

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

BREAKING NEWS: TELAPREVIR APPROVED!!

DAWN OF A NEW ERA FDA APPROVES VICTRELIS (BOCEPREVIR)

We Hep C patients have had no new treatments in over 10 years. Now at last, we have a US FDA-approved protease inhibitor, which, when combined with yesterday's standard treatment, will become the new standard treatment in the US, and most probably in Canada...soon. And it is approved for treatment in patients never before treated, as well as for non-responders to previous treatment. This translates into more successes and shorter treatment time for some patients. The drug is taken orally, 3 times daily.

It is thought that tens of thousands of patients have been "stockpiled", waiting for the new drugs which should give them a better chance of responding on their first try at treatment. Merck is prepared to ship the drug this week. The "cure" rates, quoted as 66% for Victrelis, are much better than the 35-40% resulting from standard treatment (pegIFN + RBV).

Vertex's protease inhibitor Telaprevir is expected to be approved later this month, as well. That drug has shown a 79% "cure" rate. Both drugs have shown the potential to cut treatment time in half, depending on the patient's initial response.

Source: <u>www.reuters.com/article/2011/05/13/us-merck-victrelis-idUSTRE74C76P20110513</u>

STRANGE BEDFELLOWS

Who would have guessed that arch-rivals Merck and Roche would unite? It's true. Their astounding alliance was announced on May 17th. Roche will be encouraging its clients to use Merck's protease inhibitor Victrelis (Boceprevir) with Roche's Pegasys. All of the clinical trials for Vertex's protease inhibitor Incivek were done combining the drug with Pegasys, which is why this new partnership is so surprising to many of us. The label on Victrelis suggests that it will work with either pegylated interferon.

Why would they do this? Incivek

(Telaprevir) is expected to be approved by the US FDA in a few days. A marketing duel is expected to take place before our very eyes. Under the new agreement, Roche can have the same kind of arrangement with Vertex, but doing so would mean that Roche would have to promote two competing drugs. But Vertex may not need Roche's help, since Incivek has already proven itself in the clinical trials. The two protease inhibitors have not been tested against each other in any clinical trial, but Vertex's Incivek is believed to produce better "cure" rates than Victrelis (80% vs 60%).

In case you were wondering, the price of Victrelis has been set at \$1100.00 wholesale for a week's supply.

Source: www.thestreet.com/story/11122275/1/ merck-girds-for-hep-c-battle-with-rochedeal.html?cm_ven=GOOGLEN



INSIDE THIS ISSUE:

News: Dawn of a New Era / Victoria Day	1
Angry? Who Me?!!!	3
Overcast Sky / Recipe	4
Research Update 1996	5
Hep C on the Internet / HepCBC Marathon	6
Conferences	7
PegCARE/PegAssist/Neupogen/Compensation	7
Coming Up	8

HepCBC 1st PRIZE

(Telaprevir) is expected to be approved by the US FDA in a few days. A marketing duel is expected to take place before our very eyes. Under the new agreement, Roche can HepCBC is proud to have won 1st prize at the **Victoria Day Parade** in the category "Decorated Car, Community Group", our way of celebrating May: Hepatitis C Month.

From our Executive Director:



The parade was SO much fun, and really helped to promote awareness and fight stigma. THANKS everyone!!! Special thanks to Natasha and friends who worked so hard to help Steve with decorating, to Grasi who came from Brazil to

Kelly O'Dell Cheryl Reitz

Stephen Farmer

volunteer with us before she'd even been in Canada a week, to Kelly and Joan (and Allan) who also came from afar, to June who came at my request, probably not knowing what she was getting into, and kept



on smiling through the whole parade, and to Douglas who helped so much with the signs but had to work and couldn't march with us.

Steve, thank you! The van and trailer were amazing, and the BBQ was a wonderful way to end the day, wow. All 3 dogs were a super addition to our float! Oh, and thanks to whoever was responsible for the SUN-SHINE!!



HEPC.BULL JUNE 2011 ISSUE NO. 145 Page 1

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 1.I6

Name:
Address:
City: Prov PC
Home()Work()
Email:
□Please email me a PDF copy, free of charge.
☐Membership + Subscription (1 year)\$20.00
☐Membership Only\$10.00 (Doesn't include the <i>hepc.bull</i>)
☐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."

