

THE HEP C MYSTERY FROM A CHILD'S POINT OF VIEW

I am a long time veteran of hepatitis C. It has been my unwelcome companion for 50 years. As a ten year old in 1955, I, as a pedestrian, was hit by an impaired driver. He got a rap on the knuckles. I got a life sentence. My injuries were a broken ankle, multiple cuts and bruises, and concussions on my forehead where it hit the truck, and the back of my head where it hit the ground. My injuries were not life threatening, however I was in shock so they administered a blood transfusion. As they say, the rest is history.

After several months the obvious injuries had healed and I was expected to be back to normal, but I didn't feel back to normal. I was very weak. I was no longer able to keep up with my younger siblings, let alone my peers. I kept pushing myself with the expectation that once my muscles were strong, I would be back to where I'd been before the accident. My younger sister noticed that I was no longer playing and thought it must be because I was getting close to being a teenager. I felt that the adults in my life considered that, at best, I was suffering from some type of post traumatic shock and would eventually snap out of it, or at worst, I was malingering.

Something was wrong but I had no idea what. Was I lazy? Was I crazy? Did everyone else feel just as tired as I did, but was trying harder? Or had the concussions caused some kind of brain damage? As a typical teen, I was embarrassed at appearing different, so tried keeping my difficulties to myself. I tried to compensate for my inability to keep up physically by being the best student I could be. But Physical Education, was a nightmare. I found myself trying to participate when the teacher was looking and conserve energy when she wasn't. After a while I was also dealing with frequent nau-

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VICTORY!!!

"The 'forgotten victims' of Canada's tainted blood scandal, an estimated 5,500 hepatitis C sufferers, will be compensated in excess of \$1 billion, Stephen Harper announced today." These 5500 people were left out of a \$1.1-billion deal made in 1998 which compensated approximately 10,000 people who contracted hepatitis C through contaminated blood between 1986 and 1990. The government said that there was no test in place before then to screen for the virus, but information has emerged and was made public that shows testing could have been done earlier.



It is the opinion of many that it is just for these forgotten victims to be compensated. They are usually the sickest, since they have been infected for a longer time. They have lost their jobs, homes, families, businesses.

"In April 2005, the Liberals had a change of heart, hours before the Commons was to vote on a bill, introduced by Conservative MP Steven Fletcher, to extend the financial help to victims who became ill before 1986 and after 1990. The money, however, was not paid out before the last federal election and the Conservatives pledged to rectify the problem if elected."

(Continued on page 7)

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Neil Van Dusen

June 17, 1958-August 14, 2006

Our community has lost another of its young warriors. Neil Van Dusen, 48, of Lower Sackville passed away after a long battle with hepatitis C. Neil worked for Canada Post, was vice-president of Canadian Union of Postal Workers, Breton Local, and served as president of the Nova Scotia Chapter of the Canadian Hemophilia Society. He was a hockey coach and enthusiastic fan. He leaves behind his wife Kim, his 4 children and their families, as well as 9 siblings. His brothers Eric and David predeceased Neil—five of the brothers were infected with hepatitis C from the blood system.

Neil, a hemophiliac diagnosed with HCV in 1998, fought tirelessly for the compensation issue, even though he knew he was dying of liver cancer, and after he had been compensated. His letters were still appearing in newspapers in August (2006). "The tainted blood scandal has taken a lot away from us—our health, our dignity, and our loved ones—but the one thing it can't take away is our hope. A hope for a cure to hepatitis C and chance to continue to live day to day." (*The Herald (NS) August 16, 2006*)

"I am beyond bitter over this issue, yet don't dwell on the past. It's the future I look forward to, no matter how long." (*Edmonton Sun, Mon, August 7, 2006*)

In lieu of flowers, donations may be made in Neil's memory to Canadian Hemophilia Society of Nova Scotia. On-line condolences may be sent to the family by visiting: www.atlanticfuneralhomes.com

Sources:
pubs.cpha.ca/PDF/P20/21520.pdf,
<http://www.andrepicard.com/60000.html>
 Photo: CBC News August 18 2006

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

"I want to volunteer. Please contact me."

"I want to join a support group. Please call."

(Note: The *hepc.bull* is mailed with no reference to hepatitis on the envelope.)

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

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

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

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LETTERS TO THE EDITOR:

The *hepc.bull* welcomes and encourages letters to the editor. When writing to us, please let us know if you do not want your letter and/or name to appear in the bulletin.

NEW!!! FAQ v7

Peppermint Patti's FAQ Version 7 is now available, and Version 5.6 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 125 pages of information for only \$7 each, plus postage. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2005; the FAQ V6; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. The Resource CD costs \$10, including S&H. Please send cheque or money order to the address on the subscription/order form on this page.

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

REPRINTS

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

THANKS!!

HepCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Roche Canada, the Provincial Employees Community Services Fund, Brad Kane, Chris Foster, Judith Fry, S. Segura, The Four Mile Restaurant, Victoria Bridge Centre, Erik, Irene, Chateau Victoria, the Victoria Symphony, the Victoria Conservatory, the Shark Club, Recollections, Thrifty Foods, Patisserie Daniel, Preview Hair Studio, and the newsletter team: Tanya, Beverly A., Diana Ludgate, ALP and Ernie. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com



BE PART OF THE TEAM!

