

# Canada's Hepatitis C News Bulletin

"Promoting HCV Wellness"

## **MARCH 2001**

Issue No. 32

## Living Well With Hepatitis C: Two Days with Alan Franciscus

CLINIC FOR VICTORIA?

By Joan King



n Thursday, February 15<sup>th</sup>, and Friday, February 16<sup>th</sup>, Alan Franciscus, the founder and editor–in-chief of the HCV Advocate, gave 2 presentations. The verdict was unanimous. They were excellent.

What struck me and most of the sixtyfive or so persons who attended the workshops was how well organized the information was.

For each presentation, Alan developed original slide presentations, which he has kindly donated to HepCBC, and which we are including in our Resource CD. Aside from the slide presentation developed specifically for Victoria, there is a slide presentation on Co-infection and another on Methadone, IDU's and HCV.

The Thursday session was held at the Capital Health Region on Cook Street, and it was intended for health care professionals. Alan also showed the excellent video, "Hepatitis C - A Viral Mystery," at this workshop. This video, by Stephen Steady,

is definitely one of the best I've ever seen. This video, as well as "I Have Hepatitis C," which was shown on Friday, is available for viewing



Alan Merv & Joan

in the HepCBC Library at 541 Herald Street.

On Friday, despite the SNOW and the fact that in my hepfog I had reversed the locations on the press releases (but given the right directions on the phone, and thus managed to confuse just about everyone), the turnout was still respectable. It was sad, however, that many people could not attend because they assumed—and with good cause—that the event had been cancelled.

Turn out was not only local. Ken Thomson from ANKORS in Nelson, Merv McLeod, from ARC in Kelowna, Linda Manzon, a nurse from Grand Forks, and Ane Kunga Palmo from Frontline in Seattle were also there.

At the Thursday workshop, Drs. Linda Poffenroth and Dennis Petrunia broke the news that the CHR is seeking to establish a Hepatitis



C Clinic in Vic- Sandy Newton & Ken Thomson

toria (see column to the right), urging the community to get involved.

At the Friday session we were joined by Dr. Chris Fraser from the Swift Street Clinic, who was there to answer any questions the audience might have regarding treatment issues, side effects or whatever.

None of this would have been possible

without the cooperation and hard work of Hermione Jefferis of SOS, Michael Yoder of VARCS, David Hillman of VPWAS and HepCBC, as well as the assistance of various individuals in the CHR.

My sincerest thanks.

C.D. Mazoff

Victoria, February 16, 2001: Yesterday, at a round table forum focusing on educating healthcare providers and community support workers about the issues facing their Hep C clients, Dr. Denis Petrunia announced that the CHR has approached the Provincial Government with a "bare-bones" proposal for a much-needed hepatitis C clinic in Victoria, which, if accepted, would also bring a hepatologist to Vancouver Island.

If you like this idea, please consider circulating a petition with the following, or similar wording:

### "Dear Minister:

We, the undersigned, understand that the BC government is considering opening a hepatitis C clinic in Victoria, under the auspices of the Capital Health Region, and we, the undersigned, strongly urge you to do so. Many of us have to travel, sick as we are, to Vancouver to get treatment. The doctors here are overworked and don't have the time to dedicate to learn about all the nuances of We desperately need a this disease. hepatologist here in town, to whom the GPs can turn. Such a clinic would help to curb the spread of this epidemic, already so prevalent in our city."

Include the "blurb," the name, signature and address of each person signing, and a maximum 25 signatures on each sheet, and send to:

The Honourable Corky Evans Ministry of Health and Ministry Responsible for Seniors

PO Box 9050 STN PROV GOVT Victoria, BC V8W 9E2 Canada

hepc.bull MARCH 2001 Issue No. 32 Page 1

## SUBSCRIPTION/ MEMBERSHIP FORM

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

Newsletter Ads:

\$20 for business card size ad, per issue.

There will be a maximum of 4 ads in each issue, and the ads will be published if space allows. Payments will be refunded if the ad is not published. Ads are also posted to the Web.

## **HOW TO REACH US:**

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HepCBC 2741 Richmond Road Victoria BC V8R 4T3

# 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.



Peppermint
Patti's FAQ
Version 4
Available
NOW!!

Peppermint Patti's FAQ Version 4 is now available. The new version includes an HIV co-infection section as well as updated Canadian Links and the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only \$5 each plus S&H—but if you can afford more we'll take it. Contact HepCBC.

HepCBC Resource CD: The CD contains back issues of the *hepc.bull* from 1997-2001; the FAQ V4; the Advocate's Guide and the Slide Presentations developed by Alan Franciscus. The Resource CD costs \$10, including shipping and handling. Please send cheque or money order to the address on the subscription form on this page.



epCBC would like to thank the following institutions and individuals for their generosity: Lexmark, David Klein, J.J. Camp, Bruce Lemer, Elsevier Science, Blackwell Science, Medical Massachusetts Association. Health Canada. The Legal Services Society of BC, Pacific Coast Net, BC Transit, Margison Bros Printers, Carousel Computers, Island Collateral, David Lang, Alan Franciscus and Arlene & Frank Darlington. Special thanks to Danielle Hanna for helping with the pamphlets and the bulletins.



# CANADIAN CONFERENCE ON HEPATITIS C

The 1<sup>st</sup> Canadian Conference on Hepatitis C will be held in Montreal from May 1 to May 4, 2001.

The Conference will be community driven and focused, presenting a three track program that includes Basic and Clinical Science, Public Health and Social Science and Community issues.

Early registration is set for February 28, 2001. Scholarship programs are also available.

For information on this conference, information can be obtained at www.hepclconf.ca. You can also phone 1-866 420-1684. Or you can email hepcl@hemophilia.ca.

PLEASE PLAN TO ATTEND THIS CONFERENCE. WE NEED YOUR REGISTRATIONS SO THAT WE CAN GO AHEAD WITH THE CONFERENCE.

Thank you.

BRUCE REMPEL, rempel@citytel.net.