SUBMISSIONS: The deadline for any contributions to the hepc.bull[©] is the 15th of each month. Please contact the editors at jking2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

(Note: The hepc.bull is mailed with no reference

You may also subscribe or donate on line via

PayPal at www.hepcbc.ca/orderform.htm

to hepatitis on the envelope.)

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

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

HOW TO REACH US:

EDITOR: PHONE: FAX: EMAIL: WEBSITE:

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HepCBC 306-620 View Street Victoria BC V8W 1J6

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 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 1997-2011; 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.

HepCBC thanks 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 have helped us: Top Bookkeeping, Thrifty Foods, Samuel's Restaurant, Margison Bros. Printers, Roche Canada, VanCity, Merck Canada, Shoppers Drug Mart, and the Victoria Foundation. 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

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

To place an ad, write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send a cheque payable to HepCBC, and mail to HepCBC, Attn. Joan, #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.



Got Hep C? Single? Visit:

http://groups.yahoo.com/group/HepCingles2 http://groups.yahoo.com/group/ NewHepSingles/ www.hcvanonymous.com/singles.html www.hepc-match.com/ www.hepcsinglesonline.com/

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

NEED A BETTER RESUME?

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

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

Page 2 **HEPC.BULL JUNE 2011 ISSUE NO. 145**

ANGRY? WHO. ME?!!!

by Joan King



From the hepc.bull September 2000 page 1.

www.hepcbc.ca

I don't know about you, but I've never run into a group of "unreasonably" angry people in my life like some of those I have encountered in Hep C support groups, both "live" and on the internet. Don't get me wrong. Some of these people are my best friends, but I can't but help feeling there is some sort of physiological connection there. And to be fair, I'll even include myself. Have you felt yourself reacting in a way that you know is illogical? I sure have, especially before treatment. I did a search on the internet to see what I could find.

Indeed, I found several sources that linked anger with a diseased liver, and the sources were both holistic and medical. The holistic view is that anger is a negative emotion that can get stuck in the liver, especially a liver that isn't functioning well.

The medical point of view is that hepatic encephalopathy, or brain and nervous system damage caused by liver disorders, can cause changes in consciousness, behaviour, and personality. It can even cause coma. It can also cause forgetfulness, confusion, disorientation, delirium, dementia, loss of memory, intellect, reasoning, changes in mood, decreased alertness, daytime sleepiness, progressive stupor, decreased ability to care for oneself, loss of small hand movements, muscle tremors, seizures, speech impairment, a strange musty odour to the breath and urine, and, well, you get the idea. An EEG will show characteristic abnormalities, and blood tests can confirm this phenomenon. No, it's not your imagination.

No wonder we're angry! The severe symptoms are usually experienced only with cirrhosis, but two research groups have recently reported that HCV can affect the brain in people with less advanced disease, even with mild fibrosis. This disorder was not just related to hepatic encephalopathy. In an Austrian test comparing 58 healthy subjects to 58 subjects with HCV patients without cirrhosis, all of the HCV patients showed a "subclinical neurophysiological impairment." So maybe my observations aren't a figment of my imagination. The other study, done in the UK, reported that those with HCV scored worse in "physical and social functioning, energy and fatigue, and other measures," and ruled out any effect of previous IV drug use. Interestingly, the researchers found that patients with mild Hep C were slower in memory tests, but just as accurate as healthy subjects. A test was done in the US on both HCV positive and negative drug users, and those with Hep C scored higher for depression.

So what causes the anger? Is it all physiological? Maybe some of it is related to dealing

with a possibly deadly disease. It may be related to the fatigue or depression caused by Hep C.

What is the mechanism that allows the brain to be affected in liver disease? In the case of people with cirrhosis, the liver can no longer convert ammonia, so it collects in the brain. Ammonia is produced by the body when protein is digested. The blood no longer circulates through a diseased liver where it would usually be filtered and detoxified. Toxins can damage the brain and spinal cord. Encephalopathy can be triggered in people with stable liver disease by several things: loss of blood, too much protein, electrolyte imbalances, especially low potassium levels caused by vomiting or diuretics (eat your bananas!), draining of abdominal fluid, anything that causes alkaline blood pH. low oxygen levels in the body, medications such as barbiturates, tranquilizers, surgery, or any illness.

