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Canada's Hepatitis C News Bulletin

www.hepcbc.ca

TAINTED BLOOD TRIAL BEGINS

The trial involving Dr. Roger Perrault, former head of the Canadian Red Cross, 3 other doctors—Michael Rodell, Donald Wark Boucher and John Furesz—and Armour Pharmaceutical, began on February 6.

Crown lawyers requested approval to bring in 46 expert witnesses. The defense is protesting. Judge Benotto has not yet ruled. The defendants are charged with allowing tainted blood products to be used in the 1980s and 1990s. As many as 20,000 Canadians were infected with hepatitis C, and more than 1000 others, with HIV because of tainted blood. The death toll was about 3000 in 1997. The trial is expected to last over a year.

"This is a criminal trial, this is not a public inquiry," Greenspan, the defence lawyer, argued. His client, Perrault, was not in court on opening day. On February 8, Judge Benotto decided to allow publication of the tainted blood victims' identities. Our hero, co-infected hemophiliac James Kreppner, a retired lawyer, was pleased that his interview on TV will now show his and his family's faces.

The defendants have not entered pleas. The defence says that there has not been adequate disclosure.

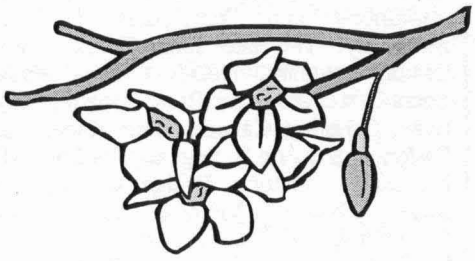
On February 13, Dr. Graham Dukes, a physician, lawyer and professor in Norway and one of the key prosecution witnesses, reversed his original position of December 20th and told the judge "I do not believe that there is, in the documentary evidence available to me, a sufficient basis for the criminal charges against the blood transfusion service and its directors."

James Kreppner "was distraught at the development," and said he would be very angry if the charges would be withdrawn. Michael Bernstein, federal prosecutor, pointed out to the judge that parts of the report from Duke showed that some charges might be valid.

Judge Benotto gave prosecutors until Feb. 21st to decide whether or not they will proceed with the trial, after Dr. Dukes' change of opinion. His reports have not been made public.

Defendant Perrault is also charged in a case in Hamilton, where it is alleged that he let a tainted blood product be given to Canadians who were hospitalized. It is not known whether or not Dr. Dukes' reversal will affect the Hamilton case or not, and it is expected that the Hamilton case will have broader ramifications. There is no date set yet for that trial.

Sources:
http://news.yahoo.com/s/cpress/20060206/ca_pr_on_he/crime_tainted_blood_4
http://cnews.canoe.ca/CNEWS/Law/2006/02/08/pf-1431320.html
http://www.chron.com/disp/story.mpl/ap/world/3656613.html
http://www.mytelus.com/news/article.do?pageID=cp_health_home&articleID=2163270



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NEWS

KETEK

The antibiotic Ketek, or telithromycin, often used for penicillin-resistant pneumonia, is thought to have caused three cases of serious liver injuries this year at a medical centre in North Carolina. One patient died, a second received a liver transplant, and the third survived. These are only three cases, all in one centre, but just in case, we with hepatitis C should be aware of any worrisome side effects of medicines we are taking.

Source: www.upi.com/ConsumerHealthDaily/view.php?StoryID=20060120-054254-4979r

DONORS BY PRESUMED CONSENT

In most parts of the world, people are considered to be organ donors unless they explicitly say they decline. This is not true in Canada, but this may change.

Ontario's Peter Kormos is planning to reintroduce a private member's bill which could establish automatic "presumed consent" donations. This should create a lively debate. Right now, potential donors must sign a donor card and have it with them to permit doctors to use their organs. Because of this, thousands of people are waiting for organs.

Other provinces have asked their governments for presumed consent, but it hasn't happened, even though more than 20 European countries have approved this policy, and in some cases 93% of patients waiting for organs receive them.