# C

### **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 15<sup>th</sup> of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to **HepCBC**, and mail to **HepCBC**, **Attn. Squeeky**, **2741 Richmond Road Victoria BC V8R 4T3**. Give us your name, tel. no., 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.

## SINGLE? LONELY?

Alberta Hepatitis Singles web http://clubs.yahoo.com/clubs/ albertahepatitissingles

# Got HepC?... Single? ...Visit

http://clubs.yahoo.com/clubs/ ontariohepcsingles

We can't fix the Hep.. but we can help make sure you're not alone..

Drop by and say hello ...

Page 2 hepc.bull MARCH 2001 Issue No. 32



# THE SQUEEKY W HEEL



# VOLUNTEER APPRECIATION

## Promises, Promises:

s Joan reported, last week, at the HepCBC Workshops in Victoria, representatives from the Capital Health Region mentioned that they have put forth a proposal to the BC Government asking that a Hepatitis C Clinic be established in Victoria, and also that we have a resident hepatologist. Whew!!!! That's a big one.

While I'd love to believe Dr. Poffenroth—I have no reason not to believe her (she has done much for other communities in Victoria and is held in high regard by many of my colleagues)—I am still reluctant to invest emotionally.

Two years ago, the BC Government urged a group of us to form HepCBC, which we did. They promised us assistance. We were abandoned. Then the boys from Health Canada came out—lots of them: Dave Hurford, Moffat Clarke, Stephen James, and who knows who else. We were wooed; we were smiled at; we were encouraged; we were praised; we were dismissed.

Today I read a post on the HepCAN from Darlene Nicolaas, in which she says, "I wouldn't hold my breath with regard to a compensation package of \$ 10,000 from the provincial government. I personally, after listening to the lawyers in court, think this is far in the future - if at all - and probably not even close to that amount."

And just a few days ago, I heard from Health Canada. I was asking why the Hep C groups had not received funding applications. I was told by the person on the phone that there wasn't much money left—(this, of course, is because it has all been given out to AIDS and special interest groups). I wasn't surprised. Marjorie Harris told me months ago that this would probably happen. She also told me that by the time we had the opportunity to file our applications, most of our projects would either be superfluous or redundant, or both.

It's not that I wouldn't welcome some funding from the government, BC, Health Canada, or even Botswana, but I wouldn't get my knickers in a knot over it either. Promises, promises.

squeeky

# TRANSMISSION DURING COLONOSCOPY

**WARNINGS** 

These doctors report a case of a husband and wife in their 50's who had symptoms, and tested positive for HCV in October 1995. Both were regular blood donors for 20 years, and tested negative for the virus in January 1995. They had no blood transfusion or IV drug use. Both had family histories of colon cancer, and decided to have their first colonoscopies done in March 1995. Their ALTs were normal one week before. No fibrosis was present on either spouse's biopsy. The doctors, suspecting transmission via colonoscopy, investigated patients who had a colonoscopy the same day, and staff members present that day. Staff members were all HCV-negative. They found a patient, a 42year-old woman, with HCV and compared the viruses of all three by doing a genotyping test and PCR. A PCR was also done on the blood collected from the couple in January, and came out negative. The results comparing the 3 patients showed that all were infected with the same virus. The colonoscope and other tools had been immediately soaked for 10 minutes in water and detergent, and then soaked for 5 minutes in 2% glutaraldehyde. (The article goes into more detail.) The doctors suspect that the biopsy-suction channel used was not cleaned with the correct brush to remove residual tissue. Another problem was that the biopsy forceps and diathermic loop were not autoclaved between patients. Although the IV lines and needles were changed between patients, the same syringes to administer drugs were used. The anesthesiologist justified this, saying he used a check valve to avoid backflow. The authors state that equipment and ampules should be used only once.

Source: Brownowicki, JP, et al, The New England Journal of Medicine -- July 24, 1997 -- Vol. 337, No. 4, Brief Report: Patient-to-Patient Transmission of Hepatitis C Virus during Colonoscopy

#### **NEVIRAPINE**

Patients with HIV who take the antiretroviral drug nevirapine (Viramune) may risk liver damage, according to the US Centers for Disease Control and Prevention (CDC). The drug has not yet been approved for needle stick injuries, but some doctors may have used one-dose to prevent HIV mother-to-child infection. **More than one dose can be very toxic to the liver**. Twelve such cases have been reported. Between 1997 and 2000, some requiring liver transplantation.

Source: Emma Paten Hitt, comPotential Liver Toxicity1/05/01 http://www.hivandhepatitis.com



I t was with great pride that HepCBC was able to present a Service Award to Arlene & Frank Darlington. Arlene and Frank have been *active* members of the Victoria hepatitis C community since before I can remember.

Frank Darlington was poisoned during open heart surgery in the early 80's, and now, despite the cirrhosis, the problems with his spleen and a blocked artery, he remains as active as possible. Frank regularly contacts politicians and health officials, helps send out the bulletin, and attends demonstrations.

Arlene Darlington is an example to us all. She helps with the books, attends demonstrations, writes letters, comes up with great ideas—so does Frank—and we don't know what we'd do without her.

Both Frank & Arlene have been active fundraisers, a skill they no doubt learned as Kiwanians. When they are not doing a zillion things for the Hep C community, Frank and Arlene enjoy their family and fishing.

# TIP OF THE MONTH:

Check all medications with your **pharmacist** to see if they are bad for the liver.

hepc.bull MARCH 2001 Issue No. 32 Page 3

American Journal of Gastroenterology, Jan 2001, Vol 96, Number 1.

C.D. Mazoff, PhD

his month several articles caught my attention. An editorial and a research article were devoted to the problem of psychiatric disorders and IFN treatment, and the doctors concluded that anyone with a past or present history of psychiatric disordersmost notably depression—should undergo a thorough psychiatric examination and be closely monitored during treatment. It is widely known that IFN can trigger neuropsychiatric symptoms, and even lead to suicide. Mostly, the neuropsychiatric symptoms lead to failed treatment. The study concluded that since many persons with hepatitis C have pre-existing neuropsychiatric disorders/ depression (alcoholism, IDU), a team approach is the best way to go. Now, just for the record, has anyone here in BC/Canada a) ever tried to get to see a psychiatrist? How long did it take? And if you are on a disability pension, or on income assistance, b) how were you to pay for the services? And last, how many of you were denied or delayedtreatment because you couldn't get past a or b?