There is a theory that the hepatitis C virus may actually invade our central nervous system. Some brain cells normally die. As many as 30% of the dead brain cells can regenerate a year. They are nourished by circulating monocytes (a type of white blood cell). These monocytes can possibly be infected with Hep C and make their way into the brain, attacking the brain cells and causing neuropsychiatric symptoms. Scary! But this is just a theory. Post-mortem tests are now being done in London on brain tissue. Researchers also suggest that the virus may hide in the brain, where it is safe from attack by antiviral therapy. There seems to be no relationship between the severity of hepatitis and the cerebral symptoms.

All this sounds very discouraging. So what can we do? If we are constantly exploding with rage, we will alienate our family members, friends, co-workers...

First of all, when we are dealing with our friends with Hep C, we can try to be patient. We can show this article to our significant others, and hope they will understand better. People usually are more prone to anger than usual when taking interferon. Information can help arm us. Then we can start to take action.

Watch your diet:

First of all, don't drink alcohol! Watch your proteins, especially if you have cirrhosis. A high protein diet may cause increased levels of ammonia. Try to get your protein from vegetable rather than animal sources. Keep your blood alkalized and blood sugar levels stable by eating a high carbohydrate, low fat and protein diet. Eating bananas and whole grain foods promote relaxation and sleep. Foods with soy protein and eggs lead to

alertness.

Eat your biggest meal in the early part of the day to avoid restlessness and insomnia. It's good to keep a journal to see how your eating habits relate to your emotions, moods, and physical health. Avoid preservatives, additives, colours and illegal drugs or legal drugs, or at least use the smallest dose possible. Sugar is a drug which leads to fat storage. Fructose may be a better choice. Eliminate white flour products, fried foods, processed or fast foods, pasteurized and homogenized dairy products, antibiotic and hormone fed animals, addictive substances of all types, and chlorinated or fluoridated water.

Alter your lifestyle:

Smoking by the patient, or even smoke in the atmosphere, will increase measured levels of ammonia. Did you know that one cigarette smoked 1 hour before a blood test will increase the blood ammonia?

Avoid all toxins, antacids, any medication with ammonium, and if possible, sedatives and tranquilizers. Things like chiropractic, acupuncture, yoga, breathing exercises, visualisation, and/or meditation can help ease your stress levels.

Just like your mother said: Get as much exercise, fresh air and sunshine as you can.

Calming audiotapes or CDs can help, and there are some good ones with positive selftalk. It's important to maintain a positive, happy attitude.

Try stress-reducing herbs such as chamomile, thyme, lavender, lemon balm, calendula, marjoram, peppermint, rosemary, and St. John's Wort, (there are warnings about taking St. John's Wort with other anti-depressants) in reasonable amounts, and after consulting with your doctor.

Channel your anger into something positive, like letter campaigns for more clinical trials, and volunteer work.

Get medical help. At present there is not much the medical profession will do to help with subclinical neuropsychiatric complications of HCV, since many doctors do not recognize them as such. If, however, you are suffering from clinical (more serious) encephalopathy, your doctor can be of immense help. What can a doctor do to treat encephalopathy? Lots! Blood loss can trigger brain fog. The doctor can stop blood loss from gastrointestinal bleeds with endoscopy and cauterization.

To get rid of the toxins like ammonia that collect, the physician can prescribe laxatives, such as Lactulose, and enemas. A reduced- or no-protein diet may help, but this is not for everyone. Tube feedings may be necessary, and Neomycin can reduce ammonia production by intestinal bacteria. If the Hep C is "cured" with interferon or interferon plus ribavirin, this stops the inflammation and fibrosis, and, of course, the brain fog. (It can even

(Continued on page 4)

OVERCAST SKY, THE WEATHERMAN SAID

By Douglas Laird

It is Friday the thirteenth and the Supreme Court of Canada is, at present, still pondering who has jurisdiction over Insite, the supervised drug injection site in downtown Vancouver, BC. Jurisdiction... Jurisdiction... My mind can't get around this word! Oh well! I do know only a person with Hep C could fully appreciate the full laugh value of the following stories.

Stephan sat watching Stampeder's football when she walked by the couch behind him.

"Lor' grab me another beer from the fridge while you're up, would you?"

"What?" she asserted back, "Have you got a piano tied to your butt!!?"

