

## **NEWS**

### **MEMORANDUM** Pre-86/Post-90

Health Minister Ujjal Dosanjh and lawvers for those infected with HCV through the blood system outside the 1986-1990 "window" announced on November 18 that they have signed a Memorandum of Understanding (MOU) whereby the government commits to compensate these people. Amounts and categories are being negotiated. Discussions have been taking place over the past year. Minister Dosanjh said, "The federal government will compensate the pre-1986/post-1990 class because it is health authorities are converting to the rethe right and responsible thing to do."

Investigations are taking place as to how many people belong to this class, how sick they are, and how likely it is that their illness will progress. This should take at least several months, and those involved know that the victims are waiting for the outcome.

Once an agreement has been reached, there will be a further announcement as to what claimants must do to apply.

Source: www.hc-sc.gc.ca/ahc-asc/media/nrcp/2005/2005 126 e.html Memorandum of understanding marks progress in Hepatitis C compensation discussions Nov.18, 2005

### **PERRAULT'S TRIAL** POSTPONED

The former medical director of the Canadian Red Cross, Dr. Roger Perrault, age 68, on trial for criminal negligence for allegedly allowing the distribution of tainted blood to hemophiliacs in the '80s and '90s, has had his trial postponed because of his poor health. The trial, which will probably last one year, was supposed to begin in early December, but has been put off until February 6, 2006. Perrault has heart problems.

Source: <u>www.ctv.ca/servlet/ArticleNews/sto</u>rv/ CTVNews/20051129/

taintedblood case 051129/20051129? *hub=TorontoHome* Trial postponed for doctor in tainted-blood case. Nov. 29 2005

### **RETRACTABLE NEEDLES** IN BC

Unionized BC health-care workers are demanding that the Workers' Compensation Board order the use of safety needles, which could protect them from needlestick injuries which are infecting them with blood-borne diseases such as AIDS and hepatitis B and C. Only Saskatchewan and Manitoba use safety needles at this time, although 3 of the 6 BC tracting needles. 6800 BC hospital employees receive injuries from medical devices each year, costing the system \$13.6 million for testing and treatment. The savings would more than cover the extra cost of the needles. Some of the unions want not just the hospitals, but all health facilities to convert to the retractable needles. The US mandated safety needles in 2001.

Source: <u>www.canada.com/health/story.html?</u> id=b912eba7-e3b2-40aa-ad8d-727e25610706 Camille Bains. Health care workers want safety needles made mandatory in British Columbia November 12, 2005

(Continued on page 5)

## **INSIDE THIS ISSUE:**

News/Care in Rural Communities		1
Cupid's Corner		2
Write it Down/Tanya's Tidbits/IFN Swite	ch	3
Gems from AASLD 2005		4
Recipe/Responding? Celebrate!		5
MedicAlert/Midnight Musings		6
Ottawa Rally/Compensation		7
Coming Up		8
	N.	0

### **HCV CARE IN RURAL COMMUNITIES** By Robin Tomlin

A report on rural issues dealing with care, treatment, education and community support. November, 30/2005

One of the major flaws I found during my research is the lack of qualified training for pharmacists in the dispensing and instructional advice to HCV patients starting treatment, such as side effects, and where to go for help. There is no communication between them and the medical practitioners in their areas. The other big difference I found in rural communities compared to major centres is the waiting time to get treatment and to get an appointment at the local liver clinics and the lack of access to the clinics. More knowledgeable information coming from local GPs would save time and much needed space in the liver clinics, as well. In comparison to major centres, the waiting and wasted time is 25% greater in rural communities, mainly due to lack of information and education in all areas within the community.

My recommendation is to conduct more seminars within each of the specific areas of care giving, including doctors. Also included should be educational programs for mental health workers in how to deal with the mental side effects of treatments, and educational programs for the areas' pharmacists about side effects of treatment and where and when to seek professional help. In areas such as the West Kootenay Boundary where we have a nursing program at our local college, we should be targeting the students so they may have this training and knowledge of HCV and treatment before going into the real world of health care. We also need to collaborate with all of the local community health groups to have a set of guidelines about dealing with the special needs of HCV patients. In conclusion, we need to educate and inform the general population about the risks and effects of HCV.

hepc.bull

JANUARY 2006

Issue No. 85

Page 1

### SUBSCRIPTION/ORDER FORM

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

HepCBC #306-620 View Street Victoria BC V8W 1J6		
Name:		
Address:		
City: Prov PC		
Home()Work()		
Email:		
□Membership + Subscription (1 year) \$	520.00	
Membership Only \$(for those already receiving the bulletin)	510.00	
□Subscription Only \$ (for those already members of HepCBC)	510.00	
□Peppermint Patti's FAQ	\$6.00	
□Resource CD\$	510.00	
TOTAL:		
$\square$ "I cannot afford to subscribe at this time	e but	

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

□"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."