We need people to summarize articles. HepCBC needs **telephone buddies** and 2 people to help with our website. The HepCan list needs a moderator trainee. Please contact Joan at 250-595-3892 or info@hepcbc.ca

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 cheques 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.

Want a mate? Your Cupid ad could go here!

Got Hep C? Single? Visit:

<http://forums.delphiforums.com/HepCingles/>

<http://groups.yahoo.com/group/PS-Hep/>

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

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

CHAT: [http://forums.delphiforums.com/](http://forums.delphiforums.com/hepatitisen1/chat)

[hepatitisen1/chat](http://forums.delphiforums.com/hepatitisen1/chat)

Do you Have Hepatitis C?

You may be eligible to participate in a Research Study.

TO QUALIFY

We are looking for people who have hepatitis C and had no prior treatment with Interferon.

DETAILS:

You will be required to **take** investigational medication in combination with Peginterferon Alpha-2b and Ribavirin (Pegetron) for treatment of hepatitis C.

You will be required to **give blood samples**.

There will be 1 overnight stay with several out-patient visits.

If you qualify, compensation will be available.

For more information, please contact the Recruitment Coordinator at 604-875-5122, extension #7 or E-mail

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

ANTICHOLESTORAL DRUG?

Statins, generally considered anti-cholesterol drugs, have been found to possibly stop HCV replication. This in turn leads to the theory that they may be used in place of ribavirin. Certain proteins are needed in HCV replication and the statins inhibit these proteins. This may be good news for people who cannot tolerate ribavirin.

Source: <http://news.webindia123.com/news/articles/World/20060707/384975.html>

SMOKING BAD FOR FIBROSIS?

A study has found that smokers had significantly higher fibrosis scores than non-smokers. The study has led the researchers to believe that smokers may have increased risk of liver fibrosis. They found that all of the following were predictors of sever liver fibrosis: smoking, genotype 1, being male, and increased VEGF-D concentration.

Source: http://www.hivandhepatitis.com/hep_c/news/2006/070706_a.html

CAN HCV BE TRANSMITTED THROUGH COSMETIC PROCEDURES OR DRUG SNORTING?

Researchers at the University of Texas School of Public Health in Houston and the U.S. Centers for Disease Control and Prevention (CDC) have conducted a study on the correlation between cosmetic procedures, including tattoos and piercing, and drug snorting, with HCV and HBV infection. They found that these activities did not increase the risk of HCV transmission. They found that HCV was correlated to increased age, injection drug use, pre-1991 blood transfusion and incarceration. However they believe transmission by snorting/cosmetic procedure is possible.

http://www.hivandhepatitis.com/hep_c/news/2006/080106_b.html

DO YOU NEED SOMEBODY TO TALK TO?

Do you need somebody to talk to but are uncomfortable going to a group meeting or session? Not comfortable in chat rooms? If you need a shoulder to cry on, a person to rant to, or somebody to understand, please feel free to e-mail me at tanyafrizzle@hotmail.com. Not only do I live with HCV and have been through failing treatment, I have also lived through my father passing away from HCV. So even if you do not have HCV and are a concerned friend or family member who has questions, feel free to contact me.

IS THERE ALWAYS A BRIGHT SIDE?



I live by the concept of "what goes around comes around". The idea is simple. If you do your best to put good into the world, the world will do its best to give good back

into your life. And conversely, if you do your best to put negativity into the world, the world will do its best to give negativity back to you. I do not know how it came up, but one day not long after my HCV diagnosis, I said to my boyfriend that I still strongly believed in the concept of what goes around comes around. His reply was "I don't." I thought that was strange because we had talked a lot in the past about living positively and how that brings positivity back into your life. I asked him why and he said, "Look at you. You don't deserve what you got. You did nothing to deserve it, and you're a good person, but you still got it."

That took me by surprise and I did not have an answer for him. I just stood there with a dumb look on my face as I had not thought of it that way before. I had never wondered if I got what I deserved. Did I? I cannot say that I do deserve it, and I cannot say that I do not. That is for God to answer. However, after much contemplation my thought has not wavered that my boyfriend has not changed my conviction about what goes around comes around. This is because I also believe that everything happens for a reason. There has to be a reason that I have this disease. It could be that I need to learn from it. Was I taking life for granted? It could be that I need to help others. Is this a door to allow me to give back to the community? Maybe it is something to do with my family. Is this something that my family needed in order to gain unity? I may never know the exact reason that I have HCV, but I do know there is a reason and that I need to keep a positive outlook on it and in life. Otherwise I will let life eat me up with negativity.

DIAL-A-DIETITIAN

**732-9191 (Vancouver Area)
1-800-667-3438 (Toll-free
elsewhere in BC)**

HOW YOUR IMMUNE SYSTEM HELPS

HCV-specific T-cell responses (immune responses) were investigated in patients who were thought mistakenly to have recovered: 15 sustained responders to IFN treatment and 9 asymptomatic subjects who have the antibodies but don't have the virus.

