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

HEPATITIS AWARENESS MONTH EVENTS

HepC'ers in Kelowna held a breakfast event, with the mayor reading the proclamation for May 1 Awareness Day and May Hepatitis C Awareness Month. Stories appeared in the *Kelowna Capital News* and *The Kelowna Daily Courier*, and the group contacted CHBC TV.

The Living Positive Resource Centre planned a hepatitis C forum to be held at the Okanagan College Theatre on Wednesday, May 24th.

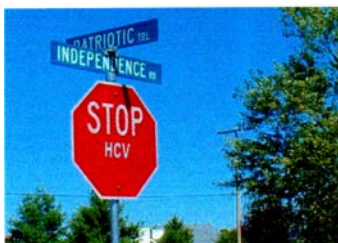
HepLife in Vernon was to hold a Hep C rally on May 27th. A couple of political speakers and 3 musical groups were booked. This event was booked by Sharon Grant before she died in August of 2005.

Cranbrook HeCSC-EK joined ANKORS by sitting at a table set up at the Tamarack Mall on May 1st. Those tending the table were appalled by how many people thought they were safe because they had their Hep A and B vaccines.

Sudbury Circle C Support Group in Ontario planned a news conference for May 23, 2006 at the United Steel Workers with Shelley Martel M.P.P. N.D.P about compensation issues. (See page 7 for more info.)

The CLF has organized "Stroll for the Liver" in several cities across Canada, during May and June. (See page 6)

HepCBC has placed bus ads, radio ads, and newspaper ads locally, and has announced the new FAQ and updated pamphlets.



EASL MINI-ABSTRACTS

2006 Annual Meeting of the European
Association for the Study of the Liver
April 26-30, 2006
Vienna, Austria

VALOPICITABINE + PegIFN

According to week 24 results, non-responders to standard treatment have a greater chance of suppressing HCV if they are treated with valopicitabine (an oral polymerase inhibitor) rather than with ribavirin. Valopicitabine seems more effective than re-treating with pegIFN and weight-based ribavirin. The results came from a phase IIb trial which included 190 subjects. Relapsers were excluded. Peginterferon alfa-2a was used in this trial. Final results will be ready in 2007.

Abstract 39.

RETREATMENT WITH PegIFN alfa-2a + RBV

According to interim results of the REPEAT trial, patients retreated with IFN alfa-2a have a good rate of response after 12 weeks. The researchers suggest an induction treatment of pegIFN alfa-2a of 360 µg/week during 12 weeks, rather than the standard 180 µg/week. Standard treatment produced a 45% EVR or less, compared to 62% with high-dose induction.

Abstract 583.

VIRAMIDINE VS. RIBAVIRIN

The VISER1 phase III study shows that 600 mg of virmidine twice daily plus pegINF alfa-2b is less likely to cause anemia than ribavirin in naive patients (5% vs 24%), however, noninferiority requirements were not met. Those with genotypes 2 or 3 were treated for 24 weeks, while the rest were treated for 48 weeks. SVR for the virmidine subjects was 38%, and for the ribavirin subjects, 52%. Virmidine may be more effective in younger patients. Researchers think a higher dose of virmidine may be more effective.

Abstract 751.

TREATING AFRICAN AMERICANS

It seems that African Americans are more commonly infected with genotype 2 rather than 3, compared to the almost even distribution common in whites, based on a review of the records of 232 white patients and 37 African American patients with gt 2 or 3. There were also differences in SVR rates—95% of African Americans have genotype 1, and their SVR is approximately ½ of that of whites. SVR is 84% of white patients and 44% of African Americans. Relapse rates in African Americans were 38%, and in whites, 9%. SVR with other genotypes is yet unknown. Researchers looked at the records of 232 white patients and 37 African American with genotypes 2 or 3. Researchers believe that the results may be due to genetic differences in the immune system's response to IFN.

Abstract 596.

LOW DOSE RIBAVIRIN

Patients with genotypes 2 or 3 may be able to achieve SVR with only 400 mg of ribavirin daily, rather than 800 mg, thus possibly avoiding side effects such as anemia. This dosage works in about 80% of patients, which is equivalent to the response rate with the higher dose. This study included 282 treatment-naïve subjects in Austria. PegIFN

(Continued on page 3)

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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) **\$20.00**

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(Doesn't include the *hepc.bull*)

Subscription Only **\$10.00**
(Doesn't include membership privileges)

Peppermint Patti's FAQ **\$6.00**

Resource CD **\$10.00**

TOTAL: _____

"I cannot afford to subscribe at this time, but I 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."