SUBMISSIONS: The deadline for any contributions to the hepc.bull is the  $15^{th}$  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 12<sup>th</sup> of each month. Rates are as follows:

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

## **HOW TO REACH US:**

EDITOR:	Joan King	
PHONE:	TEL: (250) 595-3892	
FAX:	(250) 483-3368	
EMAIL:	jking@hepcbc.ca	
WEBSITE:	www.hepcbc.ca	
HepCan LIST:	http://health.groups.yahoo.com/	
-	group/hepcan/messages	
HepCBC		
306 620 View Street		

306-620 View Street Victoria BC V8W 1J6

## **LETTERS TO THE EDITOR:**

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

# 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.

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

# REPRINTS

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



HepCBC 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, Roval 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 <u>info@hepcbc.ca</u>

# **CUPID'S CORNER**

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

To place an ad: Write it up! Max. 50 words. Deadline is the 15<sup>th</sup> 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. Parttime 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.



### 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

# LEXMARK

Passion for printing ideas."

HepCBC gives special thanks to Lexmark for printing out our *HCV* & *Treatment* pamphlets!

## PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

# **DIAL-A-DIETITIAN**

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

Page 2

hepc.bull

JANUARY 2006

## WRITE IT DOWN

after a person dies.

My father passed away in April of HCV. and what he thought would happen was the to others. Write it down. Write your wishes farthest thing from it. He thought that the family would come together, stand by each other's side, and move on with their lives. He thought that his wishes would be respected, and he kept those wishes simple. not talked to many of my father's family Throughout my whole life it was quite clear how my father felt about death (he referred down: what your final arrangement wishes to death as "heading to the pine box") and how it should be treated. He simply did not believe in weddings or funerals. Call it strange, but that was the way he was. He never went to a wedding in my lifetime, nor did he go to a funeral-not even his own father's, to whom he was close. He was dead set against a funeral for himself, and was quite clear he wanted to be put in a coffee tin after cremation: no fancy urns for him. This was a rant he had his whole life. It never changed or wavered. He never would have guessed that in his death, there were family members who wanted to ignore his wishes. They wanted a funeral, and a viewing. This is the one place my father insisted he would never go. When his wishes were reiterated, particular family members wanted to see it in writing. I was stunned. These family members were close to him, and knew his wishes very well. I have now come to realize that it was grief causing them to act this way, but it was all quite confusing.

I had a particular family member (no names) telling me at 6:00 AM the day after my father's death that if we did not have a funeral, the person would never talk to me again. I had another family member say, "If you have a funeral, I am going to hire somebody to be my executor because I will never trust you again." It was terrible, and I had all this stress the day after my beloved father died, never mind the family members who called the next day to ask for things of my father's. Material items! My father was gone and you want a material item today? Were they worried we were going to start throwing

I hate to talk about anything that does not out his stuff? It was all very Bizzaro Land. have a positive side. I live my life looking My Mother was the final say as to his forward and never doubting that I will clear wishes, and did not want to hurt any family my HCV and live to one hundred and one members, but wanted to protect the memory and three quarters. Or you could say I live in of her husband of 27 years. She compro-La La Land. Either way works for me. How- mised and allowed a few family members to ever, sometimes things that nobody wants to view him, but with no funeral. Even allowtalk about should be discussed. I do not want ing that sickened me, because I knew quite nation therapy with interferon. In the combito talk about death, or what happens after a well how he would feel about it. However, person dies, but the reality is that people do my Mom was right in allowing it as my Fa- the virus in two weeks. The study showed die, let it be from HCV or by being hit by a ther would also not want to see these family quick viral load and ALT level reductions. It car. The reason I bring it up is because not members in pain. I believe he would have was tolerated well and shown to be safe in many, let alone myself, realize what happens agreed with the compromise. In all of this the study, the most common side effect being craziness, and all of this confusion I did headache. Due to the results of this study, learn something and would like to pass it on down. If you do not, it could cause your loved ones grief, pain and anguish. If losing a loved one is not enough, try losing a large part of your family at the same time. I have since he has passed on. Please write it all (Continued on page 5)

