

hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEP C AND ME: THE INCREDIBLE JOURNEY!

by Petra Hoffman

Only just yesterday, I made the final decision, and it took me almost a year from the time I thought of it, until now, to decide that this disease and all of you who have it, are more important to me than my career. I posted my first video about hepatitis C on both of my blogs, on YouTube, and on Facebook, yesterday.

The reason that I sit and write this article is because of what happened to me last night. It was two days after my gastroenterologist handed me my prescription. It has been almost 2 years since my initial diagnosis. My treatment, which is to commence 5 days from now, has already been put off a few other times for various reasons. Due to that, I have had to put my whole life and career on hold, and my finances are completely depleted. I have spent the last month jumping through governmental hoops to get a lousy \$610.00 per month disability pay.

Anyway, 3 days ago, my specialist hands over the prescription, and then happens to mention that I will probably have to pay up to a possible \$2000 deductible for the medications. Stupefied, I looked at him in disbelief, and asked why no one had told me this before now. He did not have an answer. As I left the office, it dawned on me that I am already on Fair Pharmacare, and I do not have to pay for my or my daughter's medications, so I of course wasn't worried...until last night.

I took my prescription in to the nearest friendly drugstore, and asked the pharmacist on duty how much, if anything, this was going to cost me. Off he went to look things up on the computer and other sources. It took him a few minutes to be sure, and when he came back to the counter, he handed me a piece of paper, as though he was not even able to voice it, showing the amount I would have to pay. It was a flabbergasting \$486/week! Well, that poor man. Petra vented. I told him that no one along the way had ever said a word to me, and that all I knew was

that the specialist's office had applied to the government to pay for my treatment which they say is worth \$30,000 to \$50,000. Now, wouldn't you think that would include the medications, or am I slow perhaps?

I have cried all night and all morning over this. I feel so helpless and devastated by this news, I cannot even attempt to describe it to you. It has become such an emotional journey to gear myself up for this treatment to begin with, and then to be thrown this sort of curve ball at the last minute, literally the last minute, rendered me breathless. I know that there are other avenues I can take, but we all know that they, and all the paperwork required, take time—more than 5 days time, I am sure. Now, had someone, anyone, especially my specialist who helped to fill out all my paperwork for disability, told me this sooner, I would have jumped the extra hoops long ago, and been ready for all this. What the heck is wrong with this system? Do they think that we will be so geared and ready, and willing to receive this treatment (which we are, after all this waiting), that people will come up with the monies some way, some how? Is that not, in your opinion, just totally wrong?

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LESLIE LONG Retiring



A TRIBUTE TO LESLIE FOR HER CONTRIBUTIONS TO OUR COMMUNITY

Leslie has been involved with Hep C support work in Cranbrook for years now, as those of you may have noticed on page 8 of the *hepc.bull*. Unfortunately, that group's entry has now been deleted.

Government cutbacks have destroyed the support group in Cranbrook that she has been helping to run for years now. For the last few years, Leslie has continued to support people from her home. She says that she won't be abandoning the community completely. She is still scheduled to give talks to young people at the Local Party Program, in hopes that she may change and even save some of their lives.

Besides Hep C support work, Leslie has taken in international students since 1991. They come from all over the world and stay for anywhere from a few weeks to 3 years.

Now that she will have fewer responsibilities, she will be investigating the possibilities of treatment, but has the same problem as so many of us do of fulfilling Phar-

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"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:

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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.

NEW!! 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 1997-2007; the FAQ V8; 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.

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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 HepCBC.

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, A-Channel News, The Ocean, JackFM, Health Canada, Community Living Victoria, Provincial Employees Community Services Fund, Dr. C. D. Mazoff, Lorie FitzGerald, Michael Yoder, Chris Foster, Judith Fry, Ernie, Bruce Lemer, United Way, and the newsletter team: Beverly A., 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, tel. 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.*

Hello Fellow Hep. C'ers, **Ad 29**

I am a single white female, 5' 10", approx. 140 lbs, with long auburn hair. I am in my mid 50's, living in Metro Vancouver. I would like to meet a single man of the same persuasion, to share conversations with, perhaps over coffee. Please, only serious inquiries—not interested in a one night fling. I would prefer our meeting to focus on other mutual interests between us.
Sincerely, A.

