

# Canada's Hepatitis C News Bulletin www.hepcbc.ca

SAME DRAGON, SAME SILENT KILLER

Information about Hep C seems fractured and variable, just like those who have it. Not being the ultimate homogeneous group, we have so many variables on how we are affected/infected, that how we respond to those differing groups is complex and fractious, to say the least.

We have the '86-'90 Compensation group, small, as most people could not qualify due to other variables, i.e., lost records, drug use or no known points of contamination. Like, who knows?

Then we have the disallowed groups such as all the blood product people, especially women. This was a group that received blood products, primarily for pregnancy-related difficulties, sometime between 1972 and 1990. Prior to 1972, women who were Rh-negative but became pregnant with a child with a Rh-positive man, ran the risk of the child being born with Rh+ blood. This at one time was a matter of life and death for the baby (commonly referred to as 'blue babies'). They had to have blood transfusions at birth. It was a miracle when it was discovered that a blood product stopped all this anguish with a simple shot at the time of delivery. Complications in this and subsequent deliveries could be thwarted.

The same was true of the complications from exposure to German measles. Once a huge threat to an unborn fetus in the first trimester, the reaction was miraculously cured with Rhogam, Anti-D or gamma globulin, or so we thought! Not allowed!

In the Krever Commission Report, this was listed as a definite route of transmission, but somehow seemed to get lost when the first victims of compensable blood transmitted infection were compensated via the deal reached with hemophiliacs who got HIV/ AIDS. After that, via lawyers and government guys (supposed to be our employees, working FOR us), the watered-down version (Continued on page 5)

### NEWS

#### SUSPENDED

A surgeon in Birmingham, England, has been declared guilty of professional misconduct because he performed more than 18 invasive procedures while he was infected with hepatitis C. Government guidelines from 2002 prohibit medical workers from performing procedures where the blood of the worker could enter patients' bodies. The surgeon was told to stop operating, but he did not heed the warming. His license to practice has been suspended for 3 months.

Source: <u>www.dailymail.co.uk</u> September 16, 2005 Hepatitis C' surgeon suspended

### CELGOSIVIR

MBI-3253 (celgosivir) by Micrologix is a derivative of the Australian Black Bean chestnut tree. It inhibits an enzyme that affects the processing of glyoproteins which HCV requires to live. The product has an advantage of inhibiting an enzyme rather than a virus, thus avoiding resistant mutations. A phase IIa trial of the product conducted in Vancouver BC, and in San Diego, showed few side effects and some antiviral activity in HCV+ genotype 1 patients. Celgosivir is taken orally. Our own Dr. Eric Yoshida of UBC is one of the investigators, and

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PRISCILLA UDALL-EKMAN September 3, 2005

### MEET PRISCILLA

I had a nice, interesting chat with Priscilla, a member of our local chapter, the other day, and found her to be a most interesting, charming person!

Did you know that she was born in Brazil, and lived there until she was 28? She was a nurse. Now, I'm not just gossiping about her without her permission. She kindly said I could print her story in the news bulletin. I asked, because I heard that, besides having Hep C, she was diagnosed as having cirrhosis 40 years ago! Personally, I find this very inspiring, so I proceeded to try to find out how she has succeeded so well in battling the Hep C dragon.

I asked her about her symptoms: At first, she had none. She lived a normal life. Once in a while she'd get yellow eyes and bloating—of course, she didn't know she was sick. She says if she takes any drug or doesn't follow her dietary regimen, she gets stomach problems. She has chronic diarrhea. She also has trouble walking—a flu shot affected the nerves in her arms and legs a while ago—but she says it bears no relation to hepatitis C.

She was diagnosed with hepatitis C in 1989 or 1990. She had been diagnosed

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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

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The CD contains back issues of the hepc.bull from 1997-2005; the FAO 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.



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

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

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> TO SUBSCRIBE CALL 800-792-6397 or visit us online @

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### **DIAL-A-DIETITIAN**

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

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### WHOSE FAULT IS THIS, ANYWAY? By Tanya Frizzle

When I first found out about my HCV the first things that started running through my mind were: How? When? Who?

At least, those were my first thoughts right after "Oh my God!" cleared out of my head. Since then, many people have asked me the same questions. Family, physicians, friends, colleagues—they all want to know the answers to those very same questions. To me it seems like the million dollar question. "If you can answer this question we will give you one million dollars (evil laugh): What is the exact moment that the hepatitis C virus entered your bloodstream?" Damn! I'm still poor.