### **PEGETRON TO PEGASYS** SWITCH—UPDATE By Tanya Frizzle

I am here at another crossroad. I have completed 24 weeks of Pegasys. I was on Pegetron for 9 months and now I have been on Pegasys for 6 months. In total I have been on treatment for 15 consecutive months. Sometimes it feels like forever and I just want it to end; however I have made it this far and am not a quitter. I was just tested to see if I still have the virus. If I do, I will discontinue treatment. If I am clear, I will continue treatment for another 6 months. I am freaking out. That is the best way I can put it. I am one of those people who want to know things right away. I do not want to wait the 2 or 3 weeks it takes to get the results back. I know I cause my own stress, but I truly believe this is the worst part about treatment—the waiting for test results. I simply stress because I want to hear good news. I feel like I keep rolling down a bumpy road. However I need to see it this way: Even if I do not clear the virus with the treatment, I will still have stopped or slowed further damage to my liver. That is a good thing, and worth while. But if I do clear it: Woo Hoo! However, if I am clear and complete my year's worth of Pegasys, I will then have to wait another six months after discontinuing the medication to be (Continued on page 5)

# TANYA'S TIDBITS

### SCHERING STILL **TOP DOG?**

Schering-Plough is working on improving HCV treatment with a protease inhibitor. Phase I results of their trials show promise. Monotherapy was studied as well as combination treatment, 4 out of 10 treated cleared Phase II has been initiated on a large scale.

www.sch-plough.com/schering plough/news/ *release.jsp?releaseID*=782260

## **PEGASYS AFTER** PEGETRON

950 patients who failed to achieve SVR after being treated with Pegetron were treated with Pegasys. Forty five percent of the patients who took the standard dose (180 mcg/wk) of Pegasys had a early viral response, meaning their viral load dropped by at least two log. In the group that took a larger dose (360 mcg/wk) of Pegasys, which was reduced to the standard dose at twelve weeks of treatment. 62% achieved an early viral response. It was also found that 50% of the patients involved with advanced fibrosis or cirrhosis who received the large dose. which was reduced at week twelve, also achieved an early viral response. These are promising results for those in whom previous therapy has failed.

http://biz.vahoo.com/prnews/051114/ nvm258.html?.v=7

### A WAY TO STOP TREATMENT **CAUSED ANEMIA?**

Often side effects caused by the ribavirin can lead to HCV treatment dose reduction or early discontinuation. It has been found that epoetin (EPO) [Procrit] used during treatment can reduce anemia. This can stop the need for ribavirin dose reductions and early discontinuation. The study suggests that using EPO will allow higher doses of ribavirin to be used by patients, which lower relapse rates and increases SVR.

http://www.hivandhepatitis.com/2005icr/aasld/ docs/112305 a.html



(Continued on page 5)

**JANUARY 2006** 

## GEMS FROM THE AASLD 2005 www.hcvadvocate.org

### SHORT TREATMENT FOR **GENOTYPE 1?**

At week 12 of Pegetron (Peg-IFN 2b/ RBV) treatment a viral load test is done, and based on the results, it is decided whether or not treatment will be continued. Now a negative response at 4 weeks can identify the 46% of genotype 1 patients who can be treated for 24, rather than 48, weeks, 89% of these patients will probably be sustained responders. However, those who test positive at 4 weeks can still become sustained responders. Treating patients for less time can save money.

Source: Abstract ID: 65416 J. B. Wong, et al, .Clinical and Economic Implications of a 4-Week Viral Negative Response to Peginterferon Alfa-2b plus Ribavirin for Chronic Hepatitis C and Genotype 1 with Low Viral Load.

### TREATMENT INTOLERANCE

Patients in clinical trials treated with PEG-2a/RBV (Pegasys) had less depression and fewer side effects than those treated with IFN plus RBV. Those treated with Pegetron (PEG-2b/RBV) had side effects similar to IFN/RBV. In this study, 90% of patients who had to stop treatment because of side effects were able to tolerate Pegasys and finish therapy. Among patients who were nonresponders to Pegetron at 12 weeks, 12.5% tested undetectable at the 12<sup>th</sup> week of Pegasys treatment.