Got Hep C? Single? Visit:

<http://groups.yahoo.com/group/HepCingles2>
[http://groups.yahoo.com/group/
NewHepSingles/](http://groups.yahoo.com/group/NewHepSingles/)
www.hcvanonymous.com/singles.html
www.hepc-match.com/
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MEET NEW FRIENDS!

We need experienced **board members** to occupy the positions of **secretary and treasurer**. 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



www.facebook.com/posted.php?id=46696534978&share_id=191310943673&comments=1#/group.php?gid=2211715123



Transplant Support Group of British Columbia

All are welcome to attend and all are welcome to join the Facebook group. It is jointly administered by Hayley from the Solid Organ Transplant Clinic at the Diamond Centre, VGH, and by me, Melanie Reid, July 2008 transplant recipient.

Both groups are open. Currently the Facebook group has members across the province. The last face-to-face meeting in December had mostly people from the Lower Mainland. Minutes of that meeting are posted.

The purpose of both Facebook and the meetings is to provide a support and information forum for solid organ transplant patients of BC, for those on the transplant list, and for family and support members.

On Facebook, people post topics on discussion threads to encourage focused replies/an exchange of information. Anyone is welcome to start a discussion page.

The posts will appear on your home page, but will be seen only by members of the group or by people who navigate to this group.

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>

The face-to-face group originally met at the Solid Organ Transplant Clinic to explore ways of providing support for all involved in transplants—donors, people waiting on the lists, people who have received transplanted

organs, and all those family and support members.

Our 3rd face-to-face meeting is January 28th, from 1 to 3 pm in the Board Room at BC Transplant, 555 West 12th Avenue, Vancouver. The board room is on the 3rd floor of the West Tower. Enter off 12th Avenue and take the elevators just to the left inside the doors up to BC Transplant. If you are able to attend, please RSVP to the posted event on the Facebook site to help preparations. Currently 20 or so people attend. This meeting will have two components—the social support and exchange of information and a more structured presentation from BC Transplant.

We are also encouraging people to consider supporting an endeavour by Karen Stacey—a gala on February 11 at Red Robinson Theatre to support Stacey House, a home away from home for liver transplant patients who must remain close to VGH for that first 100 days after discharge or those needing a close location for assessment and tests.

Karen wrote the following:

We are excited to announce that our Gala Event is happening on Thursday, February 11th at the Red Robinson show theatre at 2080 Boulevard in Coquitlam! Their doors open for refreshments at 6:00 pm with a beautiful buffet dinner at 7:00. At 7:15 there will be a special presentation honouring the front line of the Liver Transplant Team. Afterwards, at 8:00 pm there will be a Vegas show: AC as the Beatles and Rod Stewart, Jeff Harris as Meatloaf, Kenny Holliday as Bon Jovi, and Samira as Tina Turner, so don't forget your dancing shoes. There will be surprise seat draws just to mix the night up. Please see the poster below for more details. All proceeds will be used to help support Stacey House.

Please contact me, Karen, at 778-990-5509 for more information, or to purchase a table and/or tickets for our upcoming Gala Event. You may also speak with Laura at The Happy Liver Society Administration Office, by calling 604-732-7117.



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>



PHYSICIANS FOR PATIENTS



Physicians for Patients is the online version of a physician mediated support group for patients, families, and friends of those with hepatitis C.

This is a group of doctors dedicated to helping people online in a way to help with high health care costs. The idea is to give a resource to people who need alternative opinions and information. There are a lot of people who have limited access to health care (either uninsured or simply can't afford it). This way it is easier for a smaller number of physicians to help a larger number of people. Dr. Shah, the doctor, is board-certified in gastroenterology and trained at Providence Hospital in Michigan.