Over the course of the next few months I went through every possible scenario in my brain, trying to figure out how the virus entered my body. But alas, I could not pinpoint any specific moment. I wanted to blame somebody. It had to be somebody's fault, and if I could just figure out whose, then maybe I would feel better. Maybe I would not have to blame myself. Then one day I figured it out. I figured out the answer to the million dollar question.

"Excuse me, sir. I have the answer! It does not matter! All that matters is that I have it and now have to learn to live with it. Can I have my million dollars now, and can I have it all in twenties?"

Once I figured that out, it seemed like a weight was lifted off of my shoulders and I could now move forward instead of floundering around in the past. It is nobody's fault. It is not mine, and it certainly is not somebody else's fault. It is simply how the course of my life is going to go. This realization kicked me out of my mental state of feeling sorry for myself and feeling like life was unfair. I have always believed that there is a reason for everything, and I had to come back to this belief and re-analyze it. Yes, I now get to live with a virus that makes me to prevent anemia. ill, that has taken the life of my father and may take my life, but I won't go down without a fight. And I've also realized what I do have and thank God every night for the life I've lived, the life before me, my family, my friends, and my fiancé. It may seem unfair that I have HCV, but who knows? Maybe



one day the reason that I get to live with HCV will be made clear to me. Or, maybe I'll get that million dollars anyway.

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

My 12 week lab results are in! Has the switch worked? I don't know, but the results give me hope! The qualitative test tells me simply whether I do or do not currently have HCV. This is a very sensitive test, and it came back positive. I do still have HCV. However, the other test that was done was the quantitative test. This test could not detect the virus in my blood! A qualitative test is more sensitive than a quantitative test for detection of very low levels of the virus. Therefore, it is possible that I am responding to the switch from Pegetron to Pegasys. I can't wait for more testing at 24 weeks!

Have I had any new side effects? Not really. I was looking back at my submissions over the last few months and realized, though, that I have failed to mention some side effects that I have experienced. I failed to mention them because half of the time I have to stop a second to recall my own name, or what I was doing five minutes ago. That is a side effect that I cannot wait to get rid of.

Due to this, I failed to mention that because of my extremely low platelets, I had my menstrual cycle for over two months. And on the weeks that I was actually due for my cycle, it was completely out of control. If you have an issue with low platelets and are female, definitely talk to your family doctor about "continuous" birth control.

You take it for three to five months on end, without a cycle. It helped me get rid of my cycle.

The other thing I failed to mention is Saturday nights. I take my injections on Friday and by 9 PM to 10 PM on a Saturday night is when I feel it "hit". At least that is how I think of it. I get the shakes, my muscles contract and ache, my eyes water, I get extremely tired and lightheaded. If I haven't had my menstrual cycle, this is when it will start again. To get rid of these side effects I go to bed. If I take Advil or Tylenol I find it simply delays the side effects. It does not make them go away. If I am busy all day Saturday it definitely makes these side effects worse. But I go to bed as soon as they start, and the next thing I know it is Sunday morning and I feel fine. Why did I forget to mention this before? Because I've never written this on a Sunday, and by Monday I've forgotten it's even happened.

Currently my platelets are at 55 and my neutrophils are at 0.4. Due to the fact that both of these counts have risen I took a three-quarter dose of my shot on Friday instead of the half dose I took the last three injections. I'm feeling fine. I have nothing more to complain about except fatigue. Hopefully there is nothing I'm forgetting!

To be continued....

### **YA'S TIDBITS**

### WHAT'S THE BEST WAY TO DEAL WITH ANEMIA?

One-third of Hep C patients taking ribavirin, part of the current standard of treatment, get anemia. Research done by the University of Los Angeles, in partnership with the Veterans Affairs Greater Los Angeles Healthcare System, suggest that instead of a dose reduction or treatment discontinuation it may be more cost effective to instead take another drug in conjunction with treatment to prevent anemia.

http://news.monsterandcritics.com/health/ article\_1052294.php/Hepatitis\_C\_drug\_costeffective\_for\_anemia