Source:www.fftimes.com/print_version.php/24492

GROWING HCV

It has been difficult for scientists to reproduce the virus in test tubes, since it only lives for a few days at the most. A study at Florida State University seems to solve the HCV mystery. These scientists have found the mechanism that makes the virus stop growing in the test tube. Better yet, the dis-

(Continued on page 4)

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☐"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 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.

Peppermint Patti's FAQ

Peppermint Patti's FAQ Version 6 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 100 pages of information for only $6 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.

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REPRINTS

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

THANKS!!

HepCBC 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, 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: Beverly A. and Diana Ludgate. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

Special thanks to Roche Canada for an unrestricted grant to help publish this newsletter!

BE PART OF THE TEAM!

We need people to summarize articles. HepCBC needs office staff and 6 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.

Ad 27

Just diagnosed. Minimal symptoms. Part-time father, mid-forties, enjoys outdoor activities, movies, dinners, talking and cuddling. Athletic, active, very positive. Fun sense of humor. Employed full time; financially stable. Respectful of others. Looking for female, similar interests, for friendship, maybe more. Victoria area. Willing to travel for the right person. Let's not live in isolation.

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/NewHepSingles/
CHAT: http://forums.delphiforums.com/hepatitiscen1/chat

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PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

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732-9191 (Vancouver Area)
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HOW BAD IS A LIVER BIOPSY? *By Tanya Frizzle*

When I found out my liver biopsy was scheduled, I decided that I was not going to search the internet to find out what the procedure is like or what others that have had it felt about it. Although the internet can be a great search tool, I also realize that it can freak you out, especially if you come across the wrong article/forum. I find that some times "fear mongers" use the internet, with what they believe as good intent, as a tool to spread their fears.

I told the nurse that I had not done any research on biopsies because I simply did not want to know and she replied, "That is probably a good idea because sometimes there are a lot of horror stories on the internet." I also decided that, since I would go through with the procedure regardless of what the possible side effects might be, there was no point in freaking myself out by reading about them.

My boyfriend pointed out that if you read the side effects of aspirin, they are pages long, but people pop those without any concern. So I went into the hospital, not knowing anything about what was going to happen, except that I knew an ultrasound would be performed, and I assumed correctly that a needle would pass through me and into my liver. I hoped my family could come with me during the procedure, but apparently it is hospital procedure where nobody else is allowed in with you. So the nurse called me in and away I went to get an ultrasound and biopsy by myself.

Thank goodness the nurse was great. She was very comforting and let me hold her hand. I went in and had an ultrasound which took about half an hour. Then the doctor came in and went straight to work. There really was not much to do. He used the ultrasound machine to find a place between two ribs where he could enter. Once he found that, he marked the area and froze it. The nurse kept telling me the freezing would feel like a bee sting, and it did, but a really long bee sting.

The next step was taking the piece of liver. This happened very quickly. I felt a pressure as he inserted the needle, at least I assume it was a needle, as I did not look. I heard a loud clicking noise, and then the needle was out and a band-aid on the hole. I was quickly propped onto my right side, the side they took the biopsy from. Apparently they want the weight of you on the biopsy area to help stop any bleeding quickly.

Then the pain began. My chest and right shoulder went instantly into spasm. I mentioned my chest really hurt, and the doctor said that was normal, as the biopsy can irritate the diaphragm. I was wheeled out into what I guess is their recovery area and was told I would have to stay on my side for an hour. Then I was free to leave.

At this point my mom and sister were called in so that they could keep me company. My mom almost had a heart attack when they called her, as none of us knew about the hour after wait time and she thought something went wrong. But she was quickly calmed and the two of them came and sat with me, which kept my mind off of the pain in my chest, shoulder and biopsy area. I demanded that I not lie on my right side to the new nurse that came by to check on my, but he laughed good-naturedly and told me I had to stay on my side. I whined that it hurt and he did his happy chuckle and told me sitting up was not going to change that.

I asked him for Tylenol and he told me he could not give me any, but if I had some, I could take it, however no Advil or aspirin was permitted. I asked him if I could eat and he said yes, so thank goodness I had put a donut in my Mom's purse for an emergency. The nurse also brought me an apple juice which was very kind of him. In fact you could see why the nurses in the area worked there. They all seemed to really care about people.