"No," he contested. "But you should see the organ on the other side!'

Over the last couple of weeks there have been a number of potential candidates roaming my neighbourhood, my jurisdiction, with integrity and cheer. On a chilly evening I was baking a balanced diet and getting ready for the next day at work. Safe razor use all done, spray bottle of rubbing alcohol for disinfection, I thought I better swab the ears and clean up quickly before dinner. At that moment the doorbell rang.

"Elections Canada, perhaps," I thought to myself as I made haste to the door. "Jurisdiction..."

Opening the door was almost as big a shock as closing it, although I will get back to closing it in a minute. There they were! The beautiful New Democrat candidate shook my hand and introduced herself. I suddenly realized I was under full television camera—up close and friendly. No problem, right? Except that I had forgotten to take the Q-tips out of my ears? In fact I had forgotten the Q-tips were there. We started to talk about health care, and I was assured health care was priority one.

The camera kept rolling. And no, I can tell you, there is no prompter.

My approval of this candidate, who was in opposition to local Green Party candidate Elizabeth May, was evident. Then I was asked 1 avocado, if my support could be counted on. While we sliced had established a lot of common ground in a 1 C. low-fat few short minutes, and it was clear we shared similar points of view, friendships even, and priorities; I had to tell her the truth. Since arm wrestling for my vote was unlikely, and she was asking for my support on election day, I had to tell her I was likely to alienate her.

Suddenly I banged the door on a Q-tip and looked up at the camera wondering if red cheeks showed up... and where? I was about to do damage to the allied cause.

It was one of those moments that could be described somewhat like the feeling you get when you move things with your mind. We all know this super power is one of the side effects of Hep C! The ability to shift shapes also comes to mind. But no, I could not tell a lie.

My vote was used strategically.

We elected Elizabeth May here, booting out a Conservative. Therefore, I really don't understand how the nation got the Conservative majority we did! We have a culture of anti-terrorism everywhere around us, yet we just elected the very people who appear to turn a blind eye to the "viral time bomb" left on the doorstep of our nation's future. Meanwhile, if anyone other than ourselves (like our mom) packed our suitcase for us, they have hired security so we won't get on a plane by ourselves! Nevertheless, we might be looking ahead to the day that the best medical check-up they can manage to arrange will be when we get screened at airports as we leave the country to buy treatment. Going to Egypt would be a good choice, since that is where they market camel's milk which may stop hepatitis C genotype four from replicating. Egypt has the highest incidence of hepatitis C in the world, as well as having many young activists, from whom we could learn pro-active measures.

Sources:

www.carbc.ca/Portals/0/PropertyAgent/2111/ Files/31/ViralTimeBomb.pdf http://hepatmon.com/view/?id=306

TORTILLA SOUP

8 tortillas cut into strips

3 chiles pasilla (large dried chiles) or chilli powder to taste

2 T cooking oil

2 tomatoes cut in quarters and boiled

2 garlic cloves

½ onion

8 cups chicken broth

Salt to taste

Cilantro—chopped, to taste

1/2 C crumbled fresh cheese or grated cheese

sour cream

1. Heat oil. Fry tortillas until

golden. Drain on paper towel.

- 2. Remove seeds and veins from chiles.
- 3. Boil tomatoes with garlic, onion and chiles, blend, and then fry until cooked.
- 4. Add chicken broth, salt, and tortillas.
- 5. Bring to boil. Simmer 10 minutes.
- 6. Adorn each bowl with cream, cilantro, cheese, avocado. Serve hot.

WORLD HEPATITIS DAY 2011



An Open House Event to promote the Education, Prevention and Awareness of Hepatitis C

> July 28, 2011 12 - 2 PM

Positive Haven 10697-135A St Surrey, BC

Events will include a short Awareness Walk to **Surrey Central Plaza** and a Flower Ceremony in memory of our loved ones.

~ Speakers ~

~ Goodies ~ Prizes ~

~ Entertainment ~

~ Confidential HCV Testing~

Contact: Joan King (604) 576-2022 info@hepcbc.ca

Looking for Volunteers! Please contact us if interested!