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

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

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

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

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LETTERS TO THE EDITOR:

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

NEW!!! FAQ v7

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

HepCBC Resource CD

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

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

REPRINTS

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

THANKS!!

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

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



BE PART OF THE TEAM!

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

CUPID'S CORNER



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

To place an ad, write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to HepCBC, and mail to HepCBC, Attn. Joan, #306-620 View Street, Victoria, BC V8W 1J6, (250) 595-3892.

Give us your name, tel. number, and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

*Disclaimer: The *hepc.bull* and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.*

Want a mate? Your Cupid ad could go here!

Got Hep C? Single? Visit:

<http://forums.delphiforums.com/HepCingles/>
<http://groups.yahoo.com/group/PS-Hep/>
<http://groups.yahoo.com/group/HepCingles2>
<http://groups.yahoo.com/group/NewHepSingles/>

CHAT: <http://forums.delphiforums.com/hepatitisen1/chat>

Have you Been Diagnosed With Hepatitis C?

We are looking for Volunteers to participate in Future Research Studies.

DETAILS:

You will be required to take investigational medication

You will be required to give blood samples
Compensation available

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

DIAL-A-DIETITIAN

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

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

SCH 503034

SCH 503034 (a protease inhibitor) plus pegIFN alfa-2b was shown to have antiviral activity for 26 genotype 1, previous-non-responders. Researchers studied safety, antiviral activity, and development of resistance to the treatment. The 3 arms of the trial included mono-therapy with SCH 503034, pegIFN alone, or pegIFN with SCH 503034. Patients received all the treatments although in different orders. "Some patients reached a 4 log₁₀ IU/mL decline below baseline within 2 weeks of combination treatment." Only one resistant mutation occurred.

The combination was well tolerated. Most adverse events were mild and/or moderate. Frequently reported adverse events were probably due to the use of pegIFN alfa-2b and included headache, myalgia, and rigor. No dose-related increase in adverse event frequency was observed with the use of the product.

Abstract 78

CPG 10101

CPG 10101 is an antiviral and immune booster. It activates TLR9 receptors, aiding immune responses. It has shown positive results in a phase Ib trial with non-responders. It was tested for tolerability and effectiveness. Other trials are underway with relapsed responders. The product is being tested with pegIFN alone or with ribavirin. This study worked with 60 mostly-genotype 1 patients, all non-responders. Viral reduction was dose dependent, and associated with enhanced immune responses. "At least a 1.0 log₁₀ copies/mL reduction was seen in all dose groups treated with a 1-mg or greater dose, and 3 patients exceeded a 2.5 log₁₀ copies/mL reduction." There were seemingly no serious side effects.

Abstract 111

A different study presented by the same doctor "as a late-breaking abstract" showed a greater proportion of subjects achieved early viral response (EVR) by adding CPG 10101 to the standard treatment.

Abstract 730

24 WEEKS BETTER THAN 16

In the ACCELERATE trial, higher SVR rates, lower relapse rates, and better tolerability was seen with standard 24-week therapy compared to the experimental 16 weeks tried in genotype 2/3 patients.

Abstract 734.

Source: <http://clinicaloptions.com/hepatitis/conference%20coverage/vienna%202006.aspx>

TAKE SOMEBODY TO THE DOCTOR WITH YOU

I had a regular "check-up" with my health nurse last week, and she brought up an interesting conversation. She started talking about how, when you are talking to a doctor, sometimes it seems you cannot remember a thing once you leave the office. This is so true. When I first found out I had HCV, I had nobody come with me to the appointment as I did not think they were going to tell me I had HCV. I thought maybe they had noticed low iron levels or something stupid. Instead a bombshell was dropped and I left the office more than a little shaken. When I got home and told my boyfriend he started asking me questions about the appointment and what was said. I could not even remember the name of the doctor, let alone any pertinent information. After that I brought my boyfriend along with me to appointments when I knew that I was going to get results that could possibly shake me up. That way I had somebody else to record information in their mind and play it back to me at a later time. I also find that sometimes there are questions that I should ask in these important appointments and forget what they are. If you discuss your concerns with whomever you are taking to an appointment with you, they may be in a better mind state to remember to ask for you. I do not take him along with me to regular "check ups", but for more important appointments, such as biopsy results, I ensure either he or a family member is with me.