HCV-specific CD4+ T-cell proliferative (reproducing) responses were found more often in apparently "cured" patients, compared with 50 chronic hepatitis C patients. Over time, T-cell frequencies and numbers usually decline and the number of HCV proteins targeted by T-cell proliferative responses was limited. The higher the viral load in the liver, the lower the immune responses, so CD4+ T-cell responders had lower viral levels in their livers. CD4+ T-cells which secreted IFN and specifically targeted HCV were not detected in all the apparently recovered patients but they were found more often than in chronic hepatitis C patients.

HCV-specific T-cells can be found in the livers of apparently recovered patients, where the virus can persist, showing that HCV may multiply if the T-cell response is not adequate.

Source: *Virus-specific T-cell responses associated with hepatitis C virus (HCV) persistence in the liver after apparent recovery from HCV infection* Juan A. Quiroga, et al, *J Med Virol*, 2006 Sep; 78 (9):1190-7

**HepCBC
ANNUAL GENERAL
MEETING**

**Wednesday, Oct 4, 2006
6 PM**

**Woodward Room
Begbie Bldg
Royal Jubilee Hospital
Victoria, BC
INFO: 250-595-3892
info@hepcbc.ca**

AGENDA:

1. Approve minutes of AGM 2005
2. Set number of directors
3. Election of those directors

AGM to be followed at 7 PM with a presentation by

Dr. Wayne Ghesquire, infectious disease specialist.
Public Welcome. Refreshments.

CLF TRIBUTE EVENT

The Canadian Liver Foundation is hosting their annual Tribute Event on Saturday, November 18, 2006 at the Plaza 500 Hotel & Convention Centre, 6:30 PM—11:30, PM to honour a true leader in the field of hepatology. This year is different from past years because for the FIRST TIME IN CANADIAN HISTORY a nurse (Natalie Rock, RN, from the LAIR Centre) has been selected for her tremendous contributions in liver disease research. Never before has a nurse been honoured at this level in Canada.

For information, please contact the Canadian Liver Foundation, BC/Yukon Region, Phone: 1 (604) 707-6430.

WARNING: RAW OYSTERS

Two deaths in Arizona in males infected with *vibrio vulnificus* and hepatitis C in past 2 months

Here are the details on two deaths related to *vibrio vulnificus* in Arizona. The first one was a 45 year-old male who resided in Pima County and became ill May 2, 2006 and passed away May 6, 2006. He had a history of Hep C, hepatic cirrhosis, and alcohol abuse. He was seen in the emergency department on May 5, 2006 due to shortness of breath, fluid retention in chest, a 2-3 day history of increasing edema and jaundice. As for his family, they always consumed oysters. The oysters were purchased from an unlicensed vendor in Tucson.

The second death was a case that resided in Maricopa County. He was a 58 year-old man who became ill on June 17, 2006 and passed away on June 19, 2006. His only pre-existing condition was hepatitis C. He and his family had eaten raw oysters at a restaurant while visiting Memphis, TN on June 15-16, 2006. The Tennessee Department of Health has been notified of the case's exposure and they will follow-up. The wife of this man is a nurse and was very concerned that she had never heard that people with hepatitis should avoid eating raw oysters. While this is thought to be general knowledge—eating raw oysters can be harmful to your health—I am not sure if there is an increased risk for Hep C carriers who consume foods contaminated with *vibrio vulnificus*.

—Laura Nathan, Arizona Department of Health via HCSP

MINI-ABSTRACTS

ANA975 TRIALS SUSPENDED

The Phase Ib trial of ANA975 (Anadys Pharmaceuticals) has been put on hold while pre-trial data is being studied as a precaution. The trial design may be modified. It has been given to over 90 healthy volunteers in Phase I trials.

Source: PRNewswire. Anadys Pharmaceuticals Suspends Dosing of ANA975 in Hepatitis C Clinical Trial Pending Further Assessment of 13-Week Pre-Clinical Toxicology Studies. June 28, 2006.

SUPER FOODS

Spices: Cloves, oregano leaf, ginger, cinnamon and turmeric.

Foods: Blackberries walnuts, strawberries, artichokes, cranberries, coffee, raspberries, pecans, blueberries, tuna, eggs, beans, citrus, bananas.

Juices: Grape juice, cranberry juice

Cereals: Bran

Best processed food: Canned chilli with meat and beans.

Other: Cocoa, Brazil nuts, garlic, yoghurt,

Sources:

http://www.health24.com/dietnfood/Diet_basics/15-1168-3481,34064.asp

http://www.health24.com/dietnfood/Diet_basics/15-1168-3481,34064.asp

BCAA

Being overweight or obese increases the risk for liver cancer in patients with cirrhosis. A multicentre, randomized, controlled trial studied 622 patients with cirrhosis. Half received 12 grams daily of branched-chain amino acid granules (BCAA), while the other half received dietary therapy. Cancer developed in 89 patients. The risk was higher in males, patients with diabetes, patients with alpha-fetoprotein (AFP) levels over 20ng/mL, patients with a higher body mass index (BMI), and patients with a lower serum albumin level. These researchers found that long term use of BCAA may lessen the cancer risk in cirrhotic patients, especially in heavier patients with a high AFP level.