Source: Abstract ID: 67504 V. K. Rustgi, et al. Interim Analysis of the Safety and Efficacy of Peginterferon Alfa-2a plus Ribavirin in Chronic Hepatitis C Patients Unable to Tolerate or Nonresponsive to Treatment with Peginterferon Alfa-2b plus Ribavirin.

### **PEGETRON "WINS" FOR GENOTYPE 1's**

This study looked at genotype 1, 2 or 3 patients treated outside clinical trials, and studied the effectiveness of weight-based treatment versus fixed dose treatment with tions. the pegylated interferons. The goal was SVR (testing negative 6 months after the end of treatment.) Taken into account were types of treatment, weight, ALT, age, sex, and race. The study was done in six sites in the US, Germany and Italy, and looked at 824 patients. SVR was higher (p=0.017) in Pegetron patients than in Pegasys patients, in the genotype 1 patients. The difference was not so great in the other genotypes.

Source: Abstract ID: 62599 P L Almasio. et al. Efficacy of PEG-IFN alfa-2b vs. PEG-IFN alfa-2a + ribavirin regimens in treatment-naïve treatment. The other two were 82 and 84 chronic HCV patients: A cumulative meta- years old, and had other medical problems. analysis of retrospective data from 6 clinic sites

### **CIFN/RBV/gamma-IFN**

Standard treatment (Peg-IFN + RBV) results in about 50% sustained responses, but only 41-44% in genotype 1 patients. This trial studied the effect of combining alpha and gamma IFN in 60 previously untreated genotype 1 patients, after a pilot trial showed improved results in non-responders.

59% of the CIFN/RBV group, in 31% of the CIFN/gamma IFN group, and in 71% of the CIFN/RBV/gamma IFN group. The triple therapy may be a good choice for genotype 1 patients with high viral loads, and alpha/ gamma IFN could be a choice for patients who can't tolerate ribavirin.

Source: Abstract ID: 66839 S. Kaiser.et al. Consensus Interferon in combination with Gamma Interferon and/or Ribavirin leads to a significant response in treatment-naive Hepatitis C Genotype 1 patients.

### VX-950

Preliminary results of a Phase Ib clinical trial testing VX-950, an oral protease inhibitor, for safety and anti-viral activity, were presented last May. Now final results have been released, showing the effects of different doses in a total of 34 patients who were erability. Then after a rest period, half were treated for 5 days, and in another part of the trail, for 14 days. The trial included a placebo arm.

In 26 of 28 patients taking VX-950, there was a viral load reduction of more than 3 log10 within 2 days. The most effective dose was found to be 750 mg every 8 hours, which resulted in an average viral load reduction of 4.4 log10 after 14 days. There was no change in the placebo group. There were no serious side effects or discontinua-

Source: Abstract ID: 62580 H. W. Reesink, et al, Final Results of a Phase 1B, Multiple-dose Study of VX-950, a Hepatitis C Virus Protease Inhibitor.

## **100% SVR IN GENOTYPE 2** EARLY INFECTION

A group of 35 HCV patients infected between 2001-2003 had a certain kind of surgery in a medical centre in Israel, possi-

bly linked to a health care worker with HCV genotype 2. 33 of the patients were offered

66% of the patients were women. The average age was 48.5. Biopsies were done on 13 patients. Treatment was given for 24 weeks. One patient dropped out after 16 weeks. All the rest had sustained viral responses (SVR). 30 received Pegasys, 1 took Pegetron, and one took non-PEG-IFN. All received 800 mg daily of RBV. One patient refused treatment, and follow up wasn't possible. This trial showed a 100% response rate Sustained viral responses were found in in genotype 2 patients when treated in the first 26 months of infection.

> Source, E. Sikuler, et al, Abstract ID: 64377Sustained virological response to treatment in 100% of patients recently infected, nosocmially, with HCV genotype 2.

### **ITCH CONTROL**

One of the major complaints of Hep C patients is severe itching. Recently, reports are suggesting that SRIs (serotonin reuptake inhibitors) can improve this symptom, but little research has been done. This study enrolled 18 liver-disease patients with several different diseases (some with HCV), and the drug sertraline was studied. The patients were not allowed to take any other medication

The first part of the study was to determine the best dose for effectiveness and tolgiven sertraline and half, a placebo. After another rest period, they were switched. The patients kept a daily diary and were observed. One patient withdrew because of dizziness. The drug improved itch scores by an average of 30% in those taking the drug, even in those with depression.