An hour later I was on my way out the door. I took a Tylenol as I was leaving and went to eat a fruit salad. By the time I finished my salad, the pain in my shoulder and chest had greatly subsided, and the biopsy area only hurt when I twisted my torso or bent from the waist. I felt pretty decent for the rest of the day.

I warn you, do not take anybody with you to the hospital who thinks they are a comedian. My Mom and sister were cracking jokes the whole hour, and it really hurt to laugh. I had to keep telling them to knock it off, and the nurse pointed out that laughter was good medicine. It really did help having them there to keep my mind off things. Although I felt good for the rest of the day, sleeping was a different story. I could not lie on my back or biopsy side, and since I am a sleeper who flips a lot, I kept waking myself up in pain.

The day after the biopsy my shoulder is still a bit sore, which is causing a mild headache, and my biopsy area still sensitive to twisting and bending, but I feel pretty OK. I

(Continued on page 5)

TANYA'S TIDBITS

DO NOT SHARE JEWELRY FOR PIERCED AREAS

It has been found that it may be possible to transmit HCV through sharing jewelry for pierced areas. A 17-year-old girl with no risk factors, who had tested negative for HCV during screening to donate blood multiple times, traded belly button jewelry back and forth with a girl who had many risk factors. A year after getting the bellybutton piercing in a sterile environment, the girl with no risk factors tested positive for HCV. It was found both girls had HCV and they had the same genotype of 3a. Although this case does not prove that the HCV was transmitted through the bellybutton ring, it remind us that this is the type of activity people may want to avoid in order to protect themselves from HCV.

Source: www.hcvadvocate.org/news/newsRev/2006/HJR-3.2.html#5

AGE AND TREATMENT

If you are an older HCV patient who is trying to decide whether to start treatment or delay it, you may want to consider the results of a study done by the Department of Gastroenterology and Hepatology at Okayama University in Okayama, Japan. The team found that combination therapy was harder to tolerate in older patients, especially in patients over 60, and they more often had to discontinue treatment or reduce the dose. In turn this leads to poorer long-term benefits of treatment and a lower sustained viral response.

Source: www.news-medical.net/?id=15189

SCHERING-PLOUGH IN A HURRY

Schering-Plough has received approval to have their new drug SCH 503034 fast tracked by the FDA. This essentially speeds up the process that gets the drug to market. This new drug is a protease inhibitor that is currently undergoing Phase II trials. To date the trial results have shown great promise with few side-effects. Unfortunately, it was not stated when they estimate this new drug will hit the market if it passes all of its trials.

Source: www.sch-plough.com/schering_plough/news/release.jsp?releaseID=809986

(Continued on page 5)

BREAKTHROUGH

It sounds like it should be something good, but when we're talking about Hep C therapy, it's not good at all. "Breakthrough" refers to when someone on treatment responds by testing negative for the virus, and then he or she tests positive again while still on treatment.

I'm taking a personal interest in this, because it just happened to me. I tested negative on Pegasys at 4 weeks, and positive again at 12 weeks. I'm genotype 1b. The last time I was on combination therapy, back in 1996, I tested negative at 6 months, only to test positive again 5 days after finishing the 48 weeks. I must admit, I suspected breakthrough the first time, and I didn't get my hopes up too much this time, but it sure felt great for a while to think to myself, "I don't have hepatitis C anymore!!" I have decided to continue treatment for as long as I can, take care of my health, and wait for the next treatment to become available. I've had this virus probably for 36 years, and no, I'm not giving up. That's not me.

But why did this breakthrough happen? The most probable is that the virus is stubborn and clever—a worthy adversary—and has mutated to withstand the onslaught of the treatment. I thought that perhaps by changing to pegylated IFN and a different brand, that it might help, and it did...for a while.

The fact is that there is no treatment plan for those who don't respond to treatment, relapse, or experience breakthrough.

Some suggestions that I have discovered while visiting PubMed are:

1. Occult hepatitis B infection (J Clin Virol. 2005 Jun;33(2):150-7), may cause treatment failure, but the treatment for that is interferon, so even if that were the case, I couldn't do much more about it.