Source: Hepatol Res. 2006 Jul;35(3):204-14. Epub 2006 Jun 5.

ALT LEVELS RE-VISITED

It has long been thought that ALT levels should be reviewed. Finally this has happened, and age and gender were taken into account, in this study of “healthy” people of all ages. Also taken into account were glucose, cholesterol and triglyceride levels, as well as weight. It was found that the value

for the upper limit of “normal” should be much lower than is currently accepted.

http://www.medscape.com/viewarticle/529695_1

CHITOSAN

Mice were given carbon tetrachloride (a liver toxin), and 12 days later they were given chitosan oligosaccharide, d-glucosamine and N-acetyl-d-glucosamine. The usual bad effects of the toxin were decreased significantly, and the mice's livers were protected to some extent. Other benefits were seen, as well.

Source: Hepatol Res. 35(3): 178-84.7 August 2006

IFN NON-RESPONDERS RETREATED

Italian researchers concluded that non-responders to IFN alone who were retreated and responded should be watched, because there is a slight chance that the virus may be reactivated within the 2 years following therapy.

Source: Am J Gastroenterol. 2006 Jun 16

THE OLDER PATIENT

6,865 patients ages 65 and up were included in this study of Hep C in older patients. 2,169 of them had biopsies, and bridging fibrosis was found more often in the older patient, no matter how long the person had been infected. Complications were more frequent. ALTs were lower than in younger patients. 170 were treated with peg-IFN plus ribavirin, and found to be effective (45%).

Source: Am J Gastroenterol. 2006 Jun;101(6):1260-7PMID: 16771947.

TRIPLE THERAPY FOR NON-RESPONDERS

Researchers found that a genotype 1b patient who didn't respond to previous peg-IFN plus ribavirin therapy did obtain a sustained virologic response to interferon-gamma plus interferon alfacon plus ribavirin. They hope this combination may be used for other non-responders.

Source: Dig Dis Sci. 2006 Jun 7

Get tested...



For more
information call:
250 595-3892

hepbc
www.hepbc.ca

KELLY'S STORY

I have never written to you but my mother may have. Her name is Karen Lynn Tripp. She got Hep C in 1973. The Red Cross said that the records were destroyed and that she would never prove that she got Hep C from them, yet I know for a fact that my mother could not have gotten it any other way. We talked many times about it and I was close to my mother.

Back a few years ago she had been very sick and went to see her family doctor. That is when she was diagnosed. She was heart stricken and like her, I was also.

She tried treatment. They called it a "cocktail" of different Hep C drugs. She couldn't inject them herself so I told her that I would do it for her, so every day after work I went over to her house and tried to give her this "cocktail". It was a fight. Sometimes I tricked her. It was tough some days. I decided to stop giving her the drug because she was becoming sick, a sick that was more mental than anything. She talked about dying and having nothing to live for, so I made the decision to stop the injection: this was a very tough decision.

Years went by and she became ill. Many days when we talked she cried—she cried about dying and leaving her boys behind and why this had to happen to her. I comforted her to the best of my abilities. I even helped and convinced her to move to Victoria, a place that was always close to her heart.

Days went by and she was seeing doctor after doctor, each less encouraging than the other. Some told her she would live three months, some six. She was doing everything to win the battle. One day after coming home from the doctor having heard that she could get a transplant, she blacked out walking up the one step to her little shanty, fell straight back and knocked herself out.

I got the news here in Edmonton that she had a broken neck laceration, so I made arrangements to be by her side to hold her during her recovery. There were some good days and there was some encouraging news, but when I spoke directly to her doctor he told me that she needed a transplant SOON. My younger brother was making the arraignments and starting tests to find out if he could donate. So far he was a match; a couple more matches and they would know for sure. So I flew back home and told my mother that I was always there for her. I loved her and would return to her if and when she needed me.

Three days after returning home I got a call. Her condition had worsened; I would

again return to Victoria and be by her side.

Most days in the hospital were long; it was just me sitting beside her bed holding her hand while she slept, and at night I would return to her house and look after her cats and make phone calls.

She often told me with a tear in her eye that she didn't want to die. I told her every time, "Fight and be strong. We will fight this together." She wanted me to take her home some days and I told her she would go home, she would be home.

A week went by and she became diabetic and along with having a feeding tube she was given pain killers and insulin, through an open tube in her vein. I would return home and fly my two brothers to Victoria to stay with her while I recharged. Two days after I returned, at 10:30 pm on April 25, 2005, she lost her battle with Hep C along with every painful thing that she was given.

I love my mom and miss her very much. She left a huge hole in my heart, and often I am bitter because of the loss. She meant a lot to a lot of people. I cremated her remains and granted her last wish: her ashes would be spread in Victoria by the train track in the sun. She always wanted to be warm.

It is about time to recognize that the government is responsible for her getting Hep C and it is why she isn't with us today. She never did drugs and was never promiscuous. She was a great woman with values.

Thank you for listening to my story.