And pardon me while I vent! There is yet another **quality of life study** trying to prove that persons with hepatitis C who suffer from diminished quality of life do so because they are alcoholics or IDUs. Give me a break!

The article "Comorbidities and Quality of Life in Patients with Interferon-Refractory Chronic Hepatitis C" is actually quite amusing. The authors set out elaborate mechanisms to demonstrate that only a select group of persons with hepatitis C have reduced quality of life, and that this is due mainly to the consequences of lifestyle or mental defect. But try as they might to prove their point, the evidence mounts up against them. Amazingly, age, educational level and employment status (i.e., unemployed dropouts vs. working professionals) did not account for differences in quality of life. Neither did a past history of alcoholism or alcohol abuse, and surprise, surprise, nor did a history of IDU or addiction. All the authors could say "The finding was unexpected." Sheesh, well I'm sorry guys.

What's really funny about this article is that you can see the authors scratching their heads trying to figure out why the square pegs won't go into the round holes. I mean, everyone knows that HCV isn't really that serious, and that if

you have symptoms it's because you're out to rip off the government.

In the end, the authors concluded that the biggest factors affecting quality of life in persons with chronic hepatitis C were "the presence of psychiatric and medical comorbidities, particularly medical comorbidities." However, they do not view the comorbidities they cited (depression, hypertension, arthritis, diabetes) as an integral part of hepatitis C, but rather as typical of the population ingen-

So, again, what we're left with is: it's either all in your head (depression) or it's all in your head (you're getting old like everyone else). The study concludes that "the prevalence of depressed mood in our population is similar to that reported in studies of outpatients with other chronic illnesses," and that they don't know why people with Hep C are depressed. It could be "due to the route of infection"—but they can't prove that—"the psychological burden of a chronic illness, or the liver disease itself."

So, what are they saying? I think they are saying what they've always been saying, and wasting more money doing it. In fact this study concludes that what is needed is vet another study.

Last, don't read this one if you're squeamish or about to get a biopsy. The last article from the AJG discusses a "Delayed Fatal Hemorrhage" after an uneventful liver biopsy.

A 41 year old man with stage 2 fibrosis and grade 2 inflammation underwent an uneventful biopsy. His enzymes were around 100, and he had no clotting or platelet problems. They sent him home after 6 hours of observation.

Five days later the man returned to the hospital complaining of pain in his right shoulder. A physical exam and bloodwork at first revealed nothing. His condition deteriorated rapidly, and his enzymes shot up to 5000. There was massive rapid destruction of the liver and massive internal bleeding. He died 5 days later from multiorgan failure.

There was no clue that this would happen. The cause was a psuedoaneurysm in the hepatic artery. From what I've read, these are more often than not fatal. Aneurysms and other complications—hematomas, hemor-

hage, and arteriovenous fistulas-can occur in a large percentage of persons undergoing liver biopsy, but these anomalies usually disappear after 1 week, suggesting rapid healing.

Biopsy anyone?

### **BILIARY DRAINAGE**

Dr. Philippe Ruszniewski, and his colleagues from the Hopital Beaujon in Clichy, studied liver biopsies from 11 men suffering from chronic inflammation of the pancreas (this often goes along with advanced hepatitis C) and stenosis (narrowing or closure) of the common bile duct. The men were treated by surgical decompression, and biopsies were repeated around 2 1/2 years later. The results suggest that "extensive fibrosis or cirrhosis in patients with well-preserved liver function should no longer be considered untreatable."

Source: N Engl J Med 2001:344:418-423,452-454. Biliary drainage reduces liver fibrosis in patients with chronic pancreatitis

### TIPS VS. SURGICAL SHUNT

Doctors from the University of Washington School of Medicine in Seattle compared the the transjugular intrahepatic portasystemic shunt (TIPS) procedure (also called an angiographic shunt) with surgical shunt (AKA portacaval, distal splenorenal shunt)), in patients with variceal bleeding in 40 patients with cirrhosis with a prior history of at least one bleed.

The team measured 30-day and long-term mortality. In addition, they assessed postintervention diagnostic procedures (endoscopic, ultrasonographic, and angiographic studies), hospital readmission, variceal rebleeding episodes, blood transfusions, shunt revisions, and hospital and professional charges.

Taking into consideration short and longterm mortality, number of rebleeds, rehospitalisations, medical costs, the doctors found that the surgical shunt is "more effective, more durable, and less costly than TIPS."

Source: Arch Surg. 2001; 136: 17-20, 19 Jan 2001, TIPS vs. surgical shunt in good-risk cirrhotic patients

#### PEG-INTRON APPROVED IN US

The US FDA has approved Schering-Plough's Peg-Intron for monotherapy. It has been approved only for patients who have not previously been treated. This, however, does not necessarily stop doctors from prescribing the drug "off label" to those who have previously failed therapy, or from prescribing it with ribavirin, now-unbundled in the US. Peg-Intron has been shown more effective than Schering's regular Intron (24% vs. 12%), but not so effective as the "combo" of IFN + ribavirin.

Do remember: Roche's Pegasys should be approved later this year, and if you're worried about prices, prices on ribavirin may go down when Schering loses it's exclusive rights to the drug next year, and there is more competition.

Source: PRNewswire, Jan. 22, 2001, First Pegylated Interferon Approved for Marketing in the United States

Page 4 hepc.bull **MARCH 2001** Issue No. 32

## TRIALS

### **LEVOVIRIN**

ICN Pharmaceuticals, producer of ribavirin, has applied to the US FDA for approval of levovirin combined with interferon to be used in stage clinical trials in humans. Levovirin **is similar to ribavirin**, but, according to animal testing, **safer**. The first round of testing would be done in healthy volunteers, and the second would be done in Hep C patients.