2. Adding amantadine to the standard therapy showed some positive results in relapsers and breakthrough patients in a small study. (Dig Dis Sci. 2005 Apr;50(4):719-26). Most trials with amantadine, however, show no significant effect.

3. Treatment with Multiferon (Scand J Infect Dis. 2004;36(5):395-9) is not available in Canada, but a Scandinavian study showed that using the highly purified natural IFN-alpha was successful in treating some cirrhotic patients who had breakthrough and low blood counts.

4. There is now a test which may tell people beforehand whether or not they will respond, so they don't go through the expense and possible side effects of treatment. It's called a core antigen assay (J Med Virol. 2004 Jul;73(3):392-6) You must take into account, though, that treatment can improve the state of your liver, even if you don't have a sustained response, and that it is not yet available in Canada.

I am grateful for having had the chance to try to beat this virus once again, and I am happy to report that for me, pegylated IFN has been much easier to tolerate than the old "combo treatment."

One thing that keeps my hopes alive is all the fantastic research that is being done. I've seen and participated in enough clinical trials to believe that some of these new products will be available in my lifetime.

Joan King

TIP OF THE MONTH:

Don't forget your sense of humour

(NEWS—Continued from page 1)

covery was made because of a new test the group developed to monitor HCV replication in the lab. The reason the virus was dying was that there weren't enough nucleotide molecules, which are like building blocks for the virus. Therapies using "nucleotide starvation" are used mostly in cancer patients, but attack healthy cells, as well. HCV gets its "building blocks" from the human cells it invades in the body, and its favorite source is the liver. The researchers have put the nucleoside molecules into a culture of liver cancer cells, and were able to get HCV to survive and multiply in that culture.

Still better, the researchers can use this new technology to quickly find and isolate HCV that has mutated in the test tube and use it to look for new drug candidates. HCV mutates very quickly. This test can find the mutants in a week or less. FSU has filed a patent for this test.

Source: http://www.eurekalert.org/pub_releases/2006-02/fsu-lfs020706.php

MORE ON VX-950

Phase II results are in for VX-950. The trial lasted 28 days and enrolled 12 genotype 1 treatment naïve subjects, who received a 750 mg. tablet every 8 hours, combined with Pegasys and Copegus. After the 28 days, the subjects continued the treatment without the VX-950. These were safety trials. No one had to discontinue treatment, and no serious side effects were reported.

At the end of the first week, 6 of the 12 subjects tested below 30 IU/mL, and 2 of them tested undetectable. At the end of the second week, 11 of the 12 patients were below 30 IU/mL. In 3 of the 12, the virus was undetectable. By the end of the third week, all patients were below 30 IU/ml, and 9 of those 12 tested undetectable. At the end of week 4, having completed the VX-950 portion of the trail, all 12 patients tested undetectable, and none showed breakthrough. Further Phase II trials are planned in the US following FDA review.

Source: www.prnewswire.com/cgi-bin/stories.pl?ACCT=104&STORY=/www/story/02-07-2006/0004275914&EDATE=

THALIDOMIDE

Are you old enough to remember the thalidomide scare back in the '50s, and all those babies affected? Well, that horrifying drug may help some of us. Italian researchers have found that the drug is well tolerated in non-responding HCV patients, and reduces liver enzymes in 6 out of 8 subjects that they treated for 24 weeks. The effect seems linked to a decrease in tumor necrosis factor. The results appeared in The American Journal of Gastroenterology, February 2006 issue.

Presently there is a large trial in cirrhotic patients to see if 8 years of IFN/RBV therapy can prevent liver cancer. Another study suggests that interleukin-11 may be effective for non-responders. Vaccines are promising for the future. More options are needed for non-responders.

Source: www.natap.org/2006/HCV/020806_01.htm

(BIOPSY—Continued from page 3)
admit I had underestimated the pain the biopsy was going to cause, as I did not know my chest and shoulder would hurt so badly. However, the bad pain only lasted the hour I had to lay on it, and then it all got better quickly. It really is not all that bad.