Kelly Wayne Krause



KAREN LYNN TRIPP

A heart of gold stopped today. After a long hard battle Karen passed away. A loving sister, mother and friend, she will be sadly missed. She is preceded by: Son Stephen, grandmother and mother, leaving behind brother Bill Tripp and sister Penny Byrnes, four special sons: Tom, Rich, Kelly and Chris, 3 wonderful grandchildren: her special Kayla, Christopher and Kylie. And her many caring friends. She will be sadly missed.

A small gathering of friends and family gathered together to say good-bye to her. In lieu of flowers donation can be made in her name to a local animal shelter. The family would like to thank all the great people at the Victoria General and Royal Jubilee Hospitals (3 Centre) for their great help.

PegCARE

PegCARE is a reimbursement program to help people who don't have third party coverage pay for their Pharmacare deductible for hepatitis C treatment. It is pro-rated, so the less someone's net family income is, the more help they get. Basically, if someone's net family income is less than \$30,000, they will get 100% reimbursement. The more they make, the less of a percent is reimbursed, up to a max of \$100,000 income.

The patients must be signed up for Fair Pharmacare to qualify, and they also need to provide a copy of their last year's T4 form to show income level.

Each treating physician and hepatitis support nurse has these forms available to them. There is a toll free number that can be called if there are any questions or if help is needed. It's only a single page, a simple form to fill out.

PegCARE: 1-800-603-2754

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 is looking for writers for the next issue of the *hepc.bull*, and is willing to pay \$50.00 for a featured article. The article should be original, consist of 500 to 800 words, and of course, 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 the disease, or a call for action. Submissions should 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

CURRENT AND FUTURE CANADIAN HCV TRIALS

1. Not yet recruiting: Trial of Citalopram for the Prevention of Depression. NCT00317746
2. Recruiting: Pender Assisted Therapy (PATH) - Prospective Study of the Treatment of HCV. NCT00247884
3. Recruiting: Neurocognitive Functioning in Patients With Hepatitis C Pre- and Post-Treatment With Antiviral Medication NCT00188201
4. Recruiting: A Study to Evaluate the Safety and Efficacy of Celgosivir and Peginterferon Alfa-2b, With or Without Ribavirin, in Patients With Chronic Hepatitis C Genotype 1 Infection. NCT00217139
5. Recruiting: Effect of Influximab on the Efficacy of Peg-Intron/Ribavirin in Patients With Hepatitis C (Study P04257) NCT00237484
6. Not yet recruiting: A Study to Evaluate the Safety, Antiviral Effect, and Pharmacokinetics of Celgosivir in Combination With Peginterferon Alfa-2b, With or Without Ribavirin, in Treatment-Naïve Patients With Chronic Hepatitis C. NCT00332176
7. Recruiting: An Extension Study to Evaluate the Safety and Efficacy of Celgosivir and Peginterferon Alfa-2b, With or Without Ribavirin, in Patients With Chronic Hepatitis C Genotype 1 Infection. NCT00292084
8. Recruiting: Screening for Hepatitis C During Pregnancy at a Toronto Inner City Prenatal Clinic. NCT00348660
9. Recruiting: Tolerability of Peginterferon Plus Ribavirin for Chronic Hepatitis C and HIV for Patients Receiving Antiretroviral Medication Vs Not Receiving Antiretroviral Medication. Conditions: Chronic Hepatitis C; HIV Infections. NCT00296972
10. Recruiting: An Open Label Study To Evaluate The Safety and Kinetics of Nelfinavir in Subjects With HIV and Hepatitis C Conditions: HIV Infections; Hepatitis C Viral Infection. NCT00141284
11. Recruiting: Clinical Utility of Monitoring for Human Herpesvirus-6 (HHV-6) and Human Herpesvirus-7 (HHV-7) After Liver Transplant. NCT00242099
12. Recruiting: Insulin Resistance Associated With Chronic Hepatitis C (CHC) and the Effect of Antiviral Therapy. NCT00188240
13. Recruiting: Antiretroviral Switch From Didanosine to Tenofovir in HIV/HCV Co-Infected Patients NCT00358696

Thanks to ALP for this list.
Source: www.clinicaltrials.gov/



MY NAME IS KEITH

My name is Keith McDonald and I have Hepatitis C. I contracted HCV from intravenous drug use many years ago. When I was doing drugs education was not very widespread. I am now 47 years old and paying for my mistakes. I agree I messed up but now my life is in danger from something that was not even known about when I was doing drugs. Shortly after I stopped they came up with HCV but it was not named. It was called hepatitis non-A or non-B. I was feeling sick for years and the doctors could not figure out what was wrong with me until 2001 when I tested for positive for HCV. Now my liver is at stage 3 grade 3 fibrosis which means I am just about into cirrhosis. HCV has destroyed my life. I can no longer work and I am on disability which makes me feel like a substandard part of our great country. Day to day living is difficult. I have extreme fatigue. I suffer from brain fog which means I can be talking to someone and half way through a sentence I forget what I was saying I feel sick most days and have many more symptoms. It is not a very nice way to have to live at all. I am very open about my HCV as I would hate to ever pass it along to anyone else, but I do pass along the knowledge that I have about HCV in my community. I am very active in spreading the word about HCV and talking about prevention, which includes education and harm reduction. Harm reduction, I know, scares a lot of people but it has nothing to do with drugs. It has to do with not spreading HCV or any other diseases. I know the majority of you know a relative or friend who is infected with HCV, whether they have told you or not. If they even know is another story. There are more than 65,000 in British Columbia who are infected and one out of three isn't even aware of having HCV. Since I found out that I had Hep C I have been on treatment twice. The first time did not work and the second time I did a study with a pegylated treatment but I went psychotic on it and ended up in the psycho ward for six weeks. So now I need to wait for a new treatment to be made available. There are a few new treatments coming out but once they are released it sometimes takes years for them to be approved in Canada and then it could take years before the provinces approve them. How many people have to die before the different levels of government pay attention? I pray that there will be a change soon. We can halt the spread of HCV but we need help. Remember, it could be you or your child who could be the next to get HCV, so all of us need to get onboard and fight this until it is under control.