(ANGRY? -Continued from page 3)

clear up early cirrhosis.) Yes, the side effects are uncomfortable, but so is end stage liver disease. Even if you don't get rid of the virus, the interferon can slow the progression of cirrhosis. Brain function seems to normalize after antiviral treatment. In the meantime, the doctor can prescribe antidepressants for those on treatment, where absolutely necessary, since the treatment itself can cause emotional disorders. Successful transplantation will take care of brain fog, but the anti-rejection medications can cause mood swings and anger.

Get counselling.

One last note: Please, if you notice any change in your mental state, or in any of your neurological functions, call your doctor. Hepatic encephalopathy can rapidly become an emergency condition!

References omitted due to space but available on request.

Page 4 **HEPC.BULL JUNE 2011** ISSUE NO. 145

MARCH 1996

Research Update From the Internet

A great deal of activity is ongoing in the development of new diagnostics, treatments and vaccines for the viral hepatitis in the United States and around the world. Several pharmaceutical companies involved in research and development have provided information on the status of their investigations.

1. You cannot cure 2. Despite your 6 worse, or may im 3. If you feel n giving too much. 4. It can be as hillness as it is for 5. Acceptance of cerned may be here investigations.

AMGEN - Will soon be filing for approval of consensus interferon, called INFERGEN, a treatment for Hepatitis C.

CHIRON - is in the final stages of preparing to begin clinical trials for a Hepatitis C vaccine. Preclinical results have shown promise for this vaccine in preventing HCV disease. If effective, trials will require five years to complete.

ROCHE - anticipates approval of ROFERON for both Hepatitis B and Hepatitis C later this year.

SCHERING PLOUGH - has agreed to pay ICN a \$23 million licensing fee to have the rights to market ribavirin for Hepatitis C. Clinical trials for the combined use of alpha interferon and the antiviral drug ribavirin for Hepatitis C are being planned.

SciCLONE PHARMACEUTICALS - Phase III of clinical trials on thymosin alphaI, with the trade name Zadaxin, have been completed for Hepatitis B and a combination therapy trial for Hepatitis C with Zadaxin and alpha interferon is being conducted.

[From the hepc.bull March 1996 edition.]



TIPS FOR COPING WITH HAVING A FAMILY MEMBER WITH HEPATITIS C

Remember:

- 1. You cannot cure your family member.
- 2. Despite your efforts, symptoms may get worse, or may improve.
- 3. If you feel much resentment, you are giving too much.
- 4. It can be as hard for you to accept the illness as it is for the ill family member.
- 5. Acceptance of the disease by all concerned may be helpful but not necessary.
- 6. You may learn something about yourself as you learn about a family member's journey through illness.
- 7. Separate the person from the virus. Love the person, even if you hate the virus.
- 8. Separate medication side-effects from the disease/person.
- 9. It is not OK for you to be neglected. You have needs and wants, too.
- 10. Your chances of catching hepatitis C from casual contact or sexual contact with a family member is extremely low, providing proper precautions are taken to avoid contact with blood.
- 11. The illness of a family member is nothing to be ashamed of. Reality is that you may encounter discrimination from an apprehensive public.
- 12. No one is to blame.
- 13. Don't forget your sense of humour.
- 14. It may be necessary to revise your expectations.
- 15. Acknowledge the remarkable courage your family member may show dealing with the illness.
- 16. Your family member is entitled to his own life journey, as you are.
- 17. Survival-oriented response is often to shut down your emotional life. Resist this.
- 18. Inability to talk about feelings may leave you stuck or frozen.
- 19. The family relationships may be in disarray in the confusion around the disease. It may be necessary to renegotiate the way things have been done in your relationship, both emotionally and physically.
- 20. Recognizing that a person has limited capabilities should not mean that you expect nothing of them.
- 21. You may experience grief issues about what you had and lost, or about what you never had.
- 22. After denial, sadness, and anger comes acceptance. The addition of understanding yields compassion.
- 23. Diseases are a part of the varied fabric 888-522-7758

of life.