Source: Abstract ID: 62020 Effect of Sertraline on Pruritus in Cholestatic Liver Disease: a Randomized Double Blind Placebo Controlled Crossover Study



hepc.bull

**JANUARY 2006** 

### **ARE IFN ANTIBODIES AT** FAULT?

IFN-neutralizing antibodies have been suspected in the failure of IFN treatment of this one, but I can't see that it can do any Hep C patients. In this study, a new testing harm. system was used to detect the IFNneutralizing antibodies in the blood of Hep C patients, called IFN-inducible Mx-promoter. That system was combined with a special PCR test (Real-time RT-PCR for MxA gene expression in PBMCs), and used on 38 patients. The antibodies were found in 3 of the non-responders, but in none of those who responded. In one patient, it is believed that his previous non-responses to IFN were due to those antibodies. The study suggests that Hep C internet mailing lists, and got some non-responders be tested for the antibodies. and should they exist, they should try choosing other types of IFN.

Source: Jorns, C, et al, J Med Virol. 2006 Jan;78 (1):74-82. Rapid and simple detection of IFNneutralizing antibodies in chronic hepatitis C non-responsive to IFN-alpha. PMID: 16299717

# VEGETARIAN PÂTÉ

4 T olive oil 8 oz tempeh, crumbled 1 c onion, chopped 1 stalk celery, chopped 1 clove garlic, minced 8 oz mushrooms, sliced or chopped  $\frac{1}{2}$  c walnuts, chopped 2 T soy sauce 2 T red wine

1. Sauté the tempeh, onion, celery, and garlic in the oil over medium heat, stirring frequently, until onion is translucent, about 6 minutes.

2. Add mushrooms. Continue sautéing about 5 min.

3. Stir in remaining ingredients. Cook, low heat, until all liquid is absorbed.

4. Let cool (1 hour)

5. Blend all ingredients until mixture becomes a smooth, brown paste.

6. Spread into bowls, cover. Refrigerate for at least 2 hours.

Serve with bread, crackers, or raw veggies. Makes about 2<sup>1</sup>/<sub>2</sub> cups 15 minutes to prepare 2 hours to chill

Source: http://veggietable.allinfo-about.com/ recipes/pate.html

## **RESPONDING? CELEBRATE. HERE'S HOW:**

Probably no doctor will back me up on

I got to thinking (Yes, I know--that's dangerous!) that here I am on treatment, and I'm negative, right? So should I really be using my old toothbrush? Should I really be using my same old fingernail and toenail clippers?

We're never immune to re-infection, even with the very same virus, so I believe that self-reinfection is a possibility. I've never heard it discussed, though.

I posted my worries on a couple of the responses. Some people said it wasn't enough blood to worry about. Others thought I had a good point.

Me? I'm not taking any chances. I had a little celebration ceremony. I threw out my used, disposable contact lenses and my toothbrush, and I will change them more often than usual during the remainder of my treatment. I changed the rubber tip for my gums. I boiled my scissors and nail clippers and contact lens case.

Looking back, I probably should have done this a week before my 12-week test, but it's probably fine now, too. I think should have changed toothbrushes once every month, starting about 2 weeks after the beginning of treatment.

As far as I'm concerned, I don't want to take the risk.

Joan King



### (WRITE IT DOWN—Continued from page 3)

are and to whom you would like to pass things on. And please, make it all clear so that your wishes can be followed exactly and vour loved ones will simply be able to mourn your loss and not stress about your wishes or your material wealth.

### (PEG SWITCH—Cont'd from page 3)

tested again to see if I am still clear of the virus. This will be one year from now, and I already warn everyone that I am not responsible for my mood or snappiness during the 2-3 week period that will occur waiting for those results.

I am still in good shape with side effects, though on the Pegasys. My only new problem is an ear infection that I simply cannot seem to clear. I have completed 17 days of antibiotics and still have the infection. Today my doctor gave me another 14 days' worth. It is not painful-simply annoying. Besides that, I continue with my shortness of breath and fatigue, but still live a full life, with some added stress at the moment.