Source: Jan. 9 /PRNewswire/Jan 9 2001, ICN Pharmaceuticals Files Levovirin IND to Start Clinical Trials

#### **CANGENE**

Cangene Corporation is **recruiting patients** for its phase II clinical trial in liver **transplant recipients**. Its product Cangene is a hyperimmune, anti-hepatitis C product.

The company's hopes are that Cangene will prevent re-infection after transplantation, and the trial is being sponsored by the Research Centre of the Centre Hospitalier de l'Universite de Montreal (CHUM) and Canadian Blood Services (CBS). Four other centers from the from the Canadian Liver Transplant Group are taking part in this trial.

Hyperimmunes are purified antibodies taken from human blood.

Source: http://www.prnewswire.com, 01/09/2001 14:44 EST, Cangene targets Hepatitis C the world's most commonblood-borne infection

# THYMITAQ FOR LIVER CANCER

Phase III trials of Zarix's Thymitaq, for **inoperable liver cancer** have been approved in Canada, which is the third country to agree to participate in the worldwide trials. Although the drug is intended for treatment of liver cancer, it may be effective in other types of cancer, as well. Phase II trials tested more than 600 patients, and the majority were deemed stable.

Thymitaq is a thymidylate synthase inhibitor.

Source: Englemed Health News, http://www. internationalmedicalnews.com, Phase III trials of Thymitaq, for hepatocellular carcinoma, are initiated worldwide

### COLCHICINE HAMPERS IFN

Italian researchers studied 65 patients, where half received IFN alone, and the other half, a combination of IFN and colchicine, an anti-fibrotic drug. The study was to last 3 years, but was stopped after 18 months, because of worse results in the combo arm of

the study. (26% compared to 6% response.) .

Source: Hepatitis Weekly, http://www.newsrx.com, January 12, 2001 Anti-Fibrotic Drug Colchicine Hampers Effectiveness of Interferon Therapy

# PHASE II TRIALS OF OMNIFERON

Viragen's Omniferon is **now enrolling patients in Europe** in the second stage of a phase II trial. Omniferon is a type of interferon that comes from human white blood cells. The phase II trials are being done on patients who have not been treated before. There were no dropouts due to side effects, and the results to date showed a significant reduction of HCV, and it looks like the reduction is more rapid than in similar products.

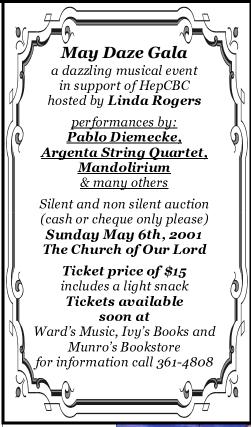
Source: Dec. 18 /PRNewswire/ Phase II TRIALS OF OMNIFERON Reports Rapid Response in Hepatitis C Patients

## RE-TREATMENT HIGH DOSE CONSENSUS IFN

Patients who have failed combo therapy may wish to try high-dose consensus IFN. In a study of more than 500 non-responders to at least 3 months of the combo (IFN + Ribavirin), all the patients were treated for 8 weeks with 15 mcg of consensus IFN daily, and then divided into two groups, half receiving 15 mcg three times a week, and the others receiving 9 mcg daily. 83% of relapsers who finished 48 weeks of treatment with 15 three times a week, and 77% who took 9 mcg daily tested negative for HCV. 16% of prior non-responders who received 15 mcg three times a week, tested negative, and **40%** of prior **non-responders** who received daily IFN were negative. Among the responders were many genotype 1 patients. Patients who failed to respond at week 24 (40%) were dropped from the study. There were fewer side effects in patients receiving daily IFN.

Researchers observed that prior non-responders fare better on 9 mcg of consensus IFN daily, while prior relapsers responded equally to either regimen.

Source: http://www.prnewswire.com 12/18/2000, High-Dose Consensus Interferon Successfully Treats Many Patients Who Failed Combination Therapy; End-of-Treatment Data Support Earlier 24-Week Results



# ABOUT TAP

The Travel Assistance Program is sponsored by the BC Ministry of Health and Ministry Responsible for Seniors.



TAP was created to help residents of BC to access health care services that they cannot obtain unless they travel.

In other words, if you have to travel to get access to specialists in Vancouver, for example, the TAP program will pay for, or give you discounts for, your travel costs, such as ferry fares, for you, your vehicle, and for an escort, if one is needed.

Please ask your doctor for a form to complete. You also need to contact MSP to verify your eligibility and to receive a confirmation number before you travel. (Phone number below)

You are eligible if you are a BC resident enrolled in the Medical Services Plan, and your travel expenses aren't covered by other insurance policies. There are regulations such as arriving at the ferry, for example, one hour before departure.

This program doesn't include meals, accommodations, car expenses, or local transportation. You must make your own travel and accommodation arrangements. You may obtain more information by calling MSP at 1-800-661-2668 from 830 am to 430 PM, Monday through Friday. You may also call 387-8277 in Victoria.

hepc.bull MARCH 2001 Issue No. 32 Page 5

## REPORT ON KELOWNA **ADVOCACY WORKSHOP JAN 18, 2001**

As representatives of HepCBC and the Trail Hep C Support Group, both Brian Brownrigg and I, Diane Brownrigg, attended the HepCBC Hep C Advocacy Workshop in Kelowna on January 18<sup>th</sup>. It was also attended by individuals from various BC regions, including Nelson, Vancouver, Quesnel, Penticton, Salmon Arm, Armstrong, New Denver and Kelowna.

The day started at 9:00 AM in the 2<sup>nd</sup> floor conference room at the Kelowna General Hospital. Marjorie Harris opened the day by welcoming those attending and allowing everyone an opportunity to introduce themselves and state what their expectations were for the workshop. Most of the attendees were either suffering from Hep C themselves, were a family supporter, an advocacy or health care worker, or members of various support groups.

Marjorie Harris is the president of HepCure. whose mission is to cultivate an international network promoting hepatitis C education, support

and research. One point that Marjorie made was that people with Hep C need to be treated with patience, as we are often dealing with cognitive and emotional problems that make it very difficult to function properly in an everyday setting. Hep C is a disease which does not show an outward handicap, but nonetheless many parts of our lives are hampered by this disease.