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

A Night With the Stars

Thurs Feb 11th 2010

Doors open: 6PM Dinner at: 7PM

We will be honoring:

Clare Bannan, Lori Fortner,
Polly Cooper, Edwina Brooks,
Isabelle Castelli, Lisa Despins,
Sandra Vojnacic, Allison Collins,
Pam Turnbull, Marlene Delacruz &
Dr. Soos, of the BC Transplant Team.

Red Robinson
Show Theatre
2080 United Boulevard
Coquitlam

Tickets are \$100.00 each

DINNER

DANCING

SILENT AUCTION

RAFFLE TICKETS

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HEP C & SEXUAL TRANSMISSION

Is HCV transmitted sexually? The answer is not as clear as we would like. Transmission in monogamous, heterosexual couples is considered to be 3% or less. There have been outbreaks of HCV in mostly HIV-infected males who engage in homosexual sex in Europe (MSM or Men who have Sex with Men), but not in the US.

There was an article in the May 2007 HIV Medicine that reported 352 cases of HCV acquired in the previous 3 years in MSM examined between 2002 and 2006—a 20% increase during that period. Another study in the May 11, 2007 issue of AIDS reported 111 such MSM cases, and investigated to see if the virus strains were related. Seven clusters were identified, all within the HIV population. The HCV was associated with sexual transmission risk factors rather than IVDU. Risk factors were the number of sex partners, risky sexual practices, sharing of drugs nasally or anally, and group sex, which was the best predictor of HCV infection, especially when combined with high-risk practices.

In the US study, the only predictor of HIV/HCV co-infection was IVDU. A report in the June 1, 2007 Journal of Infectious Diseases concluded, "Our results are consistent with prior research indicating that sexual contact plays little role in HCV transmission." (www.hivandhepatitis.com/hiv_hcv_co_inf/2007/050107_a.html)

Practicing safer sex is always a good idea for people with multiple partners. People who engage in high-risk sexual behaviour have a greater risk of contracting STDs which can cause open sores and lesions. Open sores and lesions mean a greater risk of blood to blood contact and a higher risk of contracting hepatitis C. If you have herpes, you are at a greater risk of catching hepatitis C. It might be possible that HCV piggybacks on the genital herpes virus through genital lesions. If you have multiple partners, use condoms. People with acute illness, or with compromised immune systems, should be more careful as these conditions can raise the level of virus in the bloodstream, and can mean a greater risk of infection. Sex during the menstrual period should be avoided, because of the blood in menstrual fluid.

A report from Health Canada, "Hepatitis C Prevention and Control: A Public Health Consensus," June 1999, p.6, recommends that people with multiple partners should practice safer sex.

Longstanding sexual partners do not need to change sexual practices if one of them is found to be infected with hepatitis C

"Hepatitis C virus is linked with existing hepatitis B virus and HIV infection and oral-genital transmission."

Hepatitis C can be spread through anal or even oral sex rarely, but it is much more common if the person is co-infected with HBV or HIV. (www.medscape.com/viewarticle/580034 Sept. 4, 2008) Source: *Peppermint Patti's FAO v.8.3*

(LESLIE LONG—Continued from page 1)

macare's requirement that ALTs be 1.5 times normal. She hopes there is a possibility of the drug company helping out until Fair Pharmacare takes over with the costs.

We at HepCBC and the *hepc.bull* appreciate the support Leslie has given to our community, and I'm sure others do, too. Here is an example:

"I am writing on behalf of a true guardian angel. Those are the only words that come to my mind when speaking of the most awesome person I know. Not only is she kind, but giving, too.

My husband and I first met Leslie at a Hep C workshop that she put on for people in the East Kootenay suffering from this horrific disease.

At the time my husband and I were living off of only my disability pension and times were tough!! She went above and beyond the call of duty to help us. Never did she say "No, I can't help you," but, "Let me see what I can do for you." Les gave us the most up-to-date info, and helped raise needed money for when the times came that we either had to go to Calgary, Edmonton, or Lethbridge for treatments. She even gave us a turkey for Christmas!! Les read at my husband's memorial and did a wonderful job. Even though their time as friends was so limited, Ken had nothing but high regard for Les!! When we had to go to Cranbrook for appointments, Les was on the top of the list of people to see.