### EUROPE APPROVED SHORTER DURATION OF TREATMENT

If a HCV patient in Europe has low levels of the virus, is genotype 1, and clears the virus in the first four weeks of combination treatment by Schering-Plough, that patient will now take only a 24 week course of treatment instead of 48 weeks. This has been

passed by the European Commission. Whether or not the same trials will be conducted in the U.S. is unknown.

http://today.reuters.com/business/ n e w s a r t i c l e . a s p x ? type=health+storyID=nN05398332&imageid=& cap=

## GENERIC HEP C TREATMENT?

In December Roche no longer has complete control over its Copegus (ribavirin) tablets. The FDA has tentatively approved a generic ribavirin tablet by Teva Pharmaceutical Industries Ltd. Teva figures that the tentative approval should receive final approval at the time of expiry.

http://news.morningstar.com/news/DJ/M09/ D16/200509161259DOWJONESONLINE000837. html



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### FAO PREVIEW: PROTEASE AND POLYMERASE INHIBITORS

#### **Protease Inhibitors**

Once HCV enters a liver cell, its genes guide the production of proteins that will become the inner core and surface coat of new viral units. First of all, the HCV makes an immature protein—a kind of unfinished sheet of material, which the Hep C protease cuts into the finished proteins, which then become the virus's outer cloak.

Scientists have developed protease inhibitors, which stick to protease and stop its scissor-like function. These drugs have been used in the treatment of HIV for years, and hopefully they will be valuable in Hep C treatment as well. (www.veritasmedicine.com).

IDN-6556: Idun Pharmaceuticals is designing small molecule caspase protease inhibitors to inhibit cell death in tissues and organs. Its product IDN-6556 was found safe and well tolerated in a Phase I clinical trial involving 50 adults, some with Hep C. (PRNewswire Jan. 31, 2002, Idun Pharmaceuticals' Clinical Trial Demonstrates Safety Of Liver Disease Drug, and May 20, 2002, IDN-6556, a caspase inhibitor completes Phase I clinical trial for HCV). Phase II trials were to have finished in May 2005. The product was taken orally once or twice daily for 14 days. It lowered aminotransferases and was well tolerated.

(www.hivandhepatitis.com/2004icr/39easl/ documents/0503/050304 hcv a.html) It has been given orphan drug status in the US for use in transplant patients.

VX-950: Vertex Pharmaceuticals' new trials were conducted over a 14 day period involving 34 people with HCV genotype 1. Seventeen, or half of the people in the trial, went below viral detection! Five of these seventeen did return to having detectable virus a month after stopping VX-950. There did not appear to be many side effects, but they only tested over a 14 day period. Phase **II** trials for VX-950 will involve testing over a one- to three-month period, and will involve testing the drug on its own and in combination with an interferon. (http:// hepatitis-central.com/mt/archives/2005/05/ *vertex* update.html)

SCH 503034: Schering, producer of HCV NS3 Protease Inhibitor, taken orally, is preparing for a Phase II clinical trial in genotype 1 non-responders to standard treatment. The trial will consist of two arms. Both will use peg-IFN; one will substitute SCH 503034 for ribavirin in this randomized, double-blind, placebo control trial.

**SCH6:** Researchers have found a trigger. which releases IRF-3 (interferon regulatory factor 3), and were able to find the protease that blocks the IRF-3. Schering-Plough's SCH6, a protease inhibitor, is being used for research with HCV genotype 1. It is hoped that it may make IFN treatments more effective, even with lower doses (Sciencexpress, April 17, 2003). It is still in pre-clinical

(www.pnas.org/cgi/content/ stages. full/102/8/2986)

BILN 2061: Boerhinger Ingleheim's clinical trials are on hold because of heart problems found in monkeys receiving high doses, but the results in 31 genotype 1 patients confirm that a two-day oral dose reduces HCV viral load impressively, even in cases of advanced fibrosis. BILN 2061 was well tolerated. (http://mp.medscape.com/cgibin1/DM/v/hkXq0ELdzJ0D1C0GJNK0Aw and 2005) Gastroenterology 127(5): 1347-1355. November 2004.)