### (TANYA'S TIDBITS—Continued from page 3) **DO HCV GENOTYPES 2 AND 3 NEED BIOPSIES?**

It can be reasoned that, due to the high rates of SVR achieved from treatment by genotype 2 and 3, there would not be a need for a liver biopsy, particularly if the transaminase levels are normal. However, cirrhosis may have begun before treatment and go undetected. Not knowing this could lead to early release from follow-up and surveillance from a doctor. The study found that, although high rates of SVR are achieved from these genotypes, a significant portion of patients had cirrhosis (33.5 %). Therefore, it was concluded that liver biopsies should still be preformed on these patients.

http://www.natap.org/2005/AASLD/aasld 10.htm

### VX-950 IS MOVING FASTER

The FDA has approved fast-track designation for VX-950. The company developing this drug is Vertex Pharmaceuticals, Inc. This means the FDA will assist in the progress of the drug and accelerate the final regulatory evaluation.

This drug is a protease inhibitor that has shown promising results in Phase I clinical trials. VX-950 has now moved into Phase II trials that include testing the drug with ribavirin and interferon.

www.bizjournals.com/boston/stories/2005/12/05/ daily47.html?t=printable www.natap.org/2005/HCV/120805 01.htm

hepc.bull

**JANUARY 2006** 

### **MedicAlert**

### One in five Canadians could benefit from the protection provided by MedicAlert®

When it comes to living life, there's a lot to enjoy. But if you have a health condition, drug or food allergy, or take medication on a regular basis, you may be exposing yourself to undue risk every single day. That's why there is MedicAlert. The medical information service provided by the Canadian MedicAlert<sup>®</sup> Foundation helps protect you in the event of medical emergencies so you can live your life to the fullest.

Research shows that one in five Canadians has a medical condition that should be known in a routine medical situation or an emergency. These individuals could benefit from the protection provided by MedicAlert.

Should an emergency occur – anywhere in the world – one call to the MedicAlert<sup>®</sup> 24-hour Emergency Hotline will immediately provide first responders and medical professionals with your complete medical record. Along with your medical information, MedicAlert also provides the names and telephone numbers of your doctor and family contacts. All this information is critical in assisting health care professionals with quick diagnoses and appropriate treatment quickly.

Many people think that carrying their list of medications, medical conditions and emergency contacts in their wallet or purse is all the protection they need to alert emergency responders to their situation. Unfortunately, you can't be guaranteed an emergency responder will have time to search for your list and there is the possibility that you may be separated from this vital information.

the internationally recognized symbol and custom-engraved information worn as a health care professionals are trained to look dian healthcare community. Canadian Medifor MedicAlert<sup>®</sup> products. In fact, 90 percent cAlert Foundation is endorsed by CAEP of emergency health care professionals surveyed stated that MedicAlert helped save cians) and NENA (National Emergency them time, and 94 percent said it helps them Nurses Affiliation), establish a diagnosis and determine treatment. These are critical factors in emergency nership with a Cansituations when every second counts!

There are more than one million people of health organizaacross Canada who rely on MedicAlert to tions, protect their lives every single day. No other body-worn personal medical identification also provides a portable emergency medical record service. No other medical identification service is more respected and trusted *tact* HepCBC: than Canadian MedicAlert<sup>®</sup> Foundation.

## **CONFERENCES**

### 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/

## **CARE-LINE**

CARE-Line, is available in Canada for some people receiving Pegetron. Patients can call 1-800-603-2754 extension 2121 to find out if they are eligible for help from this program. Health care providers who wish to make inquiries about their patients' access to CARE-Line may call 1-800-463-4636 exten- Five months was all it took. sion 346.

Source: http://www.hepcyorkregion.org/ docs/352,1,Slide 1

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

The heart of the MedicAlert service is Established in 1961, Canadian MedicAlert<sup>®</sup> Foundation is a national member-based registered charity. The services provided by bracelet or a necklet. Paramedics and other MedicAlert are also recognized by the Cana-(Canadian Association of Emergency Physi-

and works in partada-wide network hospitals. pharmacies, doctors' offices, medi-

hepc.bull



cal clinics and public health centres.

For a special offer for subscribers, con-250-595-3882, or info@hepcbc.ca

## MIDNIGHT MUSINGS II

There is a hole in my heart That once was filled with love. My soul mate was taken from me But that obviously wasn't enough. I now have Hep C. *My blood is diseased.* Sometimes it is more than I can endure. To be kicked while I am down. I guess in a way, A weird horrid turn of events. My love and I will be together again, Because of diseased blood events.