She herself has this terrible disease, and I don't blame her for wanting to finally take care of herself.

I think it is sad to see this happening with the Hep C program in Cranbrook. There are so many people out there who don't even know they have it. To be shutting down a great program, because of lack of funding is sad. Your society is truly going to be missing this angel!! God bless Leslie." —Sonia McPeck [Editor: Sonia's husband Ken Milley had Hep C and 2 liver transplants. He died because of a broken hip.]

(HEP C & ME Continued from page 1)

I write this not so much for myself, but for all of you out there who are struck by this, or know someone who is, to give YOU the heads up which no one gave to me. I cannot imagine all the people who have come to this before me, and all the poor souls whom this will happen to after me. If I can spare even one or two of you from the same fate, then it is worth putting myself out there. Please check out my journey, and my attempt to educate the public at <http://www.youtube.com/petrabilities>.

My specialist did make it a point to let me know that this does happen to too many people all the time, and that he also thinks it is wrong. The system is failing some people. I posted a link on Facebook from a CBC interview of a Vancouver doctor, who says that about half of those with Hep C are being turned down for treatment, and that half of them have no drug or alcohol dependencies.

[From the editor: There are a few recourses for those of us who fall through the cracks. Those on welfare have complete coverage. Those who have an income, but can't afford the cost of the medicine before Pharmacare starts paying can go to page 7 of this edition of the hepc.bull and find the contact information for the drug companies. Often they will be able to help you with some or all of the costs. I am happy to say that Petra has started treatment as scheduled.]



There is NO vaccine for hepatitis C!

Hepatitis C is spread by blood-to-blood contact. 251,000 Canadians are infected with hepatitis C, and because there are often no symptoms, 95,000 of them don't know it.*



Are you Infected? It's a Simple Blood Test.

For more info or support

hepcbc

Call HepCBC

595-3892

www.hepcbc.ca

*Stats from Public Health Agency of Canada Hepatitis C

HEPATIC ENCEPHALOPATHY

From Peppermint Patti's FAQs v8.3:

Hepatic encephalopathy is a serious complication of advanced liver disease probably caused by cerebral toxins, including ammonia, certain amines, and fatty acids. It is clinically manifested by personality changes and impaired intellectual ability, awareness, and neuromuscular functioning.

Hepatic encephalopathy refers to the changes in the brain that occur in patients with advanced acute or chronic liver disease. If liver cells are damaged, certain substances that are normally cleansed from the blood by the healthy liver are not removed (mainly ammonia, or possibly certain fatty acids). A patient with chronic hepatic encephalopathy may develop progressive loss of memory, disorientation, untidiness, and muscular tremors, leading to a form of chronic dementia. The ingestion of protein invariably aggravates these symptoms.

The treatment of hepatic encephalopathy involves, first, the removal of all drugs that require detoxification in the liver and, second, the reduction of the intake of protein. Restricting the amount of protein in the diet will generally lower the levels of amino acids and ammonia in the bloodstream and brain.

Most physicians advise their patients with this condition to eat only about 40 grams of protein a day, and will prescribe lactulose or neomycin to lower amino acid production. Non-meat proteins, such as those found in vegetables and milk, are also recommended. Certain amino acids are used in treatment, since they are considered less likely to cause mental impairment. A dietary supplement rich in these amino acids is used at many liver treatment centers.

BRAIN FOG

This is the mental fuzziness and forgetfulness that some people experience. It's not the same as encephalopathy, and seems to occur in all stages of the illness. Some people have found taking CoEnzyme Q10, also known as CoQ10, to be helpful (2 30mg capsules per day). Others recommend taking Ginkgo Biloba.

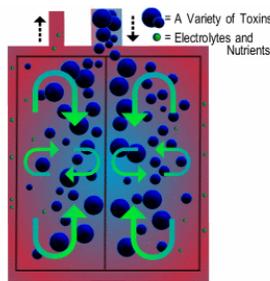


Source: www.hepcbc.ca/faqsenglish.htm

WHERE DID THE HEMOCLEANSE GO?