I think the worst part of it all is now having to wait for the results. I am a lot more scared of the day I need to go in for the results than I was for going in for the procedure.

POTATO STUFFED CABBAGE

Categories: Vegetarian, Slow cooker
Yield: 8 servings

1	Head cabbage
5 lb.	Potatoes peeled
2	Onions
1/2 c	Rice, raw
1 t	Dill, dried
1/4 t	Black pepper ground
2	Egg whites
1 can	Tomatoes (28 oz)
1	Apple peeled and sliced
1/4 t	Ginger, dried ground

Parboil cabbage and separate the leaves. Slice off part of the heavy stalk of each leaf by slicing parallel to the leaf (do not cut into the leaf).

Grate potatoes, small inner leaves of cabbage, and one of the onions. Mix together. Add rice, dill, and black pepper. Beat egg whites until frothy and add to potato mixture.

Set aside two or three of the largest leaves. Fill each remaining cabbage leaf with approximately 2 Tbs. of the potato mixture. Fold up bottom of leaf, then fold in the sides, and roll up. Secure with toothpick if necessary.

Slice the reserved leaves and line the bottom of crock pot with them. Slice second onion and layer on top of cabbage. Add tomatoes, apple, and ginger. Place rolled stuffed cabbages into pot.

Cook at low heat for 4 to 5 hours.

Hepatitis C - Are you at risk? Get tested...

For more information call:
250 595-3892
hepcbc
www.hepcbc.ca

WHERE ARE WE NOW? RESEARCH FROM 10 YEARS AGO

Published in the *hepc.bull*
March 1996 issue

Research Update
From the Internet

A great deal of activity is ongoing in the development of new diagnostics, treatments and vaccines for 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.

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 alpha, 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.

CLEANING ALTERNATIVES

Surface cleanser: Mix 1 quart of hot water with 1 teaspoon of vegetable oil-based soap or detergent, 1 teaspoon of borax and 2 tablespoons of vinegar.
Glass cleaner: Mix 1/4 cup of white vinegar with 1 qt. water.
Tub and sink cleaner: Use straight baking soda, it acts as a scouring cleanser.
Toilet bowl cleaner: Mix 1/2 cup of borax with 1 gallon of water to clean and deodorize.
Laundry Detergents: Use natural, unscented laundry soap and add borax, washing soda or baking soda as a water softener.

For more alternative cleanser recipes, visit the Environmental Protection Agency's Website

(TIDBITS—Continued from page 3)

WHAT IF A BABY IS BORN WITH HCV?

I am petrified that if I have a baby, I could possibly pass my HCV on to my child; this is known as vertical transmission. I know the chance is small as I have been told it is somewhere around 6%. However, if I do decide to have a baby regardless of my HCV I want to be well informed of what that may mean to my baby if he or she is infected. Very little information seems to be available on this topic and I was happy to find a study that examined it. It was found that 20% of children born with HCV clear the virus, 50% have chronic asymptomatic HCV and 30% have chronic active infection. In essence, an infected woman has a 6% chance of passing HCV on to her baby. Of the 6% born with this unfortunate circumstance, 30% will have chronic active infection. This means that when babies are born from mothers who have HCV, 6 out of 100 will be infected. Of those 6 only 1.8 will have chronic active infection. These seem like acceptable odds to me.

Source: http://clinicaloptions.com/Hepatitis/Journal%20Options/Articles/EPHN-CID-2005-07/Capsule.aspx

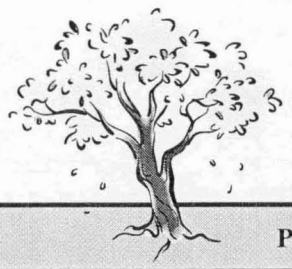
PegCARE

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 that $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



STIGMA: MY NAME IS ERNIE

Hi, my name is Ernie and I have hepatitis C. I'd like to talk a bit about the stigma surrounding hepatitis C. When I was first diagnosed, I was ignorant about hepatitis C. I didn't know what it really was. When I asked my family doctor what hepatitis C was he said, "Don't worry. You won't die from it; you'll die with it." I asked him how I got it. He asked me if I drank, I told him that I didn't drink. Then he asked me if I used drugs. I told him that I took only the drugs he prescribed for me. What I'm getting at is that even my own doctor thought the worst before asking if I had a blood transfusion. At that time I didn't even know that I had a blood transfusion. As he was my doctor for over thirty years, he began looking through my records and found that I did have a transfusion when I had a back operation by a specialist.