- 24. It is absurd to believe you may correct a physical illness such as hepatitis with talk, although addressing social complications may be helpful.
- 25. Symptoms may change over time, while the underlying disorder remains.
- 26. The disorder may be periodic, with times of improvement and deterioration, independent of your hopes or actions.
- 27. Don't shoulder the whole responsibility for your ill family member.
- 28. Forgive yourself and others for mistakes made.
- 29. Physicians have varied degrees of competence.
- 30. If you can't care for yourself, you can't care for another.
- 31. The needs of the ill person do not necessarily always come first.
- 32. It is important to have boundaries and set clear limits.
- 33. Chronic illness affects the entire family, not just the person who actually has the disease.
- 34. It is natural to experience a cauldron of emotions such as grief, guilt, fear, anger, sadness, hurt, confusion, etc. You, not the ill member, are responsible for your own feelings.
- 35. You are not alone. Sharing your thoughts and feelings with others in a support group is helpful and enlightening for many.
- 36. The chronic illness of a family member is a trauma for the entire family. You pay a price if you do not receive support and help.
- 37. Support your local hepatitis C group and the search for a cure!

Source: www.hepcbc.ca Peppermint Patti's FAQ

my **ehealth**

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

Hep C Sites on facebook

FIGHT Against Hepatitis C

http://www.facebook.com/pages/Victoria-BC/HepCBC/274985724940



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 by using this URL: http://www.facebook.com/group.php?gid=311699175404&ref=share

twitter

How thoral

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/

HEPCBC LIVER WARRIORS HALF-MARATHON WALKING TEAM

On Sunday, October 9, 2011 in Victoria, BC, join the HepCBC "Liver Warriors" and participate in the Victoria Marathon. We will walk 21.1 km in 6 hours (or less) to publicize the benefits of exercise such as walking, particularly to those with liver disease.

If you are interested in training with this team or participating in this walk, go to www.runvictoriamarathon.com/events/

<u>register.php</u>. Be sure to select "Half-Marathon" and "Open" and "Hep C BC Liver Warriors" as your team. You must pay a \$64.86 registration fee with a credit card. You don't have to pledge anything else–only that you'll WALK with a SMILE!



Phone Cheryl at 250-360-4068 if you need help with registration or require lodging in Victoria.

If you want to join the full (42.2 km) running marathon, please phone Rachel at 250-853-3424.

See you there!

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

COMPETITION!

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

PHYSICIANS FOR PATIENTS



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

http://hepatitisc.physiciansforpatients.com/

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@hepcbc.ca and say, "Send me the email version, please," and you, too, can enjoy this newsletter in glorious colour, free of charge.

The Combo Survival Guide from A to Z

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

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.



Call HepCBC 595-3892 www.hepcbc.ca

*Stats from Public Health Agency of Canada Hepatitis C

Page 6 HEPC.BULL JUNE 2011 ISSUE NO. 145

CONFERENCES

6th International Workshop on Hepatitis C, Resistance and New Compounds.

June 22-23, 2011 Boston MA, USA

http://www.virology-education.com/

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/

AASLD 2011 The Liver Meeting

Nov. 4 - 8, 2011 Moscone West Convention Center San Francisco, CA

http://www.aasld.org/lm/Pages/default.aspx

HEPATITIS C TELECONFERENCES

Join us every Tuesday 7-9 PM CST. Listen to speakers discuss various hepatitis C related topics, followed by a Q&A session, and time to "chat." The teleconference is free and confidential.

More info: http://www.hepcmo.org



J. Lemmon

hcvresearch@rogers.com

Experienced in medical and legal research Assistance with HCV compensation claims and appeals

High success rate / Low payment rate References are available

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

PEGCARE

PegCARE is a reimbursement program to help people who have been prescribed Pegetron and need assistance with any copayment 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% reimburse-The ment. income maximum \$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-

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 Lookback Programs, Canada: 1-800-668-2866 start, stay on, and complete their treatment successfully. PegAssist Reimbursement 1-888-332-5663 (local 3467) or 604-707-3467 Specialists are available (Monday to Friday, 10 AM- 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or copayments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients homes or to the clinics.

NEUPOGEN VICTORY PROGRAM

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

Lauzon Belanger S.E.N.C. (Quebec) Toronto, ON

Phone 416-362-1989; Fax 416-362-6204

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

Roy Elliott Kim O'Connor LLP.