Some of you may remember from way back in the 90s all the talk about a liver dialysis machine called HemoCleanse. Like kidney dialysis, the apparatus cleaned the blood. It was approved by the US FDA in 1996 and was called the BioLogic-DT. HemoTherapies licensed the technology, but went bankrupt in 2001, so the technology was returned to the original developer, HemoCleanse, in 2003.

The HemoCleanse machine, now managed by HemoCleanse Technologies, LLC, is a device that cleans the blood, removing toxins and other unwanted substances. The blood or plasma enters into the centre of a "swirling sorbent suspension" and as it moves outwards again towards a membrane



HemoCleanse-DT/PP

that separates it, it is cleansed and returned directly to the patient. The process reduces toxins in the blood and may improve the

health of the patient. The device can remove both small, unbound toxins, as well as larger, bound toxins.

The company has US FDA approval for the device and is preparing to make liver dialysis cost-effective. They hope to take advantage of clinics that already perform kidney dialysis. The new devices can convert any hemodialysis device for kidneys into one for liver dialysis. This is good news!

The device may be useful in treating autoimmune diseases like lupus, rheumatoid arthritis and psoriasis. It can provide temporary help for those waiting for a transplant, and perhaps give the liver a rest and a chance to heal itself.

Source: <http://www.hemocleanse.com/LLC/>

Coma: a state of unconsciousness from which the patient cannot be aroused, even by powerful stimuli.

Hepatic coma: results from reversible biochemical abnormalities of the cerebrum, caused by elevated blood levels of toxic substances such as ammonia, amino acids, short-chain fatty acids and beta hydroxylated biogenic amines that accumulate in severe liver disease.

Source: medical-dictionary.thefreedictionary.com

LOST

by A. York

I can hear people mumbling amongst each other. I ask, "Where am I?" No one answers. I ask again, "Excuse me, where am I?" Can't they hear me? I think its time I went back home. I feel nauseous; I'm freezing cold; I'm tired; everything is spinning. Darkness engulfs me.

All around me has changed; I'm surrounded by human-looking robots; back and forth, folding, fussing, moving around me, adjusting this, inserting that, opening curtains, closing curtains, busy, busy, busy.

I'm in a different room now; the robots are gone. On one wall I see a massive window. Through the window there are buildings all in different geometric shapes: round, square, pyramid style, all made of earthen colour clay. The ground appears to be white soft sand; the sky is a washed out pale blue; there aren't any clouds; it seems motionless, still, void of any people, trees; it's barren, empty, and desolate.

I look back inside the room. There are people now; they are all different ages and dressed the same. The room is fresh with plants; shelves filled with books; white tables laden with food. Some of the people are sitting; others are standing; some are conversing with each other. I have the feeling they are waiting. I ask one of the women, "Are you all waiting for something?"

"Yes," she replies, "We're waiting to go outside."

"Should I go?"

"I don't know. Are you ready yet?"

I'm feeling dizzy, I slip into

I open my eyes. The room has changed again; in the doorway stands a beautiful woman with white hair and dark skin, draped in a lavender robe; there is a gentle presence about her; she looks familiar to me; I can see my mother's image in her. She smiles, moves slowly towards me and softly whispers I drift away.

I am feeling heavy, disoriented. In the distance I can hear... "Ms. York, Carol, Ms. York, Carol! Carol!! You have to wake up. It's time to wake up."

I try to swallow and clear my throat. It's parched and dry. Where am I? "You're in the hospital. I'm your nurse. You have been in a coma for quite sometime."

I roll over; I look at her. "A Coma?"

Note: This is a very condensed version of my experience during a hepatic coma.

A. York, 2010

ASK THE NURSE

Thanks to Lori Lee Walston, LAIR Centre, Vancouver, BC

Q: It has been said that if you have been on interferon/ribavirin before and it did not work (or if you relapse) that Pharmacare will not pay for another treatment.