HCV is the most common chronic bloodborne infectious disease in Canada and the United States, with nearly 300,000 people infected in Canada and nearly 4 million in the U.S. HCV presents physical challenges to its victims, but it also carries with it a stigma that negatively affects the quality of life for those infected, including reduced self-esteem, diminished mental health, less access to medical care, and fear of disclosing a positive status, with the possibility of losing social support at a time when it is sorely needed.

I was talking to a pre-86 Hep C victim from BC not too long ago. He called his health care worker, and somehow the topic of compensation for the pre-86/post-90 came up. He was asked, "If your house burned down, do you think the government should compensate you?" His reply was, "No, but if the government lit the match, then that's another story."

How many people here have heard "Johnny or Sally, I don't want you hanging around Harry or Jane because he or she has hepatitis C, and if you hang around that person, you'll get AIDS?", or, "I was told that you have hepatitis C AIDS, so I would appreciate that you don't baby-sit for me anymore.", or "I just don't understand why he or she is always sleeping. I think he or she is just a lazy couch potato and using this hepatitis C as an excuse to get out of work," or "Hi, I just came to visit you but I left the dog in the car because I don't want the dog to catch what you have."

This one really happened to me: As a pre-86/post-90 hepatitis C victim, I have been trying to push the federal government to compensate us. I was in a group of supporters, with the media in attendance. After the news conference I asked one of the cameramen if he wanted some literature on our cause. His reply was, "No, I don't want propaganda." This took me by surprise. I asked him if he thought that hepatitis C issues were propaganda. His reply even shocked me more. He said, "Yes, and get off the bandwagon."

Another time I was coming back from Toronto by plane. I had a very hard two days and the fatigue must have showed. I sat down in my seat and the flight attendant came and asked me if I was feeling okay. I told her that I was very tired because I have hepatitis C and suffer from chronic fatigue. She then jumped back and said, "Don't touch me. I don't want to catch AIDS." I told her, "I don't have AIDS. I have hepatitis C," and because I always carry a brochure on hepatitis C with me, I gave it to her to read. In the middle of the flight she came back to my seat and said she was sorry for not understanding. I asked her if she learned anything and she replied that she wouldn't ask to use my toothbrush in the morning.

These are just a few examples of stigma. Now you remember the airline attendant? After she got the proper information, her whole outlook changed. We as people living with hepatitis C do not need sympathy. We need the public to be educated properly.

I believe the caregivers are doing a great job in educating people who are infected with hepatitis C, and I feel that they deserve a great hand. But I feel that our government has failed in understanding our needs. We need more public education.

The implicit connection between HCV infection and drug use causes HCV-positive people to often be viewed as having made poor choices: that is, they are seen as having "chosen" to engage in illicit and dangerous behaviors that resulted in their contracting a serious illness. This slots them under the label of "drug user." These individuals are deemed immoral and tainted. Notably, this debilitating stigma impacts HCV infected people regardless of how they actually contracted the virus, whether through contaminated blood or blood products, the reuse of unsterilized equipment, an accidental needle stick, through rough sex, or through the use of injection drugs during a season of life that has long past.

We need more awareness and understanding available to the public about the facts surrounding hepatitis C. Without public education made readily available to the public, the stigma will remain.

There are many people infected with hepatitis C who are still in the closet and who, because of the lack of education, live in fear of family members, friends and coworkers finding out that they have hepatitis C. These people may never come out of the closet due to the stigma and discrimination surrounding the disease.

We must work together in getting our message out to the governments that we need public education. Without Public education the stigma surrounding hepatitis C will only increase and some people infected with the virus will stay in the closet, denying themselves support, healthcare and quality of life. We are heppers, not lepers.