Daryle Roberts, Executive Director of the AIDS Resource Centre in Kelowna (ARC), took care of the ground rules such as "no cell phones" and "no smoking" (Brian-was that directed at you?). He suggested that we could take some direction from the AIDS struggle and the ways they were successful in their fight (such as lobbying the government), and stop putting so much effort into the compensation issue and get on with other more important things.

Merv McLeod, HIPPO (Hepatitis Information Project) Coordinator, spoke next. His words were directed towards 4 areas: awareness, education, information gathering and working with health units after diagnosis.

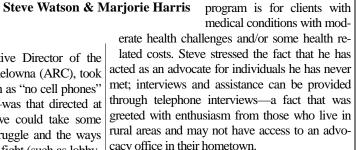
The key note speaker was Steve Watson, a BC / Canada Pension disability advocate from Vancouver. He supplied all of us with some excellent information on the application process. He pointed out that one in seven disability applications are now Hep C related, and that most doc-

tors are not informed on how to make application. He stated that for CPP disability claims, medical evidence is most important. If your claim is denied, make an appeal and be sure to include the information from the original application. Often times when the application is looked at a second time, the claim is not re-read in its entirety. Letters of support from people who have witnessed your difficulty in performing everyday type tasks is one of the most important pieces of the application. Letters from family members, even children, are totally acceptable. Mental health components have a huge impact on an individual's lifestyle and ability to function fully. He stressed that no one should enter into making application without using an advocate, and that chances are the first application will be denied. That should not deter you from appealing and re-applying. Many handouts related to CPP and the application process were available to take home to offices, support groups, etc. Ample opportunity was given to those in attendance to ask questions and interact with the speaker.

Steve then moved on to discuss the Disability Level I and Disability Level II benefits available

> through BC Benefits, Ministry of Social Development and Economic Security. His advice was mainly that no one should attempt to apply without the assistance of an Advocate. Disability with significant health challenges and/or disability related costs, whereas the Level I Disability Benefits

program is for clients with



After a break for lunch, Steve continued on to discuss the Schedule C program. Schedule C is designed for those already receiving Level I or Level II benefits and who are in need of special equipment and supplementary diet requirements.

A nutritionist from the Kelowna Hospital Colleen Harris, spent about 20 minutes giving an overview of nutrition services currently available through Schedule C at the Kelowna General Hospital.

Participants attended a lunch supplied by the sponsoring groups at the Okanagan Grand, and the afternoon session continued with a presentation by Chris Charbonneau, a staff lawyer at the

## **CLF VANCOUVER** LIVING WITH LIVER DISEASE **WORKSHOP SERIES**

VANCOUVER The Canadian Liver Foundation will be hosting a free seven week wellness and educational program for patients and their families affected by liver disease. These workshops are designed to help patients and their families cope with liver disease.

The "living with Liver Disease" Workshops will be held beginning February 22<sup>nd</sup> and running for 7 consecutive Thursday nights. Starting at 6 PM, they will be held at the Coal Harbor Community Centre. All are free of charge.

- Mar. 1: Diet and Nutrition- Lori Fortier
- Mar. 8: Co-Infection HCV/HIV Dr. Chester
- Mar. 15: Traditional Chinese Medicine & Acupuncture Lorne Brown,
- Mar. 22: Resources & Relaxation- Robert & Marlaina
- Mar. 29: Milk Thistle and More! -Dr. David
- Apr. 5: HepC Treatment information Dr Frank Anderson

For more information and to register please call the Canadian Liver Foundation at (604) 681-4588.

Level II is aimed at clients Kelowna branch office of the Legal Services Society of BC. He discussed the legal criteria and definitions of "persons with disabilities." He explained the role of an "assessor" as being an impartial individual who has a professional knowledge of the applicant's disabling or medical condition, explained the need for applications to be completed fully and completely, and then went on to discuss the "Tribunal" process as well as the 'Appeal' process for applications that are denied. Chris and Steve finished up the afternoon session answering any further questions that the group

> Marjorie Harris has drawn up an agency contact list from those workshop participants and can be contacted for the advocacy resources in your area (250-546-2953; amberose@sunwave.net).

> We learned a lot of different things and were able to bring back some valuable points to our support meeting that was held on Tuesday night. We would like to thank all of those who attended as we were able to learn from each other. Many thanks

Diane Brownrigg Trail Hepatitis C Support Group Brian Brownrigg Trail Hepatitis C Support Group Regional Director, HepCBC

Page 6 hepc.bull Issue No. 32 **MARCH 2001** 

# **UPDATE FROM NIAGARA FALLS**

## **SEATTLE SUCCESS**

# **NEWS FROM SMITHERS**

Opring is in the air, as are great workshops in Ontario for hepatitis C.

March 8<sup>th</sup> and 9<sup>th</sup>, 2001, Health Canada's Population and Public Health Branch has booked Courtyard by Marriott in Toronto, Ontario. The keynote speaker is Dr. M. Elkashab, whom I've heard speak, and he is well educated in hepatitis C and a key doctor for treatment in Southern Ontario. This will be crews. The best part of this is that, for the first time, I an afternoon filled with networking and project information sharing. Day 2, Friday, is a full day of skill-building and informational workshops, with a keynote speaker, Ron Shore, Street Health, Kingston, and concluding with project evaluation

HeCSC has also planned a three day Skills Development Workshop in Toronto, March 23-25, 2001, bringing many of their chapters together for: 1. Strategies for Public Education on Hepatitis C; 2. Advocacy; 3. Support, Information and Referral. We're all looking forward to the time to share

Like the rest of Canada, we're invited to the 1st Canadian Conference on Hepatitis C in Montreal May 1-4 2001. The conference is organized by the Canadian Hemophilia Society (Host Organisation), the Canadian Association for the Study of the Liver, the Canadian Center on Substance Abuse, the Canadian Liver Foundation, Canadian Public Health Association, the Hepatitis C Division of Health Canada, Hepatitis Society of Canada, and the Prisoners with HIV/AIDS Support Action Network. Guest Speakers include Harvey Alter, MD, Patty Daly, MD, and Jenny Heathcote, MB. Ch.B. They have a full agenda for everyone. This all shows we're ready to move forward with the fight against this silent killer, hepatitis C, and we're not alone anymore.