EXPERIMENT ON THINKING

I am a true believer that what you think greatly affects your everyday life. The mind is a great and wondrous thing that controls our body, thoughts and feelings. Think about this: If you tell people under hypnosis that they are being burnt by a hot rod, some will form a blister where you tell them they were burnt. The mind can control everything in your body. That is why I think it is important for people with HCV to have a positive outlook. If you focus on feeling ill, sad, nauseous, weak or tired you will forever be in that cycle. I am not saying you are creating those symptoms with your mind. An illness is an illness. However, you may be perpetuating them. If you focus on feeling good and that tomorrow you will feel better, you are giving yourself the best natural medicine you can. Try this out as an experiment: pick out a day and think to yourself every half an hour or so, "Goodness, am I tired." Gauge at the end of the day how you feel. The next day think to yourself every half an hour or

so, "Goodness, I feel like I could go dancing tonight." Gauge at the end of the day how you feel. My bet is that the day you thought more positively you felt better.

VX-950 IN COMBINATION WITH PEGASYS

Vertex Pharmaceuticals has released the results of another phase 2 trial. They did a 14 day trial of VX-950 in combination with pegylated interferon alfa-2a (aka: Pegasys). Eight people were enrolled and all had genotype 1. At the end of the 14 days, 6 of the 8 had HCV RNA levels below 30 IU/ml and 4 of the 8 were below 10IU/ml. All were offered straight Pegasys treatment for 12 weeks at the end of the trial. At the end of the three months, all eight had undetectable virus levels. There were no serious side effects reported.

<http://www.vpharm.com/Pressreleases2006/pr042906.html>

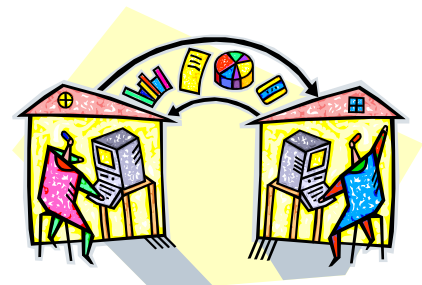
VACCINE

St. Louis University is enrolling 200 volunteers to test the new HCV vaccine created by Chiron Corporation. Previous smaller studies have already been done with good results. This study will be looking at safety and effectiveness. This would be a huge breakthrough for HCV if it works.

<http://www.news-medical.net/?id=17783>

DO YOU NEED SOMEBODY TO TALK TO?

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



LETTERS TO THE EDITOR

Dear Joan & Ian:

I came across your Hep C news bulletin [*Editor's note: from 2003*] today and shed many tears as I eagerly read from cover to cover. I was overwhelmed and impressed by the emotion I felt as memories stored away flooded back.

I was pregnant in 1990 when I became extremely ill. My urine was like coca cola, my stool was pale and I was unbearably itchy all over. I thought I would go mad. I gave birth two months prematurely to a beautiful baby girl who today is a healthy, vibrant 16 yr. old. My doctor was at a loss. The Hep C test was not yet available. My health degenerated until I was so fatigued I could hardly function. It took years and many doctors before a rheumatologist finally suggested a Hep C test.

Finally! I had Hep C and had been infected for many years I was told. My children were young and I was alone with them. When treatment was first offered, I refused because I was afraid and did not know if I could care for them and did not have any extended family to help.

The second time, a few years later, my doctor advised me that if I did not take treatment, my chances of responding would be much lower because of my age and viral load.

I am one of the lucky ones. The treatment was a success. It was the worst year of my life but worth it. I have been given back hope and life. It has been a few years now, and I am still well and energetic.

Reading your newsletter made me realize that I still have strong feeling for people who suffer from this disease.

I have done very little to give back, so I decided today to plan retreats for people with Hep C, their partners, children, families and those recovered from Hep C.

People would have the opportunity to connect with others, start to heal, come out of shame and isolation and encourage each other in a warm, non-judgmental environment in a beautiful country setting at my home in Ontario. People can call me for more info at 705-488-3133.