Ernie Zivny, Sudbury Hepatitis C Support Group. Circle C Support Group

LIVING WITH LIVER DISEASE WORKSHOPS 2006

VANCOUVER

Mar 2nd Pain and Fatigue Management, Exercise, Energy Conservation: TBA; Diet and Nutrition for Liver Disease Patients—Karen Mornin

Mar 9th Emerging Treatments for Hepatitis B and C: Current/Upcoming Clinical Trials— Dr. Frank Anderson and Natalie Rock; Hepatitis C: Current Treatments, Managing Side Effects and Self Care—Dr. Frank Anderson and Natalie Rock

Roundhouse Community Centre: 181 Roundhouse Mews (Davie and Pacific Blvd), Multimedia Room: 7-9pm. All workshops are free. To register, please contact the Canadian Liver Foundation at 604.707.6430.

NANAIMO

March 14, 21, 28 and April 4th (Tuesdays) from 7 - 9 pm at the Nanaimo Regional Hospital. Speakers are still to be determined. More info: Mid Island Hepatitis C Society midislandhepc@hotmail.com

These workshop series are made possible through an unrestricted educational grant courtesy of Schering Canada.

Victoria and 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

REMEMBERING THE REAPER

[Editor's note: Ron Theil died March 13, 2001. We honour the 5th anniversary of his death]

Ron was a founding member of HepCBC. Ron, like Kirk, went where none had gone before. His polite audacity, his dogged perseverance and his determination served as an inspiration and incentive to many of us.

Dr. C.D. Mazoff, PhD
Past-Executive Director, HepCBC

I have known many people who have died from hepatitis C, but I have to say Ron has had the most impact on my life. I am so grateful to have seized the opportunity to tell Ron what an awesome, inspirational and selfless human being he is. Ron truly was a gentleman, a scholar and a friend. I am so glad I got to say these things to him before he passed away. I will miss him greatly. I made him a promise we would continue the fight for equal compensation for those outside of the window. I told him it would be wonderful if he would guide us from above.

Leslie [Gibbenhuck] Sharp

CONFERENCES

Mar. 21-21, 2006
Sudbury, Ontario

Giving Voice to the Silent Epidemic: Hepatitis C. Sponsorship possible for those with HCV. Contact: Claire Cressey-Forsyth, (705) 670-9682, ccf@vianet.ca

March 25--28, 2006

Shanghai - Hong Kong
International Liver Congress 2006
Shanghai, China
www.livercongress.org/en/news/20041015.htm

March 31 - April 2 2006
The Toronto Hilton
CASL
2nd Annual CASL
Winter Meeting
Updates in Hepatology
www.hepatology.ca/cm/

LETTERS TO THE EDITOR

I would suggest that all pre-86/90 victims send an email to our new Prime Minister, Mr. Harper, reminding him that it was his party that made a motion on April 20, 2005 and it was decided by all parties that all hepatitis C victims be compensated fairly, equally and immediately.

I would ask how soon is immediately? We also need government sponsored educational programs dealing with stigma and prevention. There are over 350,000 Canadians infected with hepatitis C and 1/3 don't even know that they are infected.

Ernie Zivny Sudbury Hepatitis C Support Group. Circle C Support Group

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Hi Joan,

First let me give you a pat on the back for your great efforts in bringing the *hepc.bull* to us every month; I appreciate it. I hope the readers have the sense to substitute non-alcoholic wine, at least *[Note from the editor: the offending recipe appeared in our January issue]*. Now I'd like to make a gentle suggestion for the recipe column: I'm sure it was simply an oversight, but please don't publish more recipes that include alcohol, even just a couple of tablespoons of wine, because alcohol is an absolute no-no for anyone with Hep C. Some readers might get the impression that a little bit is okay; others of a more alcoholic nature might rationalize having a glass or two while preparing dinner; still others might lose respect for *hepc.bull* as an accurate, supportive and informative resource for those with Hep C.