Rhonda **HepCNF**  The first "Dancing With the attendance, according to ticket stubs was 103, but I believe that there were actually around 120

saw around 70% new faces. This is really a good sign that we reached folks.

Shelly Mc Kiernan, of the Seattle-King County Department of infectious diseases, spoke to open the event and addressed current epidemiology issues and hosted. The second meeting was in Port had packets there with harm reduction info, and how to, and where to, get information for testing options. She gave good statistics to a "new" crowd of persons.

We tested for HCV with the help of Terry Baker and our VP Bruce Burkett, Jaime Hart and other volunteers.

The silent auction proved a good way to bring in extra monies to help cover the costs and the payments made to the three bands and the MC, Sylvia Stayformore. Selling fresh chicken chili also helped reality. At all our meetings, we had interest cover costs. We did this without any outside funding and we still came out ahead by some amount of money. The music was very good and folks danced starting a Smithers Support Group. The and ate and got informed and educated and had a first meeting will be on Wednesday, March general good time and hopefully left with some insight into this situation.

We hope to plan another event each year and grow with the next one to a National Band and a larger room. People seem eager to learn, once they are aware of the situation with HCV; it's just that Doreen. some are in denial who are still in active addiction.

Thank you. Ane, Frontline http://frontline-hepatitis-awareness.com

Last week Deb and I went to the Oueen Dragon" Frontline musical and Charlotte Islands. I had heard so many stotesting event on January 27<sup>th</sup> was ries about the rough rides on the ferry, but a success in several ways. The it was just great both ways. What a unique place it is. I had never been there before and I just fell in love with it: friendly people, wonderful meals, walks on beaches, there, plus the musicians and informative meetings and great weather. What more could you ask for?

> We had our first meeting in Skidegate. It was a shared meeting between Skidegate and Queen Charlotte City. The public health nurse for Skidegate, Cindy Talarico, Clements and the third in Masset. The Masset meeting was hosted by the public health nurse, Catherine Martin. Catherine took Deb and me to her home for tea and a walk on the beach, and then to her favourite spot for dinner. How can you not love the place? We stopped in Hell on our way through, and Wendy invited us to supper and another wonderful walk on the beach. Then it was time to catch the boat back to and great input. It was very worthwhile.

> We are also happy to say that we are 14<sup>th</sup>, from 7-9 at Positive Living North West. We feel good about this and hope that we have a good response.

Lots of Hugs,



# THE B.C. PALLIATIVE CARE BENEFITS **PROGRAM**

This program just began on February 1, 2001, and helps people in the end-stage of a life-threatening illness such as Hep C to stay at home by covering the cost of medication, medical supplies and equipment all at no charge.

Previously, dying at home surrounded by family and friends was often not possible because drugs and medical supplies given to patients in hospitals and care facilities were not given to patients at home.

To access this service for patients with 6 months or less to live, the patient's doctor must submit an application form to Pharmacare for the patient, and send a copy to your local health unit. Once the patient is approved and entered on PharmaNet, prescriptions can be filled for eligible OTC and prescription drugs and supplies, at no extra cost, other than dispensing fees and costs that exceed those covered by the program. (Ask the pharmacy.) Upon receiving the application, a home care nurse will contact the patient to set up a home visit.

For more information, contact:

Ministry of Health information line at (250) 952-1742 or toll-free 1-800-465-4911, http://www.gov.bc.ca/hlth/ B.C. Hospice Palliative Care Association (604) 806-8821, Fax: (604) 806-8822, bchpca@direct.ca, 1-877-4BCHPCA (1-877-422-4722)

> hepc.bull Issue No. 32 Page 7 **MARCH 2001**

## RESEARCH

#### HCV + HGV

This trial compared liver tissue of patients with hepatitis C, with and without co-infection with the hepatitis G virus (HGV), to see if there was any characteristic of HGV. The study consisted of 194 patients with Hep C, who were tested for HGV. Eighteen of the patients were HGV-positive, and those patients showed more severe bile duct damage, fibrosis around the veins, and irregular regeneration of cells, than those patients without HGV. The researchers concluded that co-infection with HGV worsens liver disease.

Source: Moriyama M, et al Liver 2000 Oct;20(5):397-404, Hepatitis G virus coinfection influences the liver histology of patients with chronic hepatitis C.

## LIVER CANCER IN PATIENTS **OVER 70**

Patients older that 70 years old are as good candidates for liver cancer operations to remove the tumor(s) as younger patients, according to this study, which dealt with 103 patients over 70, and 283 under 70. More of the older patients were infected with Hep C and had more accompanying diseases than the younger patients, but otherwise, the results were the generally equal regarding survival rates and disease-free survival rates.

The investigators report that there may have been some bias in patient selection, and believe that further studies should be done to confirm these results.

Source: J Am Coll Surg 2001;192:38-46 Age not a contraindication to hepatocellular carcinoma resection

#### **BAD BREATH?**

Excess blood ammonia causes many problems in people with cirrhosis, including hepatic encephalopathy (brain fog). Patients with this kind of brain fog have a special type of bad breath called "fetor hepaticus," which the doctors in this experiment studied. They compared the levels of ammonia in both the breath and the blood of 20 patients with cirrhosis and in 10 healthy volunteers. Ammonia in the breath was collected in expired air and measured using electrodes. Helicobacter pylori (an organism that causes ulcers) was also measured, since it produces ammonia. They found that breath ammonia corresponded to blood ammonia, leading them to conclude that measurement of breath ammonia may be useful in diagnosis of hepatic encephalopathy.

Source: Shimamoto, C et al, Hepatogastroenterology 2000 Mar-Apr;47(32):443-5, Breath and blood ammonia in liver cirrhosis.