Thank you for taking the time to publish such a valuable newsletter.—*L. Bennett, Ontario*

Dear Joan,

I was given this site (www.nutritiondata.com/index.html) by the nutritionist I am seeing at Dr. Anderson's office in Vancouver. He's a wonderful doctor and specializes in the treatment of HCV. You can use all the tools for free and input the foods you eat into your "pantry"; then you

can fill in the foods and amounts you eat in a day and ask it to analyse it for you. You can also input items from your favourite recipes and get an analysis, and you can request better substitutes if you want. I think this is a really wonderful tool for everyone, especially those of us struggling with our weight.—*Lisa*

Dear Joan,

I thought I would send you a link to the Fibromyalgia Network site. It might be useful for all of us with Hep C to check out the site. I have had a three year struggle to get my physicians to recognize that I may also have fibromyalgia, which may be Hep-related as far as I am concerned. So far I have had no success.

The home page for the Fibromyalgia Network is: www.fmnetnews.com/

I especially urge those with Hep C to check out the Fibromyalgia Basics page. You can get it from a link on the left from the main page, or from the following link: www.fmnetnews.com/pages/basics.html

If you check out the symptoms, you will see that many of the symptoms are the same as with Hep for many of us. Since there is no definitive test for fibromyalgia, I feel it is important that those of us who suffer with the daily headaches, joint and muscle pain, brain fog, etc., start our doctors thinking along these lines.

As I stated earlier, I have been trying for three years to get my doctors to recognize the fact that I may also have fibromyalgia. I still haven't succeeded, but by the process of elimination, I feel confident that they will recognize it before the end of the year.

—*Timo Ahonen*

HCV & FIBROMYALGIA

Hepatitis C often goes hand-in-hand with fibromyalgia (FM) and chronic fatigue symptoms. The symptoms of FM are muscle, ligament, and tendon pain. You ache all over. Does this sound familiar? If you are a woman, you are more likely to suffer from these symptoms than a man. It's like having a bad flu. The pain can be described as aching, stabling, shooting, burning or throbbing, and it is usually worse in the morning, when the stiffness seems to be worse. The accompanying fatigue can vary from mild to incapacitating, and may be accompanied by a lack of ability to concentrate (brain fog). Most people with these symptoms have sleep disorders, resulting in sleep that doesn't refresh them. Other associated complaints are irritable bowel syndrome (IBS),

migraines, and TMJ (jaw pain). FM is thought to be triggered by a viral or bacterial infection, an accident, or some disease like rheumatoid arthritis, lupus or an under-active thyroid. It is thought that changes to the chemical transmitters related to pain may be at fault, or perhaps changes in the immune system, sleep patterns, or hormones.

Treatments include improving sleep quality and relieving pain. If you have Hep C, you must be careful about medications, but you may ask your doctor if there is a low-dose of something that will boost serotonin and norepinephrine. Physiotherapy is a good option for people with Hep C, as are acupuncture, relaxation techniques, chiropractic, massage, and exercise. Notice what things make your symptoms worse and avoid them. (http://adam.about.com/reports/000076_1.htm)

"Secondary fibromyalgia has the characteristic symptoms of fibromyalgia but unlike primary fibromyalgia, a specific cause can be identified. Possible causes include... Hepatitis C. Hepatitis C may prove to be a trigger for some cases of fibromyalgia." (<http://www.fmnetnews.com/pages/basics.html>)

Studies have been done to see if FM can actually be linked to HCV infection. One was done in Turkey, where 190 people, half with and half without HCV, were examined for FM, using the criteria of the 1990 American College of Rheumatology, which include looking for the symptoms above, plus a count of tender points and the presence of sicca- and Raynaud-like symptoms. FM was diagnosed in 18.9% of the Hep C patients, and only in 5.3% of the healthy subjects. (*E Kozanoglu and others. Fibromyalgia syndrome in patients with hepatitis C infection. Rheumatology International 23(5): 248-251. September 2003*)

On the other hand, a recent study was done in Spain (*J Rheumatol, 2005;32(6):1118-1121*) and the researchers concluded that HCV was not a cause of FM, making the association still controversial. The researchers say the previous studies did not use optimal control groups. This study tested 115 subjects with FM for HCV, and then compared the infection rate with the general rate in the community at that same time. Only 3 patients were found to have HCV antibodies. They admit that the rate of HCV infection was slightly higher in those with FM than in the general population. The researchers concluded, "From our results, it seems unlikely that HCV infection plays a pathogenic role in FM."

Even though the studies have conflicting results, I know people with HCV often have these symptoms.