—Keith

(THE HEP C MYSTERY—Continued from page 1)

sea, lack of appetite, dizzy spells and a periodic nagging pain in my right side. As far as my family doctor was concerned I was healed, so I saw another doctor visiting my school. After ruling out appendicitis he declared the pain in my side to be “growing pains”. When I was 15 and had finished growing, I saw another doctor whose first conclusion was that I may be pregnant. His second guess was some type of gastrointestinal infection. Through my teens I resorted to keeping as much of my body covered as possible in hope that people wouldn't be aware of how excessively thin I was. I tried to act as normal as possible with other people and get as much rest as I could otherwise. I had a very limited social life. Most days seemed to consist of going to school, doing my homework and sleeping. The silver lining was that I didn't have the opportunity to get involved in any risky behavior that could have made the outcome worse.

A few attempts at berry picking to earn a little summer cash made me realize that if I didn't get over whatever was wrong, I was never going to be able to support myself at anything involving physical labour or even just being on my feet for a number of hours. The 60's were a time when women were celebrating new opportunities to be independent. We were assured that we could be whoever we wanted to be and do whatever we wanted to do—with equal pay. But as I studied all the options available to me I was also burdened with the nagging fear that I was going to have to find someone who would support me if I couldn't make it on my own. After starting university I met my first serious boyfriend, but he had a sister, and his mother was a nurse, so it didn't take long for him to recognize that my constant fatigue, and frequent spells of dizziness and nausea were not normal. Eventually he gave me the ultimatum of seeing a doctor and getting a cure for what was wrong or discontinuing our relationship. After ruling out an ulcer, the doctor was at a loss. I lost the boyfriend.

It was another 30 years of medical misdiagnoses and challenges in employment, marriage and motherhood before the mystery was finally solved, and it now has been a further 12 years of knowing what I'm living with and that there doesn't appear to be a solution. Despite that, there have been many joys among the frustrations. I am choosing contentment, and am thankful for a slow rate of deterioration.

—Diana Ludgate

FORGOTTEN VICTIMS DISCUSS THE DEAL

It looks like the government will finally be compensating the "forgotten victims" sometime in the not-so-distant future. They are still working out the details.

I have been following the sometimes heated discussion on the HepCan list among some of those who qualify and lawyer David Harvey, who has been very patient, and it has been exciting to see how he is listening to suggestions about how this payment should be formulated.

Should everyone get the same amount all at once? Should the payment be modeled after the 1986-90 compensation deal that gives people more according to how damaged their livers are? Hep C attacks other parts of the body—not just the liver. Should that be taken into account?

If you want to see what has been said, and maybe even take part in the discussions, you may wish to visit this Yahoo group. It is free to join, but even if you don't join, you may look through the archived messages, and of course, if you do join, you may write to the group. You don't have to be a blood recipient to join, either. Anyone affected by Hep C is welcome.

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

You may or may not wish to consider, what one of the '86-'90 members on the HepCan list. Dale has kindly given me permission to quote him:

"Lawyers deserve none the compensation money. I never used a lawyer to collect from the first payout. I filled out the forms and sent them in myself. I was paid within 6 weeks. This is really sick that all these lawyers are gonna pocket all your money cuz you can't fill in the forms for yourself. At any rate, happy spending, whatever you see after the slick lawyers get done. The money does not last long and you'll still be sick when it's all gone and you will have more bills to pay! That's the way it is. Ask to submit the forms for yourself. You can and don't need a lawyer to do it. The lawyer will pocket 40% or better of your money for something you can do yourself! Please think twice." —"Canada Dale"

This is one person's opinion. The lawyers have done a lot of work. I don't know if the do-it-yourself method is the way to go or not, but if I were involved, it would certainly be something I would want to consider and investigate.

—Joan King



(VICTORY—Continued from page 1)

As a result, the compensation class-action lawsuits that exist in 4 provinces will come to an end. It is unclear how the money some people have already received will affect how much they will get from this new package. It may take a year for the package to be approved. The form of the payout is being discussed. It is believed that the victims will receive somewhere between \$10,000 and \$200,000, depending on how sick they are.

The final agreement between the government and lawyers for the victims will still need to be signed, and win court approval. Stephen Harper said, "No distinction should be made" between the two groups. "All of these people were victims who suffered."