#### **Polymerase Inhibitors**

The NS5B region of the HCV virus contains the polymerase. That region looks like a flat donut and contains 3 areas which interact, called fingers, palm and thumbs. These areas form a circle around the active site, creating a hole. This hole, or cleft, is a target for drug development. The NS5B region is very similar in all the genotypes, and is unique to HCV. (McHutchison, J. MD, Hepatology, November 2002)

There are two types of polymerase inhibitors: nucleoside analogs, such as ribavirin, whose mechanism is not completely understood, and non-nucleoside inhibitors, none of which has yet reached stage I testing. (www.centerforaids.org/rita/1204/pipeline.htm)

NM283 (Valopicitabine) is an oral drug. Phase IIa trials including 19 patients showed a 99.94% reduction in viral load after 12 weeks of treatment in those taking the IFN/ NM283. The trial is being extended, and will enroll 30 genotype 1 patients. Idenix is recruiting 170 genotype 1 non-responders for Phase IIb clinical trials starting July 2005, using Valopicitabine with Peg-IFN-alfa (www.clinicaltrials.gov) There will be a trial for naïve patients, as well. (Idenix Press release January 10, 2005)

**R803** Rigel Initiates multi-dose clinical trial is a double-blind, placebo-controlled, dose-ascending Phase I/II Trial in subjects with HCV. The results of a Phase I clinical trial R803 in healthy volunteers showed no adverse effects. It is given orally. The drug has been shown to work effectively with IFN in pre-clinical trials. (www.rigel.com/rigel/ pr 1085185520 Press release 5/24/04)

JTK-003, a polymerase inhibitor, was well tolerated in Phase I studies. Data has hibitor (/PRNewswire 9/3/03), not been made public. Larger-scale trials were being planned for genotype 1 nonresponders. A study sponsored by Akros Pharma (enrollment complete) will compare the safety and efficacy of JTK-003 combined |s u p e r f r a m e b u s i n e s s . a s p?with Peg-IFN to Ribavirin and Peg-IFN in a 12 week study. (Walker M, et al, Curr Opin hepatit.asp) Pharmacol. 2002;2:534-540 and hcvadvocate.com, and McHutchison, JG, MD, Hepatology, November 2002) (www.jti.co.jp/JTI E/IR/03/ P.L.20030508 E.pdf)

HCV-796 Pharmaceutical company partners ViroPharma and Wyeth have applied for an evaluation of HCV-796, a polymerase inhibitor. They are planning a clinical trial later this year in healthy volunteers to check for safety and side-effects. Studies so far have shown this to be probably the most powerful anti-HCV drug the two companies have. Their drug HCV-086 is already in clinical trials. (www.viropharma.com Feb. 14, (www.viropharma.com/healthcare/ *current3.html*)

PSI-6130 Roche and Pharmasset will collaborate to develop polymerase inhibitors to treat hepatitis C. The product will be combined with Roche's Pegasys. (Roche press release October 27, 2004) Roche is also developing these polymerase inhibitors: R 1270, R1479, R1626,

7-deaza-2'-C-methyl-adenosine Two polymerase inhibitors, triphosphates of 2'-Cmethyl-adenosine and 2'-C-methylguanosine, have been shown to be effective against HCV. In this study, these substances were changed by including another substance called a 7-deaza modification, making them 20 times more powerful. These have been tested in animals and in mice. The researchers believe that 7-deaza-2'-C-methyladenosine is a good candidate for further studies. (I hope they find a catchier name for it.) (Olsen, DB; et al Antimicrob Agents Chemother. 2004 Oct; 48[10]: 3944-53)

BC2125 (XTL-2125) and BC2329 by XTL Pharma is being studied in their Trimera mouse. The products merit further investigation, having shown acceptable toxicity and effectiveness against HCV. BC2125 may be able to be taken orally. The company hopes to apply to the FDA in late 2005 or early 2006. (www.xtlbio.com/products/ xtl6865.html)

(www.hivandhepatitis.com/2004icr/39easl/ documents/0421/042104 hcv b.html 04/2004)

Abbot Labs, Merck & Co, Tularik and Biocryst are formulating gene therapies aimed at inhibiting HCV polymerase (www.veritasmedicine.com), (www.biocryst.com/ hepatitis.htm).

ViroLogic, Inc. was awarded a grant from the U.S. National Institutes of Health, to develop a Hepatitis C virus (HCV) drug susceptibility assay for its polymerase in-

Medivir has focused its research on inhibitors of HCV polymerases and proteases, as these virus enzymes can be studied in in vitro trials. (www.medivir.se/v2/eng/ title=Product+Portfolio&url=hepatit\_b\_c/

Other companies are working with polymerase inhibitor candidates: BioCryst, (www.biocryst.com/hepatitis.htm) Enanta, Chiron.