Joan King

NUTRITION

Malnutrition is very common among people with liver disease, especially those with cirrhosis. Those who are weak from malnutrition have more complications during and after transplantation. Malnutrition shows up along with progression to liver failure. Patients who are not well nourished have a higher rate of infection, encephalopathy (severe brain fog), ascites (fluid buildup) and bleeds. It is not known which comes first: the malnutrition or the cirrhosis.

One of the problems to deal with is the lack of sufficient calories and proteins in ESLD (End Stage Liver Disease). This may be due to changes in the sense of taste, caused by a lack of vitamin A or zinc. The stomach may feel full because of the pressure of a swollen liver, or because of high levels of leptin. Restrictions such as salt, protein and fluids discourage eating, as do fatigue and encephalopathy. Malabsorption may be due to reduced bile-salt or bacterial overgrowth, or the use of neomycin for encephalopathy. About 1/3 of ESLD patients have a very high metabolism. Removal of ascites can help. Every patient with cirrhosis should have a nutritional evaluation, which can be tricky. Weight is not a good indicator of health. Albumin and prealbumin may be low due to low levels of synthesis.

Using triceps to measure skin-fold thickness and mid-arm circumference can usually assess fat storage and skeletal muscle mass. These items should be observed: Weight loss over the last 6 months, changes in the amount of food eaten, intestinal complaints, functional ability, metabolic demands, any muscle wasting, and the presence of edema. Muscle function can be tested quite well by hand-grip strength.

Other tests that are useful are BCM, Isotope Dilution, Whole-Body Potassium, and *in vivo* neutron activation analysis, but these are costly and not very practical. Bioelectrical Impedance can be useful in assessing BCM (Body Cell Mass). Energy metabolism can be measured by indirect calorimetry.

Oral, enteral or parenteral methods can be used to treat malnutrition. Early treatment is important. Supplementation of 1000 calories and 34 g of protein can help, but does not work if the patient substitutes the supplement for his/her regular amount of food. 2500 calories daily is considered adequate. If patients can't maintain this, a tube can be inserted into the nose (enteral feeding). If this doesn't work, then parenteral feeding may be used. Some doctors think enteral feeding after transplantation or after place-

ment of a shunt is as good as or better than parenteral feeding.

In 1997, the European Society for Clinical Nutrition and Metabolism developed nutritional goals for ESLD patients, including enteral feeding when the patient doesn't maintain adequate oral intake. Cirrhotic patients need 25-35 calories per kg of body weight of non-proteins each day, and 1-1.2 g per kg of protein or amino acids. In patients with malnutrition, non-protein should be 35-40 cal per kg and protein, 1.5 g per kg. In patients with encephalopathy, protein was reduced, but more recently, no protein reduction is recommended, even with encephalopathy.

"A typical recommendation for patients with advanced liver disease is to consume four to five small meals per day, as well as a late evening snack," so that the patient avoids long fasting periods and resulting fat oxidation. This may balance nitrogen.

A 2003 study of 11 trials found that branched chain amino acids (BCAAs) diminish hepatic encephalopathy, especially when administered. Most studies agree. It may be that, taken at night, they work to synthesize protein, and taken during the day, they provide physical energy.

Nutrient deficiencies can be corrected, depending on the cause. Alcoholic liver disease may create thiamine, folate and magnesium deficiencies. A patient with fat malabsorption may create a vitamin A deficiency, but **vitamin A supplements may be toxic and can cause liver scarring, even at approved doses.** Malabsorption can also cause vitamin D deficiency, resulting in osteoporosis. "A proposed guideline is to supplement all patients who have chronic liver disease with calcium (1 g/day) and vitamin D3 (800 IU/day)."

Zinc deficiency is controversial in patients with encephalopathy. It may improve their mental function.

"Malnutrition is a potentially reversible condition which, when identified and treated appropriately, can lead to improved outcomes."

[Source: www.medscape.com/viewarticle/529582_1](http://www.medscape.com/viewarticle/529582_1)



PegCARE

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

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

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

PegCARE: 1-800-603-2754

PEGASSIST

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully.

PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM- 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating any financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or co-payments.

In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

COMPETITION!

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

CIRCLE C SUDBURY PRESENTATION TO THE PRESS

On March 27, 1998, our health minister announced \$1.2 billion federal-provincial compensation limited to victims infected between January 1, 1986 and July 1, 1990 and the Federal Liberals denied the pre '86/post-90 victims compensation.