[Lori Lee] It is true that Pharmacare will not pay for the same treatment, but if a new and improved treatment becomes available the situation changes. Initially, Pharmacare will only pay for naive patients who meet their criteria, which may or may not change from those presently in place. (Currently it is two ALT's, done at least 3 months apart, elevated >1.5 times normal both times.) We then start writing letters to Pharmacare requesting the new treatment for patients who do not meet criteria (usually our relapsers and non-responders to a previous treatment). We base our request on liver biopsy reports, potential progression of liver damage, CASL guidelines and blood work. We do receive many denials, but fortunately we are given approvals as well. The longer the new medication is in use and the more information that is gathered on the response rates from clinical trials, the better chance we have that Pharmacare is more willing to approve retreatment. (This process can take several years).

Q: Is this also true if the patient has been on treatment before (once by prescription, once in a trial), but it was not in BC, and the patient now wants treatment in BC under Pharmacare?

[Lori Lee] There is no communication between the provinces so BC Pharmacare does not know who has been treated elsewhere—just those in BC. So a patient who is "naive" by BC records can receive treatment as long as they meet the criteria, although we would not recommend retreatment with the same medication, as the end result will likely be the same as the first time. Clinical trial participation and the outcome are not shared between Pharmacare and the Pharmaceutical companies (patient confidentiality is a top priority). So again, a patient who is involved in a clinical trial could receive treatment paid by Pharmacare as long as the criteria are met.

Q: Can the patient still get a BC doctor's prescription for therapy (not paid for by Pharmacare), or are doctors forbidden to prescribe standard treatment to previous treatment failures?

[Lori Lee] Doctors are not forbidden to write a prescription but sometimes retreat-

ment is not the best option for the patient. The pros and cons of retreatment need to be discussed with the attending physician and the patient has to understand that statistically the response rate (and subsequently the cure rate) will be lower than for naive patients. They have to be prepared to cover 100% of the cost of the medication unless they have an extended health plan that will help. (Most will not).

Q: Is there a doctor across the BC border (Washington) who will treat Canadian HCV patients? If so, do you have his/her contact info?

[Lori Lee] We do not know any doctors in Washington state. It would be very difficult to get treatment in the States and costly. (You may as well pay for the treatment yourself in Canada). Again it is not that we will NOT treat, but that retreatment with the same medication is costly financially, emotionally and physically and is not usually recommended by most specialists worldwide.

YORK REGION HEPATITIS C EDUCATION GROUP

We hope everybody had a good start of 2010. Our next meeting will take place on January 20th.

We would like to invite you to join us and to educate yourself about Hepatitis C through discussions with members who volunteer to share their experiences. This is a great opportunity to share your frustrations and successes or to ask any questions you may not be able to ask your doctor. You'll be amazed at how much you can learn from our knowledgeable public health nurses and our members, some of whom are now cured and some of whom are going through treatment.

The meeting starts at 7:30 p.m. at the York Region Health Services office (Ontario). All are welcome to attend and to bring a friend or family member. We are located at 4261 Highway 7 East (east of Warden) in the Shoppes of Unionville plaza. Parking is available both in the front and at the back of the plaza. You can call 905-940-1333 or 1-800-461-2135 for further information or visit our website at www.hepcyorkregion.org.



Happy New Year everyone! HepCBC Fraser Valley has had its 3rd meeting. Our December 22nd meeting went very well. We want to thank Dr. Frank Anderson for supplying us with a ton of useful information, and for taking the time out of his busy schedule just before Christmas.

We had even more people at the January meeting. Word is spreading about the group. Our guest speaker at our January meeting was Sue Lal, Insurance Specialist with RBC Insurance. Sue had some unique insights, and a lot of useful information to share with the group. We hope to see YOU at the next meeting. Remember: Family, friends and caregivers are always welcome.