#### (SAME DRAGON—Continued from page 1)

of those who would get compensation was set to doom. It seems those who did manage to qualify through the artificial years (1986-90) might be OK, but then, who knows? I think they are still waiting or getting stupid, ridiculous sums that in no way reflect the ions, no one seems to be dealing with Hep C distress or difficulties this disease carries.

Now it has become more complex. Compensation has been opened to pre-'86 people. That of course ensures a lot of money goes to the lawyers, as they have to argue to and fro about who is and who is not compensable. And of course add to that the years it takes to get this stuff finalized, worked out and people getting their money. But the lawyers already got their money!

So I did a little more chasing and came across this site and found this stuff, so now I wonder: Is chronic fatigue also compensable?

#### www.newmediaexplorer.org/sepp/2003/07/05/ hepatitis c epidemic where is the virus.htm

Regardless, compensable or not is not the issue all the time. The biggest issue is, in fact, a cover-up that does not reflect the current epidemic for what it is. We would NOT have this disease running rampant through the "addict community" if it had not been allowed to run rampant in the Canadian Community. If, in fact, it had been dealt with as it should, as swiftly and with the passion, expertise and medical fervor as SARS, it would not have come to infect more than 300.000 Canadians, as it has now.

We have moralized this disease, as we did HIV, all those years ago when we tagged it a disease of gay males and forgot that some gay males are "bi", and so it escaped this population we tried to denigrate, and so it crept into the "heterosexual", "female", and any other group you want to name. While the gay male population is still the most impacted, all segments of society have been impacted thus ensuring a uniform but ongoing spread of an epidemic that is hidden and blamed on its recipients.

It also escaped attention that people were infected by "tainted" blood or blood products or the fact that not all people practice safer sex and so unknowingly infected others. Add to that medical spreading, razor, dental implements, piercing and tattooing equipment, and lord knows what else, and a disaster was waiting to happen, did happen and is still going on because we have now lost the ability to control the dragon.

To be sure, we are all denied treatment in a fair manner. PharmaCare does its best to say, "No, the reason you have Hep C is not at issue; PharmaCare sets the standard for

treatment, not your doctor." Despite much (*PRISCILLA*—Continued from page 1) letter writing involving the need for liver biopsies, and the fact that ASTs or ALTs are *not* indicative of hepatitis C progression, and despite the begging, writing, physicians' requests, and professional and expert opinfor the killer it is.

The provincial government seems to be proud of having roughly 700 people treated in 2004, not the fact it took a year or more to add the latest treatment added to the formularies under PharmaCare (while they still tion, but they didn't say it was because of hepaset the criteria for treatment).

truth still stands that, if this disease had been dealt with as the epidemic it is, when it was recognized (I recall a 1958 article about that), we may have escaped some of the hell, needless deaths, and moralizations we are has eaten organic produce for 2 years going through today.

Look through some of the reports, writings and information from the first released findings and if it doesn't make your blood boil or your hair stand on end, then I have a bridge in New York to sell you, cheap.

I often wonder if the Coroner's office keeps records on Hep-related deaths. Would it tell the truth about the "Silent Killer", or are we just a bunch of whining Canucks?

Carol Romanow S.O.L.I.D.V.A.R.C.S.~Mobile X With thanks to "a cancade" through http:// groups.yahoo.com/group/hepcan/



as having hepatitis Non A-Non B in the '80s, which was probably contracted during an operation 40 years ago, to remove her spleen. She doesn't think of herself as sick. She gets itching, usually together with liver pain once in a while. She will occasionally take 1/2 Tylenol for pain. She's never had a biopsy. Her CAT scan doesn't show any scarring. I asked how they decided she had cirrhosis, if they haven't done a biopsy. She says they saw the cirrhosis during her operatitis. She rarely drank alcohol, and never drinks We can pick and pull all we want. The now. Years ago, her symptoms were worse. We the possibility that perhaps she had discussed hepatitis A or B, and it was cured, and then got hepatitis C.