Sources: Janice Tibbetts, CanWest News Service, July 25, 5,500 Hepatitis C sufferers to share \$1-billion compensation package
http://www.bloomberg.com/apps/news?pid=20601082&sid=a7T9VsyqnG_g&refer=canada
Canada to Pay C\$1 Billion to Hepatitis C Victims, Harper Says July 25, 2006

COMPENSATION LINKS

Many thanks to Wendy, who sent these links (<http://www.wendyswellness.ca/links.htm>)!

1 - Pre-86 Hep C Compensation Update: An update page regarding compensation for people infected through the Canadian blood system before 1986 or after 1990.

<http://hepccc.blogspot.com/>

2 - The Hepatitis C Compensation Coalition was formed to promote fair and equal compensation for Canadians infected with hepatitis C through the blood supply.

<http://www.hepccc.ca/>

3 - Yahoo group: Tainted Blood Trials and Proceedings related to the tainted blood tragedy in Canada

<http://ca.groups.yahoo.com/group/TaintedBlood-TrialsandProceedings/>

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/hepc/intro.html

David Harvey
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204

Lauzon Belanger S.E.N.C. (Quebec)
www.lauzonbelanger.qc.ca

Roy Elliot
Roy Elliott Kim O'Connor LLP.
hepc@reko.ca www.reko.ca

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

The Canadian Blood Services, Vancouver, BC
1-888-332-5663 (local 3467) or 604-707-3467
Lookback Programs, Canada: 1-800-668-2866
Look back Programs, BC: 1-888-770-4800
Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056
Hema-Quebec Lookback/Traceback & Info Line:
1-888-666-4362
Manitoba Traceback: 1-866-357-0196

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
Ontario Compensation: 1-877-222-4977
Quebec Compensation: 1-888-840-5764
ca/en/ms/hepatitisc/forms.html

ADMINISTRATOR

1986-1990

To receive a compensation claims form package, please call the Administrator at 1-877-434-0944.
www.hepc8690.com info@hepc8690.com
<http://www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf>

Pre-86/Post-90

Hepatitis C Settlement Fund—KPMG Inc.
Claims Administrator
2000 McGill College Avenue, Suite 1900
Montreal (Quebec) H3A 3H8
1-888-840-5764 (1-888-840-kpmg)
HepatitisC@kpmg.ca
<http://www.kpmg.ca>

COMING UP IN BC/YUKON:

Armstrong Hepatitis C United Resource Exchange Contact: 1-888-HepCURE ambruse@sunwave.net www.hepcure.ca

AIDS Vancouver Island HCV support
 • **Campbell River:** Drop in, harm reduction, support, education. Contact: 830-0787, jeanette.reinhardt@avi.org leanne.cunningham@avi.org
 • **Comox Valley** 355 6th St. Courtenay; Contact Phyllis 338-7400 phyllis.wood@avi.org Drop in, harm reduction, support, education.
 • **Nanaimo** Each Wed 2-4 PM #201-55 Victoria Rd. Contact Anita 753-2437 anita.mcleod@avi.org.
 • **Port Hardy** (Sayward, Port McNeil, Alert Bay, Sointula and Woss) 7070 Shorcliffe Ave, Contact Andrea 949-0432 andrea.walters@viha.ca Mobile harm reduction, support
 • **Victoria** 1601 Blanshard St., 384-2366 info@avi.org Harm Reduction.

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

Castlegar Contact Robin 365-6137 eor@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Phone support. Contact Leslie 426-6078, ldlong@shaw.ca

Kamloops AIDS Society of Kamloops (ASK) 433 Tranquille Rd. Office 376-7558 Support/ Referral. ask@telus.net 1-800-661-7541 www.aidskamloops.bc.ca

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Sep-May, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 768-3573, eriseley@shaw.ca, Lisa 766-5132 ljmor-tell@cablelan.net or 1-866-766-5132.

Kootenay Boundary: Individual support & info Contact Brian Reinhard 364-1112 reiny57@yahoo.ca

Mid Island Hepatitis C Society 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Cindy 756-4771 midislandhepc@hotmail.com

Nakusp Support Contact. Contact Vivian 265-0073 Claire@columbiacable.net

Nelson Hepatitis C Support Group 1st Thurs. monthly 7-8:30 PM. ANKORS Offices, 101 Baker St. Drop-in library M-Th 9-4:30. Contact Alex 1-800-421-2437, 505-5506, info@ankors.bc.ca www.ankors.bc.ca/ alex@ankors.bc.ca

Mt Waddington Harm Reduction Each Tues. 10-12 8635 Granville, Pt. Hardy. Contact Dan 250-902-2238 mtwreduc@hotmail.com

New Westminster Support Contact Dianne Morrissette, (604) 525-3790 before 9 PM. dmorrissette@excite.com

Pender Harbour Hep C Support & Info Contact Myrtle Winchester 604-883-9911 or 604-883-0010 myrwin@telus.net

Powell River Hep C Support Group Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact: 485-3310

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 421. Contact Gina 963-9756, lse 565-7387 lse.kuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Public Health Unit 624-7480

Princeton Contact the Health Unit (Princeton General Hospital) or Brad at 295-6510 CitizenKane@hepcan.ca