That out of the way, thanks again for all your hard work with the *hepc.bull.*

Myrtle Winchester
Pender Harbour

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

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

Goodman and Carr LLP
pre86hepc@goodmancarr.com
www.goodmancarr.com

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

MISCELLANEOUS

Excellent Website!!: HCV Tainted Blood, Canada: http://creativeintensity.com/smking/tainted.htm

COMING UP IN BC/YUKON:

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

AIDS Vancouver Island HCV support
- **Campbell River**: 1st Mon. monthly, 1-3PM 1249 Ironwood 830-0787, jeanette.reinhardt@avi.org leanne.cunningham@avi.org Drop In; Harm Reduction
- **Comox Valley** 355 6th St. Courtenay; Contact Phyllis 338-7400 phyllis.wood@avi.org Drop In; Harm Reduction
- **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 Educational sessions/ Phone support. Contact Katerina 417-2010, hecsc-ek@shaw.ca 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 ljmortell@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 alex@ankors.bc.ca www.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 Morrissettie, (604) 525-3790 before 9 PM. dmorrissettie@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: Karen Peal 485-3310

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

Prince Rupert Hepatitis C Support Contact Ted 624-7480 Ted.Rogers@northernhealth.ca

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

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy 557-2487, wmm@island.net, www.island.net/~wmm/ http://health.groups.yahoo.com/group/CANhepc/

Salmo Hep C Support Group 2nd Wed. monthly 6 PM, 311 Railway. Contact Giselle Rogers 357-9511, Carol 357-9293 or alex@ankors.bc.ca

Slocan Valley Support Group Contact Ken 355-2732, keen@netidea.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 2nd Mon. monthly, 3-4:30 PM, Sechelt Health Unit, 5571 Inlet. Contact Brent or Karen at 604-740-9042 brent.fitzsimmons@cgh.bc.ca or Catriona at 604-886-5613.

Vancouver Native Health Three levels of training on HIV, Hepatitis STD's, drug use and harm reduction using a peer support model. Next intake: January. Contact Ken: 604-816-0192 vnhspeer@shaw.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 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, hecsc@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

Works Without Words Yukon Contact: Brian: 867-668-4483 Whitehorse for Hep C support.

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. Contacts: Smilin' Sandi smking@rogers.com Sandi's Crusade Against Hepatitis C http://creativeintensity.com/smking/ http://health.groups.yahoo.com/group/hepc-info/ 1-800-841-2729.

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, 1100 University Ave. West, Windsor. Contact 519-562-1741, amonkman@hepcnetwork.net, www.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 elroym222@rogers.com

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

Owen Sound Monthly education sessions 7 PM, Public Library Board Room, 824 1st Ave. West. 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 healthlinepeel@peelregion.ca

St. Catharines Contact Joe (905) 682-6194 jcolangelo3@cogeco.ca

Sudbury Circle C Support Group 1st & 3rd Thurs., Moose Lodge, 212 Frood Rd. Contact Ernie 705-522-5156 boomer2ca@personainternet.com

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. Nov. 16 - Dr. McNaull, Hepatitis Specialist Contact (905) 940-1333, 1-800-461-2135. info@hepcyorkregion.org www.hepcyorkregion.org

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*

QUEBEC:

Quebec City Region Contact Renée Daurio 418-836-2467 reneedaurio@hotmail.com

ATLANTIC PROVINCES:

Saint John & Area: Information and Support. Contact Allan Kerr 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:

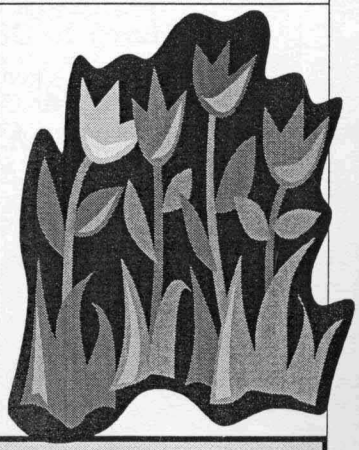
Regina, Saskatchewan Contact Doug 306-565-8593 hep-c.regina@accesscomm.ca http://nonprofits.accesscomm.ca/hep-c.regina/

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 hepSeewpg@shaw.ca

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

The Life with Hepatitis Society of Central Alberta Meets weekly. Contact Rhonda, Lana, or Chris 341-6026 crthomas@shaw.ca