> What does she do to stay healthy? She now. She doesn't eat red meat, nor does she drink alcohol. Her diet is low in fats, and includes lots of fruits and vegetables, especially carrots and beets. She has to take antibiotics occasionally for kidney problems. She eats low fat fish and drinks mostly fruit juices, and she takes digestive enzymes by Swiss Remedies (500 mg. a day) which contain pancreatic protein, lipase, pancrease, and alpha-amylase, amyloglucosidase, cellulase hemicellulase, and lactase, but that's been just recently. She's taking CoQ10. She drinks skim milk with Lactaid. She does eat yogurt and gelatos.

> She says she takes logical precautions, as well. She uses the full-serve gas, so as to not breathe the fumes. She's an artistso she uses a mask so as to avoid the toxic from fumes pens, etc. She doesn't spray her roses. She feels her Vitamin B complex has been helpful, and she injects it herself. She has been having acupuncture and acupressure for about 3 years now. She has been treated with homeopathy for the last 8 months: Arsenicum, and Nux Vomica for itching, liver pain, and bloating. (*Causticum* for other things, as well)

> So, as I said, her cirrhosis was probably not caused by hepatitis C, but she has had cirrhosis (diagnosed 40 years ago), so I presume she still does, and she has hepatitis C. Pretty amazing! Thank you, Priscilla, for sharing your secrets with us.

[Editor's Note: Priscilla turned 80 in 2004. Priscilla was a role model for me. Priscilla just passed away. She fought a long, courageous battle, and lived a long, full life.]



**NOVEMBER 2005** 

# WEBSITE REVIEW http://walking.about.com/

We all know now how important it is to control our weight and maintain an active lifestyle, so we can prevent the scarring from fatty liver. Many of us do not have the energy to do the things we used to do to keep in shape, but most of us can still walk.

I ran across this website: http:// walking.about.com/ It has all sorts of interesting tips and tools you only dreamed of:

- A Google Map Pedometer-you can map and measure your walking routes online
- Workout Calculator-calories burned, speed, pace
- Personal database to record your walks
- A buddy page
- Tips on how to walk
- Free coached walking programs
- Walking gear info
- ...and much more!

I had a bit of a problem at first with the Map Pedometer. I couldn't get it to work for Canada. But there is a solution! Click on All Google Map Pedometer Versions: From here, I chose Google Map Pedometer II which takes you to a map of the US. From there, you click on the "up" arrow if you live in Canada. It lets me zoom in nicely to my area...and you to yours, if you're in the US, Canada, Britain, or Japan.

I don't know about you, but I found it hard to start an exercise program, especially since I've had some health challenges lately. This may not work for you, or perhaps you've already done it: I bought a dog. I know—I'm a cat person. But you can't walk 2.4.1 and 5.3.2 of the society and by adopting in most cats. My puppy is now 8 months old. (I am resisting telling you all about his many virtues and how adorable Marty is...!!) He has boundless energy, and it's contagious. I actually did the 5 km. Walk for the Cure last able to vote. month, thanks to Marty's guidance and support. Sorry-I couldn't resist:





HepCBC is pleased to announce the addition of our 2 new staff members, David and Sherryl!

This means we have regular office hours with staff present to assist with any information and questions!

We would like to invite anyone who is affected by HepC (or anyone with an interest) to come by and check out our extensive library and resources.... Come have a coffee and chat. Hey! Bring cookies! ;)

#### **OFFICE HOURS**

Monday	10 am to 4 pm
Tuesday	10 am to 2 pm
Wednesday	10 am to 2 pm
Thursday	9 am to 1 pm
Friday	10 am to 4 pm

You can find us at:

306-620 View St (Same office as Volunteer Victoria) 595-3892 www.hepcbc.ca • email: info@hepcbc.ca

#### **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 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

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

#### **BE PART OF THE TEAM!**

We need people to summarize articles. HepCBC needs office staff and 6 people to help with our website. The Hep-CAN list needs a moderator trainee. Please 250-595-3892 contact Joan at 01 info@hepcbc.ca

### CONFERENCES

#### **November 3, 2005**

Royal College of Physicians of Edinburgh -Hepatitis C, Edinburgh, Scotland www.sign.ac.uk/events/index.html

### November 11-15, 2005

56th Annual Meeting of the American Society for the Study of Liver Diseases (AASLD) San Francisco, CA www.aasld.org/eweb/DynamicPage.aspx?