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

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

Smithers: Positive Living North West Contact 1-866-877-0042 or Doreen 847-2132, deb@plnw.org

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@cgh.bc.ca

VANDU The Vancouver Area Network of Drug Users: Satellite Hep C group at Health Contact Centre (HCC), 166 E. Hastings, each Thurs. 2 PM. Bus fare & snack provided. Contact VANDU 604-683-6061; Fax 604-683-6199 vandu@vandu.org www.vandu.org

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

Vancouver Hepatitis C Support Group 2nd Thurs. monthly 7-9 PM, 1141 Main St. near Sky Train -Terminal & Main, and 3rd Wed. monthly, 7-9 PM VGH, Lauener Room, LP2809, near Sassafras Cafe, Jim Pattison Pavilion, South. Contact Robert, CLF: 1-800-856-7266, 778-898-7211, radmin@liver.ca www.liver.ca

YouthCO AIDS Society HepCATS #205-1104 Hornby St., Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Program Coordinator: Stephanie Grant stephanieg@youthco.org Support Program Coordinator: Brandy Svendson brandys@youthco.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Contact 542-3092, hepsc@hepc.vernon.bc.ca <http://www.hepc.vernon.bc.ca/>

Victoria HepCBC Drop-in Office/Library, 306-620 View St. Phone support, interviews, info sessions. Contact 595-3892 info@hepcbc.ca, www.hepcbc.ca

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

If you have a Canadian HCV support group to list here, please send details to info@hepcbc.ca. Please inform us of any changes by the 15th of the month —Joan

OTHER PROVINCES:

ONTARIO:

Barrie Hepatitis Support Contact: Jeanie for information/ appointment hepcsupportbarrie@rogers.com

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. **September 14:** Karen Marks, R.N. B.A., Parish Nurse, St. Mark's United Church. Complimentary Therapeutic Touch sessions will be offered. Contacts: Smilin' Sandi smking@rogers.com <http://creativeintensity.com/smking/> <http://health.groups.yahoo.com/group/hepc-info/>, Amy Pemberton, RN 905-666-6241 or 1-800-841-2729

Hamilton Hepatitis C Network Support Group 4th Thur. monthly 6-7:45pm, Where: Hamilton Urban Core Community Health Centre—Ask reception for the room. Contact Shannon Lane (905) 522-1148 ext 312. hepc@sprc.hamilton.on.ca hamiltonhepc.net

Hepatitis C Network of Windsor & Essex County Contact (519) 967-0490, www.hepcnetwork.net amonkman@hepcnetwork.net,

Kingston Hep C Info HIV/AIDS Regional Service. Contact (613) 545-3698, hars@kingston.net, www.hars.ca.

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Kitchener. Contact: Bob (519) 886-5706 bc.cats-sens@rogers.com or Mavis (519) 743-1922 elroy222@rogers.com

Niagara Falls Hep C Support Group Contact Rhonda (905) 295-4260, hepcnf@becon.org

Owen Sound Contact Debby Minielly, 1-800-263-3456, 376-9420, Ext. 257, www.publichealthgreybruce.on.ca/dminielly@publichealthgreybruce.on.ca

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

St. Catharines Contact Joe (905) 682-6194 icolangelo3@cogeco.ca

Sudbury Circle C Support Group 1st & 3rd Thurs. Contact Nancy (705) 983-4396, Cathy (705) 522-3352 or Ernie (705) 522-5156 hepc.support@persona.ca

Toronto CLF 1st Mon monthly 7:30 PM, North York Civic Centre, 5100 Yonge Street, Committee Rm #2. Contact Gina (416) 491-3353 glipton@liver.ca

Unified Networkers of Drug Users Nationally undun@sympatico.ca

York Chapter HeCSC 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact (905) 940-1333, 1-800-461-2135.

info@hepcyorkregion.org www.hepcyorkregion.org

QUEBEC:

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

ATLANTIC PROVINCES:

Saint John & Area: Information and Support. Contact Allan Kerr (506) 633-4817 kerrs@nbnet.nb.ca

Cape Breton Island, N.S. The Hepatitis Outreach Society Support Group 2nd Tues. monthly 150 Bentinck Street, Sydney, N.S. 7-9 PM. Call Cindy Coles 1-800-521-0572, 902) 733-2486 Fax: (902) 733-2487 hoscb@ns.aliantzinc.ca

PRAIRIE PROVINCES:

Regina, Saskatchewan Contact Doug (306) 545-1628 hepc-c.regina@accesscomm.ca <http://nonprofits.accesscomm.ca/hepc-c.regina/>

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

Hep C Edmonton HCV, pre/post liver transplant support Contact Fox 473-7600, or cell 690-4076

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. Meets every Tues. 7:00 PM, United Church Crossways-in-Common, 222 Furby Street, side door, corner of Furby and Broadway, Main Floor - look for the signs) 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 bettvc2@hivnetwork.ca

Victoria & Area S.O.L.I.D. Society of Living Intravenous Drug Users, Consumers Support Group Wednesdays (except welfare week) 7-9 PM 1947 Cook St, Health Unit (Cook and Pembroke) Past and Current IDU's welcome, support, info, & referrals Contact: momma@vcn.bc.ca