On September 21, 1998, Minister Allan Rock stated in the House of Commons:

"Hon. Allan Rock (Minister of health, Lib.): 'Mr. Speaker, last Friday as Prime Minister mentioned, I put before ministers of health a proposal that included steps and suggestions that involve \$525 million of federal money that will make certain that anybody who got hepatitis C through the blood system will have access to the needed medical services and drugs for treatment and care without paying out of their own pockets.'"

We believe that when people in this country are sick, they require treatment, not payment. We show our compassion through care and not through cash.

On September 21, 1998, Federal health Minister Allan Rock announced that \$300 million over 20 years would be transferred to the provinces to provide "needed medical services and drugs for treatment and care" without paying out of their own pocket.

As Ontario has 44% of all pre-1986 hepatitis C tainted blood victims in Canada through the Canadian blood system, Ontario's share from the \$300 million over 20 years is \$132 million. So far Ontario received \$88 million. The balance is due in 2009.

On March 26, 1999, the Canadian Red Cross offered a \$60 million compensation plan for people infected before January 1, 1986 and after July 1, 1990.

According to Sudbury M.P.P. Rick Bartolucci's office the Ontario government set aside \$200 million to establish the Ontario Hepatitis C Assistance Plan in May, 1998. This was done through the Mike Harris government. To date 3,591 individuals in Ontario have been provided with financial assistance—a total of \$89 million. This leaves a balance of \$111 million.

The Care Not Cash Agreement or the Undertaking Agreement's initial intent was to help the pre-86/post-90 victims with their out-of-pocket expense, not to cover already existing programs such as O.H.I.P. services, laboratory tests, public health, prescriptions, home care, and hospital expenses for all. The initial intent was that there would be health care services for hepatitis C that are not fully insured by publicly financed health care systems. The federal government's intent was to

ensure that persons infected with hepatitis C through the blood system prior to January 1 1986 and after July 1, 1990 have reasonable access to therapeutic health care services indicated for the treatment/cure of Hepatitis C. This agreement was intended for the victims of tainted blood through the Canadian blood supply pre-86/post-90, not to prop up existing programs. Remember the word "VICTIMS".

According to Mr. Bartolucci's office there are currently 105,000 to 132,000 people infected with hepatitis C virus in Ontario. However about only 70,000 of these individuals have been diagnosed. If there are only 3,591 victims of tainted blood in Ontario through the Canadian blood supply, pre-86/post-90, where did the rest of the infected individuals come from? Is it the Ontario Government's intent that the victims pay to prop up the Ontario government's lack of response to this silent epidemic, or is it their intent have the pre-86/post-90 victims pay to prop up the Ontario's health care systems?

Once again WE ARE THE VICTIMS.

If the Ontario Government is so concerned with individuals living with hepatitis C, why did they cut back the so badly needed food supplement for people living with Hepatitis C on O.D.S.P. or Ontario Works? (*This has now been remedied!*) What will happen to the \$111 million that was intended for pre 86 post 90 victims? If \$525 million was announced by Allan Rock, where is it?

Why is the Ontario Government using the pre-86/post-90 hepatitis C victims care-not-cash agreement as a cash cow? When will the Ontario Government accept its responsibility to the victims? When will our M.P.P. Rick Bartolucci stand up and speak out for the victims on the injustice that the Ontario Government is doing to his constituents?

All across Canada there are approximately 20,000 individuals infected with the hepatitis C virus through the tainted blood supply, and approximately 1,000 individuals infected with the HIV virus. According to Health Canada there are approximately 300,000 individuals infected with hepatitis C across Canada, 1/3 of these individuals have not been diagnosed. In the Sudbury District area alone according to the Sudbury Health Unit there are 1657 individuals infected with the hepatitis C virus.

What is our Government doing to stop this silent epidemic? Hepatitis C is the most virile blood born disease in Canada. To an

individual co-infected with HIV and HCV, HCV is the killer not the HIV.

We ask that if you know some one infected with the HCV to treat them as a human being not as a disease. The only way that an individual can get hepatitis C is for an individual's healthy blood to come in contact with infected HCV+ blood.

Ernie Zivny
Circle C Support Group (Sudbury On.)
Hepc.support@persona.ca



www.liver.ca 1-800-856-7266

radmin@liver.ca

June 3, 2006

Guelph

9 to noon.