**HepCBC Happening
Wednesday February 17, 2010
7:15 – 8:45pm**

**North Surrey Recreation Centre,
Meeting Room, 10275 - 135th St, Surrey
SkyTrain: Surrey Central**

RSVP at your earliest convenience: Joan King at 604-576-2022 or jking2005@shaw.ca

If you have any questions or concerns, please contact Petra at 778.855.6074 or Joan at 604-576-2022



If you are receiving this newsletter by snail mail but have a computer and/or 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@hepcbc.ca and say, "Send me the email version, please," and you, too, can enjoy this newsletter in glorious colour, free of charge.

CONFERENCES 2010

5th National Aboriginal Hepatitis C Conference

Focus on addiction
17-19 February 2010
Ramada Plaza Hotel
Toronto, ON
www.caan.ca

Hepatitis C 2010:

Strategies for the New Decade
16 March 2010
City University of New York-
Graduate Center
New York, NY
More info in January

5th International Workshop on Clinical Pharmacology of Hepatitis Therapy

23 - 24 June 2010, Boston, MA, USA
Marriott Courtyard Boston Hotel, Boston
Registration and Abstract submission open on
1 March 2010

[http://www.virology-education.com/index.cfm/
t/Registration/vid/09F5AE11-B857-1BE3-
4F9A34758693B81E](http://www.virology-education.com/index.cfm/t/Registration/vid/09F5AE11-B857-1BE3-4F9A34758693B81E)

The International Liver Congress 2010

45th Annual Meeting of the EASL
14-18 April 2010
Vienna, Austria
www.easl.eu/liver-congress

Australasian Viral Hepatitis Conference 2010

6 - 8 September 2010
Sebel Albert Park
Melbourne, Victoria, Australia
Phone: +61 2 8204 0770
Fax: + 61 2 9212 4670
Email: info@hepatitis.org.au

The Liver Meeting 2010

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

The Combo Survival Guide from A to Z

[http://www.hepcsurvivalguide.org/
comboguide.htm](http://www.hepcsurvivalguide.org/comboguide.htm)

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.

There is a 24/7 Nursing Hotline and bilingual assistance available, at no charge. Other services are access to live translation services (150 languages) and injection assistance from registered nurses. Patients starting on Pegatron should ask their doctor or nurse to enroll them 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.

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 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

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@crowco.ca

www.pre86post90settlement.ca

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

COMING UP IN BC/YUKON:

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

AIDS Vancouver Island The following 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** 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. 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jeffers@avi.org

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

Burnaby HCV Support Contact Beverly 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-lattig@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 9AM-10PM. 250-595-3891

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

Kamloops AIDS Society of Kamloops (ASK Wellness Centre) HIV/HEPC Peer Support Group each Thurs. 11-2 PM, 433 Tranquille Rd. Support/Referral. info@askwellness.ca 250-376-7558 1-800-661-7541 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, eriseley@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 Offices, 101 Baker St. Drop-in 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 Support Contact Diane Morrissett, 604-525-3790 before 9 PM. dmorrissett@excite.com

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

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

Powell River Hep C Support Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact Rosemary rosemary.moran@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

Princeton Contact the Health Unit (Princeton General Hospital) 250-295-4442

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

Smithers: Positive Living North West Contact the Prince George group, please.

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources, contact Catriona 604-886-5613 catriona.hardwick@vch.ca or Brent, 604-740-9042 brent.fitzsimmons@vch.ca

VANDU The Vancouver Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061 vandu@vandu.org www.vandu.org

Vancouver 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. 250-308-7756

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

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 healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194 icolangelo3@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, bpotkonjak@liver.ca

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

Unified Networkers of Drug Users Nationally undun@sympatico.ca

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

QUEBEC:

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

ATLANTIC PROVINCES:

Halifax, NS Hepatitis Outreach Society Support. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767 program@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 wbbas@telus.net www.wbbas.ca

Manitoba Hepatitis C Support Community Inc. Each 2nd & last Tues. monthly, 7 PM, LOCATION CHANGE – Effective March 9, 2010: 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!

TIP OF THE MONTH:

GOING ON TREATMENT?

GET YOUR EYES CHECKED BY AN OPHTHALMOLOGIST