webcode=05 Annualmeeting

### March 25--28, 2006

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



PLEASE REMEMBER YOUR **FLU SHOT** 

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

### **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 extension 346.

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

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### **OUTSIDE, LOOKING IN**

Allan Blumenfeld was infected with Hep C by a transfusion in 1981 at Burnaby General. He is 60 and lives on a disability pension of \$700 a month. He has cirrhosis, and often has to stay in bed. He can't sleep. He had to use the money he saved for his children's college for his Hep C treatment. He was awarded money in a class action suit. The law firm took \$5407.28, \$598.56 went to taxes, and he was left with \$6434.16. Other victims, less fortunate, have not yet seen a cent. He is one of many victims outside the 1986-90 "window" who want part of the \$217,000,000 left over from the \$1.1 billion fund for those inside the "window. Perhaps different from the others, he says, "I refuse to guit."

Victims like Allan have some people on their side. Conservative MP for Newton-North Delta, Gurmant Grewal has been working for Compensation since 1998. He considers the treatment of the victims more than shameful, saying that there was a test that could have been used in the early 1980s, recommended by US experts, but nothing was done by the Red Cross or Health Canada, and around 20,000 people were infected with HCV. As a result, only those in the "window" were compensated.

The federal government promised to help the victims outside the window in November 2004. Victims in Ontario. Manitoba and Quebec received \$25,000, and those in BC got around \$16,000. When the surplus was discovered last June, the House of Commons gave unanimous support to a motion to compensate the "forgotten" victims. They remain forgotten. 5000 of them have died waiting. so far. And the worst part? The money is there.

**Source:** www.thenownewspaper.com Zytaruk 10/12/2005

### **COMPETITION!**

**U** epCBC is looking for writers for the December 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 November, stating interest in the bonus. If there is more than one submission chosen, the editors reserve the brain fog.-Joan] right to print both, or leave one for a future edition. info@hepcbc.ca

#### (NEWS—Continued from page 1)

reported, "The recent celgosivir monotherapy trial in hepatitis C patients indicates that this agent is safe and there appears to be a modest anti-HCV effect. It should be noted that ribavirin monotherapy did not demonstrate a significant anti-HCV effect alone, but in combination with peginterferon had a dramatic effect with regards to antiviral efficacy. Celgosivir may have a similar or better effect and we are awaiting a combination trial with great interest." A phase IIb combination trial is being planned.

Source:

www.migenix.com/newsreleases/092705.pdf

#### **ALBUFERON**

Human Genome Sciences' injectable drug Albuferon has obtained encouraging results midway through a clinical trial in 56 naïve, Hep C genotype 1 patients. The injections are taken once every 2 to 4 weeks, and the 69% of the patients taking the highest doses had a drop in viral load of over 99.9% only 28 days after starting treatment-more than satisfying the goals of the trial. The viral load was undetectable in 23% of these patients 42 days into the trial. The next trial will combine Albuferon with ribavirin, testing that combo against either of the standard treatments. The standard combo gives a 42% viral clearance in genotype 1 patients at 48 weeks.

#### Source:

www.reuters.com/newsArticle.jhtml? type=healthNews&storyID=8185818 Apr 14. 2005

### CORRECTION

Hi. I hope it is not too late to report an error that was made in the September Tom 2005 hepc.bull newsletter. In the paragraphs following The Right Track, I had written that I found out that I had Hep C 4 yrs 4 days after my husband passed away, but when it appeared in the newsletter, it was put that 'I have had it for 4 years, and found out 4 days after my husband passed away, on the day that was his birthday.' I have no idea how long I have been infected. If possible, I Hepatitis C Settlement Fund-KPMG Inc. would like the error to be corrected, but I realize I am getting around to writing this very late. I have just been too tired to get to this sooner. Sorry. Thanks.-Puff

[Editor's note: Sorry, Puff. It was my fault. I blame it on



LAW FIRMS

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

Pre-1986/ Post-1990 Klein Lyons

1986-1990

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 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

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



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### **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 Hep C support: ◆Campbell River: 1<sup>st</sup> Mon. monthly, 1-3PM, 1249 Ironwood. Contact Jeanette or L e a n n e : 8 3 0 - 0 7 8 7 , jeanette.reinhardt@avi.org leanne.cunningham@avi.org

Comox Valley 355 6<sup>th</sup> St. Courtenay Contact.Phyllis 338-7400 phyllis.wood@avi.org
♦ Nanaimo Drop-In each Wed 2-4PM, #201-55 Victoria Rd. Contact Anita 753-2437 anita.mcleod@avi.org