Theresa Stewart (519) 821-1681 clf@sentex.net

Stratford

Queen Street and Lakeside Drive
Stroll around Avon River 9 to noon

Linda Jones (519) 271-9336 ljones@liver.ca.

London

Harris Park 10 to noon.

(519) 659-0951 bmckenzie@liver.ca.

June 4, 2006

Victoria, BC

Elk Lake Park 9 am

1-800-856-7266 radmin@liver.ca.

Winnipeg

Fort Whyte Centre at 12:30

Kyla 204-475-1938 kdenisui@liver.ca.

Halifax, NS

Victoria Park **1:00 pm**

1-866- 423-8538 ssteves@liver.ca

Brockville, ON

Nancy Maxwell (613) 733-1433

nmaxwell@liver.ca.

Ottawa

Vincent Massey Park 9 - 2:00 am (rain or shine)

(613) 733-1433 (613) 733-1960 nmaxwell@liver.ca

Chatham

Kingston Park 9 - 11:00 am.

Sheila Hughes at (519) 351-3362

clfchatham@xcelco.on.ca.

Sarnia

Centennial Park at the Dow Centre 9 - 11:00 am

Sheila Hughes (519) 336-5223

clfsarnia@xcelco.on.ca.

Toronto

Ajax Rotary Park 9 a.m.

Gina Lipton 1-800-563-5483 ext 4931

HEPATITIS C THROUGH A PATIENT'S EYES

Hepatitis C Through A Patient's Eyes is a book of hope. It is the first one of its kind written by a patient to guide you through, in a personal way, the confusing array of feelings, tests and medical treatment. It is filled with

- * ideas about how to remain grateful and positive
- * suggestions about making treatment an easier experience
- * information about hepatitis C and interferon
- * hope for living with the disease

A book patients, loved ones and health care providers need to read, the message for all is that while someone may have this serious disease, he/she can still live a happy and fulfilling life.

Author bio:

Suzy Smith is an internationally renowned hepatitis C patient expert. Her experience with the disease and background of counseling and public service make her uniquely qualified to share with people on an emotional and professional level. She is a Certified Therapeutic Recreation Specialist, a basic hepatitis C educator and a member of the Winston-Salem Writers Group and Sierra Club. Her lifetime of adventuring and zest for life make her determined to live life fully and help others do the same. Suzy lives in North Carolina with her wonderful dog and 2 cats.

Suzy Smith, author, *Hepatitis C Through A Patient's Eyes*, executive director, Hepatitis C Empowered (HepatitisCEmpowered.org)



CLINICAL TRIALS

Have you seen the website www.clinicaltrials.gov? It is a very complete guide to clinical trials for all diseases, including hepatitis C. Here is an abbreviated example:

Official Title: A Phase II, Randomized, Active-Controlled, Multi-Center Study to Evaluate the Safety and Efficacy of Celgosivir in Combination With Peginterferon Alfa-2b, With and Without Ribavirin, for 12 Weeks in Patients With Chronic Hepatitis C Infection (Genotype 1) Who Failed to Respond to Pegylated α Interferon-Based Therapy.

Identifier: NCT00217139

Study ID Numbers: HCV-05-002

ClinicalTrials.gov Identifier: NCT00217139

The objective of the Phase II study is to evaluate the safety and efficacy of celgosivir plus peginterferon alfa-2b, with or without ribavirin, for 12 weeks in patients with genotype 1.

Expected Total Enrollment: 60

Study start: September 2005

Requisites: 18-65 years of age, inclusive, with chronic HCV infection, non-responder

Edmonton, Alberta, Recruiting
Vancouver, British Columbia, Canada;

Recruiting

Winnipeg, Manitoba, Canada; Not yet recruiting

Halifax, Nova Scotia, Canada;

Recruiting

London, Ontario, Canada; Recruiting

Contact: Jim Pankovich (604) 221-9666
Ext. 259

Study Director, MIGENIX Inc.