## **MEDICINAL MARIJUANA: A** SHREWD DISCOVERY

It has been thought for some time that marijuana helps people deal with nausea. Now it has been proven. A researcher in Missouri, Nissar A. Darmani, PhD, discovered connections between the CB1 receptor in marijuana and vomiting, using a shrew as an animal model for his experi-

Hopefully, this discovery will lead to drugs that can prevent vomiting, but do not lead to a "high."

Source: MedscapeWire February 2, 2001, Anti-Vomiting Receptor in Marijuana Discovered and Neuropsychopharmacology. 2001;24(2):198-203

## **HCV REPLICATED IN CELL** CULTURE

Dr. Charles Rice and his colleagues in St. Louis, MO, have, for the first time, grown HCV in cell culture. They identiable to multiply by themselves in cell culture, and thus study their characteristics

Studying the NS5A region of the virus, which is believed to govern the response to IFN, they discovered that, no matter what the sequence of that region, IFN stopped the replication of HCV. but they hypothe-

size that the many mutations might allow replication to continue. The next goal, according to Dr. Rice, is to define the interaction between the host (patient) and the NS5A region, and develop new drugs based on that information.

Source: Science 2000;290:1972-1974. Hepatitis C Variants Replicate in Cell Culture Dec 07, 2000

## MORE WHITE CELLS FOR **OMINFERON**

Pall Corporation and Viragen, Inc., have entered into a partnership to recover white blood cells from blood filters, with Pall's technology. Then Viragen will be able to use those cells to produce Omniferon, a type of interferon that is presently in Phase II trials in Europe for the treatment of Hep C.

Viragen has agreements with several organizations like the American Red Cross, to take the white blood cells filtered out of blood, and considered medical waste. The remaining blood is separated into red blood fied several HCV RNA parts that were cells, platelets and plasma for transfusion. The white blood cells are removed because they can cause bad reactions in the person transfused.

> Source: PRNewswire, Jan. 31, 2001 Discarded Leukocytes Are Potential Source For Treating Hepatitis C http://www.viragen.com

## HepCBC Provincial Roundtable:

Saturday, May 26 Victoria, BC Royal Jubilee Hospital, Woodward Room 9 - 5

#### Morning Session:

The morning session is open to the public. Registration is free, but pre-registration is required.

Wayne Penney-- BC Hospice Palliative Care Association Dr. Frank H. Anderson, Department of Gastroenterology, Vancouver General Hospital John Hamilton, BC Centre for Disease Control Dr. Stephen Sacks, Viridae Clinical Sciences

#### Afternoon Session:

The afternoon session is open only to member associations of HepCBC. Pre-registration is required.

"Where Are We & Where Do We Go from Here?" A strategic planning session facilitated by John Hasell.

#### Dinner:

The dinner is open only to member associations of HepCBC. Pre-registration is required.

Page 8 Issue No. 32 hepc.bull **MARCH 2001** 

# **BC SEXUAL** TRANSMISSION STUDY

#### **VOLUNTEERS NEEDED**

he sexual transmission of hepatitis C virus is an area of speculation, but not a lot of hard facts. Compared to studies of other viruses such as HIV, hepatitis A and B, not much is known. A National Institute of Health consensus statement from the USA in 1997 put the risk of sexual acquisition at less than 5% for those in a stable monogamous relationship over at least 20 years. This was published with the caveat that further research is needed to determine more accurately this risk. Other estimates have been as high as 1% of partners being infected every year. In some large surveys up to 10% of all HCV infections have been attributed to sexual transmission. We do not have estimates for the risk with each sexual contact, but it seems that the longer the contact between the infected and uninfected individual, the higher the chance of infection.

It is thought that multiple sexual partners and other sexually transmitted diseases, including HIV, may be risk factors for increased transmission. These ideas are based on studies that look at people who do not have other risk factors, and have HCV present in their blood. In individual cases the genetic makeup of the virus has been shown to be identical between partners thought to be sexually infected. So it is known that transmission does occur by this route of spread.

Based on these findings it has been suggested by Health Canada's consensus statement in 1999 that people with multiple sexual partners use condoms, but that those with long term monogamous relationships with a HCV positive partner must be aware that transmission can occur, but rarely.

It is in this context that we a doing a study of the sexual transmission of hepatitis C in British Columbia. The question of what number of sexually transmitted infections that occurs here will be addressed and we hope, too, add to the knowledge about this subject. If you have any questions about the study or this topic please call at (604) 875-3054 or toll free 1-800-839-3022.

Valencia Remple, RN; BSN, MSN(C) Research Program Coordinator Oak Tree Clinic/Maternal Fetal Medicine B4 West, 4500 Oak Street Vancouver, BC, V6H 3N1 Tel. 604-875-2463 Fax. 604-875-3063

## THE CO-INFECTION SECTION

Articles for the co-infection section are from **Infections and Complications** (HepCandHIVSupport@yahoogroups.com)

Large study finds hepatitis C virus infection linked to reduced benefit from anti-HIV drugs Hosein SR TreatmentUpdate 112 - 2000 November; Volume 12 Issue 8 http://www.aegis.org/pubs/ catie/2000/cate11203.html

### **Background and Summary**

People with hemophilia as well as injection drug users (IDUs) who are infected with HIV are also likely to be co-infected with hepatitis C virus (HCV). As co-infections can speed up the decline of the immune system, it is important to prevent and treat them. To study the impact of HCV and HIV co-infection as well as that of anti-HIV drugs. researchers in Switzerland conducted a large 2year study on more than 3,000 subjects who were taking potent anti-HIV therapy. The researchers found that those people who were co-infected with both HCV and HIV were at increased risk of developing AIDS or dying, compared to people who had only HIV infection. Active use of injection drugs also increased the risk of developing AIDS or dying. People who were co-infected and used anti-HIV therapy were less likely to have a large increase in their CD4+ cell count than people who had only HIV infection.