◆ Victoria Support & Info Needle Exchange 384-2366, info@avi.org

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

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, info@ankors.bc.ca alex@ankors.bc.ca

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

New Westminster Support Contact Dianne Morrissettie, <u>dmorrissettie@excite.com</u>

**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 alex@ankors.bc.ca

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

Smithers: Positive Living North West 2<sup>nd</sup> Wed. monthly, 12 noon, 3862F Broadway Contact 1-866-877-0042 or Doreen 847-2132, <u>deb@plnw.org</u>

Sunshine Coast-Sechelt Healthy Livers Support Group 2<sup>nd</sup> Thurs. monthly, 3-5 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

VANDU Vancouver Area Network of Drug Users: Satelite Hep-C group, each Thurs. 2 PM, HCC, 166 E. Hastings, Bus fare & snack. 604-658-1224. H.A.R.M. group each Mon., 10 AM, 50 East Hasting St. Bus fare & snack. Contact 604-683-8595 vandu@vandu.org www.vandu.org

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

Vancouver Hepatitis C Support Group 1<sup>st</sup> Tues monthly, 5-8 PM Level 2, VGH, and, Java Express, 3420 Cambie St. 3<sup>rd</sup> Tues monthly, 7-9 PM, Lauener Room, JPP 2809, Sassafras Cafeteria, Jim Pattison Pavilion, South. Contact Robert, CLF: 1-800-856-7266 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: Brandy Svendson <u>brandys@youthco.org</u> Support Worker: Matt Lovic mattl@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 Library open M-F 306-620 View St. Phone support, interviews., info sessions. Contact 595-3892 <u>info@hepcbc.ca</u>, <u>www.hepcbc.ca</u>

Works Without Words Yukon Grace Community Church, 8<sup>th</sup> & Wheeler St. Contacts: Harry & Debbie 867-667-2402 <u>harry.mckenzie@klondiker.com</u>. Brian: 867-668-4483 Whitehorse.

## **OTHER PROVINCES:**

#### **ONTARIO:**

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

Durham Hepatitis C Support Group 2<sup>nd</sup> Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Nov. 10: Dr. David MacAskill, D.C. "Managing Stress" 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, 7-9 PM. Contact (519) 562-1741 Fax (519) 256-1383 hepc@hepcnetwork.net, http:// hepcnetwork.net

Kingston Hep C Support Group 1st Wed. monthly, 5:30-9 PM St. George's Cathedral, King and Johnson St. (Wellington St. entrance) Contact: HIV/AIDS Regional Service 613-545-3698

Unified Networkers of Drug Users Nationally <u>undun@sympatico.ca</u>

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

#### bc.cats-sens@rogers.com

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

North Bay HCV Support Group 2nd Monday monthly 7 PM, 269 Main St. West, Suite 201, North Bay. Contact: Gabe Giroux, Hep C Education and Support Coordinator 705-497-3560 ggiroux@vianet.ca

**Owen Sound** Monthly education sessions 7 - 8:30 PM, Owen Sound Public Library Board Room, 824 1st Ave. West. Tues. Nov. 22, 2005 "Healthy Eating for your Liver", Kathryn Forsyth, Public Health Dietician. Contact Debby Minielly, 1-800-263-3456, 376-9420, Ext. 257 www.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

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.



#### **QUEBEC:**

Arundel Contact Andy Aitken <u>chcn.alexander@sympatico.ca</u> Canadian Hepatitis C Network http://www.canhepc.net/

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) 539-2871 FAX (902) 539-2657 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, fox@kihewcarvings.com

Fort McMurray, Alberta Hepatitis C Support Network—Info and support. #205, 10012A Franklin Ave. Contact Lyn, (780) 743-9200 Fax (780) 943-9254 wbhas@telus.net

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 Support group meets each Wed. 7 PM Turning Point Agencies 4611-50th Ave., Red Deer. Contact: Chris (403) 341-6026 <u>crthomas@shaw.ca</u>

**Winnipeg Hepatitis C Resource Centre** 1<sup>st</sup> Tues. monthly 7-9 PM. # 204-825 Sherbrook St. (south entrance—parking at rear) Contact 975-3279, <u>hcre@smd.mb.ca</u>

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

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