COMPENSATION

LAW FIRMS



1986-1990

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

Pre-1986/ Post-1990

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/hepc/intro.html

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

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

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

Kolthammer Batchelor & Laidlaw LLP
#208, 11062 – 156 Street,
Edmonton, AB T5P-4M8
Tel: 780-489-5003 Fax: 780-486-2107
kkoltham@telusplanet.net

Other:

William Dermody/Dempster, Dermody, Riley & Buntain
Hamilton, ON L8N 3Z1 1-905-572-6688

LOOKBACK/TRACEBACK

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

Hema-Quebec Lookback/Traceback & Info Line:
1-888-666-4362

Manitoba Traceback: 1-866-357-0196

RCMP Blood Probe Task Force TIPS Hotline

1-888-530-1111 or 1-905-953-7388
Mon-Fri 7 AM-10 PM EST
345 Harry Walker Parkway, South Newmarket, ON L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296
Health Canada Compensation Line: 1-888-780-1111
Red Cross Compensation pre-86/post-90 Registration: 1-888-840-5764

Ontario Compensation: 1-877-222-4977

Quebec Compensation: 1-888-840-5764

ca/en/ms/hepatitisc/forms.html

ADMINISTRATOR

1986-1990

To receive a compensation claims form package, please call the Administrator at 1-877- 434-0944.

www.hepc8690.com info@hepc8690.com
<http://www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf>

Pre-86/Post-90

Hepatitis C Settlement Fund—KPMG Inc.
Claims Administrator

2000 McGill College Avenue, Suite 1900

Montreal (Quebec) H3A 3H8

1-888-840-5764 (1-888-840-kpmg)

HepatitisC@kpmg.ca

<http://www.kpmg.ca>

MISCELLANEOUS

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

HEPATAPUS^{by #3} 9.e.



COMING UP IN BC/YUKON:

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

AIDS Vancouver Island HCV support
 ♦ **Campbell River:** Drop in, harm reduction, support, education. Contact: 830-0787, jeanette.reinhardt@avi.org
leanne.cunningham@avi.org

♦ **Comox Valley** 355 6th St. Courtenay; Contact Phyllis 338-7400 phyllis.wood@avi.org Drop in, harm reduction, support, education.

♦ **Nanaimo** Each Wed 2-4 PM #201-55 Victoria Rd. Contact Anita 753-2437 anita.mcleod@avi.org.

♦ **Port Hardy** (Sayward, Port McNeil, Alert Bay, Sointula and Woss) 7070 Shorcliffe Ave, Contact Andrea 949-0432 andrea.walters@viha.ca Mobile harm reduction, support.

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

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

Castlegar Contact Robin 365-6137 eor@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

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

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

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

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

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

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

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

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

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

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

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

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

Prince Rupert Hepatitis C Support Public Health Unit 624-7480

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

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

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

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

Sunshine Coast-Sechelt Healthy Livers Support Group 2nd Mon. monthly, 3-4:30 PM, Sechelt Health Unit, 5571 Inlet. Contact Brent or Karen at 604-740-9042 brent.fitzsimmons@cgh.bc.ca or Ctriona at 604-886-5613.

Vancouver Native Health Three levels of training on HIV, Hepatitis STD's, drug use and harm reduction using a peer support model. Next intake: May 27. Contact Ken: 604-816-0192 vnhs-peer@shaw.ca

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

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

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

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

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

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

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

OTHER PROVINCES:

ONTARIO:

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

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

Hepatitis C Network of Windsor & Essex County Contact 519-562-1741, amomkman@hepcnetwork.net, www.hepcnetwork.net

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

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

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

Owen Sound May 16th and 23rd, 7 PM, Public Library Board Room, 824 1st Ave. West. Contact Debby Minielly, 1-800-263-3456, 376-9420, Ext. 257, www.publichealthgreybruce.on.ca/, dminielly@publichealthgreybruce.on.ca

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

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

Sudbury Circle C Support Group 1st & 3rd Thurs. Contact Ernie 705-522-5156 hepc.support@persona.ca

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

Unified Networkers of Drug Users Nationally undun@sympatico.ca

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



QUEBEC:

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

ATLANTIC PROVINCES:

Saint John & Area: Information and Support. Contact Allan Kerr kerrs@nbnet.nb.ca

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

PRAIRIE PROVINCES:

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

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

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

Wood Buffalo HIV & AIDS Society #002-9908 Franklin Ave, Fort McMurray, AB Contact 780-743-9200 wbhas@telus.net www.wbhas.ca

Manitoba Hepatitis C Support Community Inc. Meets every Tues. 7:00 PM, United Church Crossways-in-Common, 222 Furby Street, side door, corner of Furby and Broadway, Main Floor - look for the signs) Contact Kirk: (204) 772-8925 info@mbhepc.org ; www.mbhepc.org

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



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

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