Leukemia was a terrible death for James.

So long, so short.

For me, it could be 5 decades Before I die a lovely shade of yel low.

Puff

## 

**HepCBC Hepatitis C Education** and Prevention Society

Extraordinary Meeting 9-915 Glen Vale Road Victoria, BC V9A 6N1 7 PM Wednesday, January 25, 2006

AGENDA

1. Approval of the agenda

2. Motion that by Special Resolution the society change its bylaws by deleting the bylaws 2.4.1 and 5.3.2 of the society and by adopting in their place the bylaws attached hereto:

2.4.1: A member is entitled to one vote at a meeting of members, and must become a member at least 30 days prior to the meeting to be able to vote.

5.3.2: All the Directors shall retire from office at the conclusion of each annual general meeting after their successors have been elected. Retired Directors in good standing are eligible for reelection.

Joan King, President 250-595-3892 info@hepcbc.ca

**JANUARY 2006** 

## **OTTAWA RALLY REPORT**

I wish to take this opportunity to talk about our trip to Ottawa on November 21, 2005. I wish to thank Jeff Rice and Ian De-Abreau for their support. Without their support the rally may not have been as successful. I say successful because if the rally had not taken place, the Liberals may not have signed the Memorandum on November 18, 2005, that brought us one small step closer towards compensation for the Pre-86/Post-90 hepatitis C victims. We would still be the know that we will not be the forgotten ones forgotten ones. At least we are guaranteed compensation. The Memorandum did not give an amount or a date, but as I say, we are one small step closer.

I wish to thank all the victims and supporters who traveled great distances to attend. I was very upset with the PCs as they made a big deal about compensation in the House, and Stephen Fletcher, the PC's health critic, came out, not to meet the victims, but for a photo opportunity with the media, along with five other photogenic PC candidates, and not one even said a word to the victims who attended the rally.

Jack Lavton and the NDP health critic showed genuine concern and took the time to talk to us. He even gave us an hour of his time to discuss our issues. We explained that we have more issues than compensation: We Thank You need trained doctors who know how to treat hepatitis C; we need education for the public. Above all, we explained the stigma that we go through every day because of ignorance from the public.

We, as victims, must keep up the fight and not let what ever party gets in power forget us again. We must encourage victims to stand up for their rights and not be ashamed of what our governments have allowed the Red Cross to do to Canadians for the sake of money. We must hold them accountable and responsible for their lack of concern and compassion towards Canadians and Pre-86/Post-90 hepatitis C victims. This is the responsible thing to do. We are not only victims, we are Canadians, and if they allowed this to happen to us, what can Canada expect on other issues? In my opinion, the Liberal Party has only one concern, and that is for its own survival. They will only look after themselves. They and the public seem to forget that they are supposed to work for us, not themselves. We are their boss. They are not our boss. When an employee does not do the job, what does the employer do? He fires that employee.

I am encouraging all Canadians and victims to go to all town hall meetings and

show the politicians that we will not let them forget us again by discriminating against us. Don't be ashamed for what you had no control over. The government is responsible, not you. I don't know about you, but the Memorandum signed on the 18th of November, still makes me feel like a sick kitten waiting for table scraps while the fat cats feed themselves.

Help in this election to let all parties any longer and whichever party gets in power, we want action now, not after we are dead. Let's make this a political issue. We have much to gain. Write to the news media. Tell them how you feel. Remember. the Conservatives had a part in the tainted blood, also. They were in power as our watch dog before the Liberals. Both the Liberals and Conservatives had a part of looking after the blood system. It was the Liberals who denied Pre-86/Post-90 victims compensation.

If you have any comments in regards to this, you may want to e-mail me. I would love to hear from you. E-mail me at boomer2ca@personainternet.com. Please. put "Hep C" in the subject line.

Ernie Zivnv Sudbury, Ontario



## **COMPETITION!**

epCBC 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 15<sup>th</sup> 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



Bruce Lemer/Grant Kovacs Norell Vancouver, BC Phone: 1-604-609-6699 Fax: 1-604-609-6688

Pre-1986/ Post-1990

1986-1990

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 207) Lookback Programs, Canada: 1-800-668-2866 Lookback 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/tran5e.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 <u>ambe-</u> rose@sunwave.net <u>www.hepcure.ca</u>

AIDS Vancouver Island HCV support • Campbell River: 1st Mon. monthly, 1-3PM 1249 Ironwood 830-0787, jeanette reinhardt@avi.org leanne.cunnin gham@avi.org Drop In; Harm Reduction • Comox Valley 355 6th St. Courtenay; C o nt a ct 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

•Victoria 1601 Blanshard St., 384-2366 info@avi.org Harm Reduction.

