in obtaining epoetin. It is the Eprex Assistance Program (EPO) 1-877-793-7739

For more info, provincial coverage and forms: [http://profiles.drugcoverage.ca/en/
default.asp?DrugID=25](http://profiles.drugcoverage.ca/en/default.asp?DrugID=25)

PEGCARE

PegCARE is a reimbursement program to help people who have been prescribed Pegatron and need assistance with any co-payment they might have, whether through their provincial coverage (i.e., Pharmacare) deductible or their 3rd-party health insurance. It is pro-rated, so the less the family income is, the more help they get. If someone's net family income is less than \$30,000, they will get 100% reimbursement. The income maximum is \$100,000. Patients must be signed up for Fair Pharmacare to qualify, and they need to provide a copy of last year's T4 form.

A 24/7 Nursing Hotline and bilingual assistance is available, at no charge. Other services are access to live translation services (150 languages) and injection assistance from registered nurses. Ask your doctor or nurse to enroll you in PegCARE. It's an easy single-page form to fill out, which they will provide. PegCARE: 1-866-872-5773

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 any 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. 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 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 Elliot

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

Other:

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

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
http://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

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

Settlement Agreement: [http://www.reko.ca/html/
hepc_settlement.pdf](http://www.reko.ca/html/hepc_settlement.pdf)



COMING UP IN BC/ YUKON:

Armstrong HepCURE Contact 1-888-437-2873 Phone support.

AIDS Vancouver Island These groups provide HCV info, harm reduction, support, education and more:

♦ **Campbell River:** Drop in, 1371 C - Cedar St. Contact 250-830-0787 leanne.cunningham@avi.org

♦ **Comox Valley** Hep C Support group-Drop in, needle exchange. 355 6th St. Courtenay. Contact Sarah 250-338-7400 sarah.sullivan@avi.org

♦ **Nanaimo** Contact Anita 250-753-2437 anita.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 each Mon, 1:15 PM**, 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jeffers@avi.org

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

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

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

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

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

HepCBC <http://hepcbc.ca>, www.hepcbc.ca

♦ **Victoria Peer Support:** 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Drop-in/Office/Library, 306-620 View St. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-3891

♦ **Fraser Valley Peer Support:** 3rd Wed monthly 7PM, N. Surrey Rec Centre Meeting room 10275-135th St. Info: 604-576-2022, petrabilities@aol.com.

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 and counseling 250-315-0098. www.askwellness.ca

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

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Sep-May, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 250-768-3573, eriselex@shaw.ca, Lisa 1-866-637-5144. ljmortell@shaw.ca

Mid Island Hepatitis C Society 2nd Thurs. monthly, 7 PM (Location to be arranged.) Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Peer Support Group 1st & 3rd Thurs. monthly 4-5 PM, AVI Health Centre, #216-55 Victoria Rd, Nanaimo. Contact Fran 250-740-6942. hepcxpeersupport@hotmail.com

Nelson Hepatitis C Support Group 1st Thurs. every 2nd month, afternoons. ANKORS, 101 Baker St. Library M-Th 9-4:30. Contact Alex or Karen 1-800-421-2437, 250-505-5506, information@ankors.bc.ca alex@ankors.bc.ca www.ankors.bc.ca/

New Westminster "C" Support Group Each Fri 10 AM. Nurse. Refreshments. Contact: Daniel 604-562-5170.

North Island Liver Service Viral Hepatitis Information, support, treatment, Fanny Bay North to Pt Hardy, Vancouver Island. 1-877-215-7005

Pender Harbour Contact Myrtle 604-883-0010 myrwin@dccnet.com

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 Group 2nd Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 421. Contact Ilse 250-565-7387

ilse.kuepper@northernhealth.ca

Prince Rupert Hep C Support Contact: Dolly 250-627-7942

hepcprince Rupert@citytel.net

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

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

Surrey Positive Haven Hep C group 2nd & 4th Thurs monthly 1 PM. 10697 135A St. Contact Sam 604-589-8678.

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 Pre/post liver transplant support Contact Gordon Kerr sd.gk@shaw.ca

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 Call Peter, Tel. 250-309-1358. pvanbo@gmail.com

Victoria CoolAid Peer Support each Wed 10-11:30 AM, 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Carolyn cshowler@coolaid.org

YouthCO AIDS Society 900 Helmcken St, 1st floor, Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Support program manager: Sasha Bennett sshah@youthco.org

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

OTHER PROVINCES:

ONTARIO:

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

Sandi's Crusade Against Hepatitis C/Durham Hepatitis C Support Group Contact Sandi: smking@rogers.com

www.creativeintensity.com/smking/ <http://health.groups.yahoo.com/group/CANHepC/>

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

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, ON. Contact Andrea Monkman 519-967-0490 or hepcnetwork@gmail.com <http://hepcnetwork.net>

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

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Waterloo Menonite Brethren Church, 245 Lexington Rd. Waterloo. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Peer Support Group 1st Tues monthly 7PM, 186 King Street, London, ON. For those infected as well as affected by Hep C. Contact: Nicole Nelliott@aidslondon.com, (519) 434-1601 ext. 260, Toll Free: 1.866.920.1601, aidslondon.com

Niagara Falls Hep C Support Group Contact Rhonda 905-295-4260, kehl@talkwireless.ca

Owen Sound Info and support. Contact Debby Minielly dminielly@publichealthgreybruce.on.ca 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, www.publichealthgreybruce.on.ca/

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

St. Catharines Contact Joe 905-682-6194 jcolan-gelo3@cogeco.ca

Sudbury Circle C Support Group 1st Tues. monthly. Contact Ernie 705-522-5156, hepc.support@persona.ca or Monique 705-691-4507.

Toronto CLF First Mon. monthly Oct. through June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. More info: www.liver.ca. Contact Billie 416-491-3353, bptonkonjak@liver.ca

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

Unified Networkers of Drug Users Nationally undun@sympatico.ca

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

QUEBEC:

Quebec City Region Contact Renée Daurio 418-836-2307 reneeaurio@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 info@hepatitisoutreach.com www.hepatitisoutreach.com

PRAIRIE PROVINCES:

Edmonton Contact Jackie Neufeld 780-939-3379.

Wood Buffalo HIV & AIDS Society #002-9908 Franklin Ave, Fort McMurray, AB Contact 780-743-9200 wbhas@telus.net www.wbhas.ca

Manitoba Hepatitis C Support Community Inc. Each 2nd & last Tues. monthly, 7 PM, 595 Broadway Ave. Everyone welcome. Contact Kirk 204-772-8925 info@mbhepc.org www.mbhepc.org

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca

If you have a Canadian HCV support group to list here, please send details to info@hepcbc.ca by the 15th of the month. It's free!