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

Kolthammer Batchelor & Laidlaw LLP #208, 11062 - 156 Street, Edmonton, AB T5P-4M8

Tel: 780-489-5003 Fax: 780-486-2107

kkoltham@telusplanet.net

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

Canadian Blood Services, Vancouver, BC

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 Registra-

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

CLAIMS ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

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

Settlement Agreement: http://www.reko.ca/html/ hepc_settleagreement.pdf

HEPC.BULL JUNE 2011 ISSUE NO. 145 Page 7

SUPPORT BC/YUKON:

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

AIDS Vancouver Island The following groups all provide HCV info, harm reduction, support, education and more:

• Campbell River: Drop in, needle exchange, advocacy. 1371 C - Cedar St. Contact leanne.cunningham@avi.org 250-830-0787

• Comox Valley Drop in 9-12 M-Th, harm reduction M-Fri, counseling, advocacy 355 6th St. Courtenay. Contact Sarah sarah.sullivan@avi.org 250-338-7400

• Nanaimo Hep C Meetings twice monthly: Contact Anita 250-753-2437

anita.rosewall@avi.org for details.

• Port Hardy (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shorncliffe Rd. Contact Tom, 250-949-0432 <u>tom.fenton@avi.org</u>

·Victoria Access Health Centre, drop in, disability applications, peer training. Support group each Tues 12:30 PM, 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jefferis@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 <u>r-l-attig@shaw.ca</u>

 $\textbf{HepCBC} \, \underline{\textit{info@hepcbc.ca}}, \, \underline{\textit{www.hepcbc.ca}}$

• 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 Meetings suspended for the summer. Support/Info: 604-576-2022, petrabilities@aol.com

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

 $\begin{array}{c} \textbf{Kamloops} \ \text{Hep} \ C \ \text{support group, } 2^{nd} \ \text{and} \ 4^{th} \\ \text{Wed monthly, } 10\text{--}1 \ PM, \ Interior \ Indian \\ \end{array}$ Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support and meeting info. 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 $1^{st} \& 3^{rd}$ Thurs. monthly 4-5 PM, AVI Health Centre, #216-55 Victoria Rd, Nanaimo. Contact Fran 250-740-6942.

hepctxpeersupport@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 "HepC" Support Group each Fri 10 AM May 13th till August 26th. Nurse. Acupuncture. Refreshments. Contact: Michelle 604-526-2522., mail@purposesociety.org

North Island Liver Service Info, support, treatment. Doctor or self-referral. 1-877-215-7005 250-850-2605.

Courtency: 2nd Fri monthly 1PM, Dropin, Comox Valley Nursing Centre (nurse)

Campbell River: 2nd Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

Powell River Hepatology Service Powell River Community Health, 3rd Floor-5000 Contact Melinda Ave. 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

hepcprincerupert@citytel.net

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

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

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

Surrey Positive Haven Hep C group 2nd & Regional Service. Contact 613-545-4th Thurs monthly 1 PM. 10697 135A St. Contact Monika 604-589-9004.

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

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.

Peter, pvanbo@gmail.com Tel. 250-309- 920-1601, hivaidsconnection.com 1358.

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

Whitehorse, Yukon—Blood Ties (**Four Directions**

Contact 867-633-2437 bloodties@klondiker.com

sashab@youthco.org

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/

Hamilton Hepatitis C Support **Group** 1st Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St, Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 mkowalski@hucchc.com

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange. 269 Main St. W, Suite 201, North Bay. Contact 705-497-3560, 1-800-387-3701 hepccommcoord@gmail.com, www.aidsnorthbay.com

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, Teen Health Centre -Street Health Program Office, 711 Pelissier St., Suite 4, Windsor. Contact Andrea Monkman 519-967 -0490 or <u>hepcnetwork@gmail.com</u>. http://hepcnetwork.net

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

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, NEW: Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Vancouver Pre/post liver transplant Kitchener. Contact Bob 519-886-5706. Mayis 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Hep C Support 186 King St, London. For those infected as well as affected by Hep Vernon telephone buddy, M-F 10-6 Contact C. Contact: 519-434-1601, 1-866-

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

www.publichealthgreybruce.on.ca/

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

St. Catharines Contact Joe 905-682-6194

<u>jcolangelo3@cogeco.ca</u>

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

OUEBEC:

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

ATLANTIC PROVINCES:

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767

info@hepatitisoutreach.com. www.hepatitisoutreach.com

PRAIRIE PROVINCES:

Edmonton Contact 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. 1st 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 Sup-

port 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 fo@hepcbc.ca by the 15th of the month. It's free!

Page 8 **HEPC.BULL** JUNE 2011 **ISSUE NO. 145**