Boundary HCV Support and Education. Support, education, presentations. Contact Ken 250-442-1280 <u>ksthom-</u> son@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, Idlong@shaw.ca

Kamloops AIDS Society of Kamloops (ASK) Contact Jane: 372-7585 Support/ Referral. <u>ask@telus.net</u> 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, <u>eriseley@shaw.ca</u>, Lisa 766-5132 <u>ljmortell@cablelan.net</u> or 1-866-766-5132.

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

Mid Island Hepatitis C Society 2<sup>nd</sup> 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 1<sup>st</sup> 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, <u>info@ankors.bc.ca</u> 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** Next meeting: Contact the Health Unit 485-3310

Prince George Hep C Support Group 2<sup>nd</sup> 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 2<sup>nd</sup> Wed. monthly 6 PM, 311 Railway. Contact Giselle Rogers 357-9511, Carol 357-9293 or <u>alex@ankors.bc.ca</u>

Slocan Valley Support Group Contact Ken 355-2732, <u>keen@netidea.com</u>

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

**Sunshine Coast-Sechelt** Healthy Livers Support Group 2<sup>nd</sup> Mon. monthly, 3-4:30 PM, Sechelt Health Unit, 5571 Inlet. Contact Brent or Bill 604-740-9042 <u>brent.fitzsimmons@cgh.bc.ca</u>

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 604-658-1224 or 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 3<sup>rd</sup> 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

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 2<sup>nd</sup> & 4<sup>th</sup> Wed. monthly, 10 AM-1 PM, The People Place, 3402-27<sup>th</sup> 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. Office closed Dec, 23-Jan. 3. Contact 595-3892 info@hepcbc.ca, www.hepcbc.ca

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

hepc.bull

# **OTHER PROVINCES:**

### **ONTARIO:**

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

Durham Hepatitis C Support Group 2<sup>nd</sup> Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contacts: Smilin' Sandi <u>smking@rogers.com</u> Sandi's Crusade Against Hepatitis C <u>http://creativeintensity.com/smking/ http://health.groups.yahoo.com/group/ hepc-info/ 1-800-841-2729.</u>

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, EXCEPT DECEMBER. 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 3<sup>rd</sup> 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, <u>hepcnf@becon.org</u>

**Owen Sound** Monthly education sessions 7 PM, Public Library Board Room, 824  $1^{st}$  Ave. West. Contact Debby Minielly, 1-800-263-3456, 3 7 6 - 9 4 2 0 , E x t . 2 5 7 , www.publichealthgreybruce.on.ca/ , dminielly@publichealthgreybruce.o n.ca

Peel Region (Brampton Mississauga, Caledon) Contact (905) 799-7700 <u>healthlinepeel@peelregion.ca</u>

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

**Sudbury Circle C Support Group** 1<sup>st</sup> & 3<sup>rd</sup> Thurs., Moose Lodge, 212 Frood Rd. Pre-86/Post-90 every 2<sup>nd</sup> Fri, City Hall, Tom Davies Sq., Committee Rm. 13 C, 200 Brady St. Contact Ernie 705-522-5156 boomer2ca@personainternet.com

**Toronto CLF** 1<sup>st</sup> 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 <u>undun@sympatico.ca</u>

**York Chapter** HeCSC 3<sup>rd</sup> 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. <u>info@hepcyorkregion.org</u> www.hepcyorkregion.org

### **OUEBEC:**

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 2<sup>nd</sup> 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 hoseb@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, <u>fox@kihewcarvings.com</u>

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 1<sup>st</sup> & 3<sup>rd</sup> 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 Contact: Chris 403-341-6026 /403-302-9918 (Please leave message) crthomas@shaw.ca

A <u>free computer training</u> <u>course</u> which will run for 6-8 weeks is being held in the Castlegar, BC, area in late January. Those with HCV, a disability, or seniors wanting info can contact Robin Tomlin at eor@shaw.ca or 250-365-6137

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 15<sup>th</sup> of the month —Joan

**JANUARY 2006**