Researchers analysed data from 3,111 subjects (29% female, 71% male) of whom 1.954 were infected with HIV and 1,157 were co-infected with HIV and HCV. At the start of the study subjects had the following profile:

#### **HIV** infection only

\* Average age - 37 years \* 5% were IDUs \* 24% had AIDS \* 52% had never used anti-HIV drugs \* Average CD4+ count - 222 cells \* Average CD8+ count - 733 cells \* Average viral load - 32,000 copies

#### HIV and HCV co-infected

\* Average age - 35 years \* 88% were IDUs \* 28% had AIDS \* 60% had never used anti-HIV drugs \* Average CD4+ count - 172 cells \* Average CD8+ count - 696 cells \* Average viral load - 40,000 copies

All subjects in the study received potent anti-HIV therapy. According to the researchers, potent therapy meant that people used "at least three drugs, with at least one protease inhibitor." Subjects who used non-nukes (delavirdine [Rescriptor], efavirenz [Sustiva] or nevirapine [Viramune]) were excluded. Researchers monitored subjects for at least two years.

#### **Results - New illnesses**

A total of 179 subjects developed an AIDSrelated illness and 181 died. The risk of developing an AIDS-related illness in the following groups over a two-year period was as follows: \* 7% - HIV+ and no active drug use \* 10% HIV+ and HCV+ and no active drug use \* 15%

HIV+ and HCV+ with active drug use.

Subjects who were co-infected with HIV and HCV were nearly twice as likely to develop new AIDS-related illnesses compared to subjects who only had HIV infection. This difference was statistically significant, that is, not likely due to chance alone. As well, the proportion of co-infected subjects who died was twice as high (9%) as the proportion of deaths in the group with only HIV infection (4%). Again, this difference between the groups was significant.

Deaths linked to liver disease were about nine times more likely among HCV co-infected subjects than among HCV-negative subjects. At the time of death, subjects in both groups had similar viral loads and CD4+ cell counts.

# HCV - Impact on viral load and CD4+ cell

Once subjects began to use potent anti-HIV therapy, being HCV+ did not have any effect on the drug's ability to suppress HIV levels. When it came to CD4+ cell count increases, however, HCV infection had a more obvious impact. A year after starting anti-HIV therapy, the proportion of subjects in each group who had their CD4+ counts increase by fewer than 50 cells was as follows: \* 25% - HCV+ \* 16% - HCV-

When researchers adjusted their calculations to take into account CD8+ counts, HIV viral load and other factors, this difference between the two groups still occurred.

The researchers found that those people infected with a type of HCV called 3a were more likely to have a very small increase in their CD4+ cell count when given anti-HIV therapy than people who did not have this type of HCV. This is the first time this association has been reported and the Swiss researchers caution that their findings in this regard need to be confirmed by other researchers.

#### **HCV** and the Immune System

The researchers analysed data from nearly 900 of their subjects who had hepatitis B virus infection (HBV). They could find no link between HBV and a poor CD4+ cell response to anti-HIV therapy.

The Swiss researchers think that HCV may affect the immune system in two possible ways. First, HCV can infect cells of the bone marrow and perhaps damage their ability to produce CD4+ cells. Another possibility is that HCV may increase the rate of CD4+ cell death by causing these cells to commit suicide or apoptosis. Suicide by T-cells and other cells of the immune system is a major problem in HIV infection. Perhaps HCV's impact on this process explains the poor CD4+ response seen in this

Whatever the reason behind that poor response, this study points to the need for effective treatment of HCV infection in HIV+ people.

Page 9 hepc.bull **MARCH 2001** Issue No. 32



## Carrying The 500 Day Flag... Marching into Manitoba with George Marcello and The Canada 500 Day Walk By Bill Buckels, February 14, 2001

I t was Jan 31, 2001. It was not such an early morning as the day before. My Dad (who is even older than I am) dropped me at The Royal Canadian Mint at 10:00 AM.

George Marcello was walking into Winnipeg, Manitoba's Capital, and as he arrived I followed him into the parking lot of The Mint.

Four Winnipeg police cruisers joined us, commanded by Ron Audet. Ron's efforts and expertise in escorting us down the main streets of Winnipeg, with lights flashing, from one end of the city to the other, kept us safe throughout the day and added power and credibility to our small party.

After the 10:30 "kick-off" (which was simply a brief media interview) we left The Mint and walked into traffic with TV cameras rolling. We got good media coverage and CTV (CKY TV) notably had 3 separate spots on the 6:00 news, while both of Winnipeg's major newspapers did articles.

I had The Torch of Life held high, still following George with his donation bucket held-out to passing vehicles. I would carry this torch throughout the day for most of the approximately 20 miles that we would walk until my arm felt like it was about to come off. (I switched arms often.)

George jokingly calls himself the "squeegee-kid of Organ Donation," lives-up to that reputation "big-time." We even had a police officer holding a coffeecup out of the window of one of the escort cars to alert passers-by to reach into their pockets and slow-down to throw money into the buckets that the rest of us carried.

We had the stereo on the Hummer blaring rock music while we did "The Walk of Life." After two and a half hours of waving and stopping traffic and collecting money in our "squeegee" buckets, we were suddenly at the corner of Portage and Main, the "windiest corner in the world."

It was there that Dr. Jon Gerrard, my MLA and Leader of The Manitoba Liberal

a Hematologist.) I passed the Torch to Jon, and thanked him for giving my arm a break. Jon obliged by carrying the torch the rest of the way to City Hall. We were a little early for the Winnipeg City Hall press conference at 1:00 and we marched to within a couple of blocks and took a coffee break.

Stan Struthers, the assistant Deputy Minister of Health and MLA for Dauphin (NDP), was heading to City Hall on foot from the Legislature to greet George officially on behalf of the Government. Jon introduced Stan. I bought coffee for everyone including the police. It was great being able to chat informally with our guests about various issues.

Even though we were there for Organ Donation Awareness, all those who know me have already guessed that hepatitis C was mentioned many times throughout the day, but I was also very low key, not wishing to distract anyone from the purpose of The Walk.

The City Hall press conference was quite a neat event, with speeches by the Organ Transplant Awareness Coordinator, the Mayor's representative, and Vince DeLucca of the Italian Community in Winnipeg, who distinguished himself by presenting George with a Donation of \$1250.00. The City and Province offered George congratulations, and cameras rolled. Unfortunately I was not invited to speak at that event since the transplant coordinator had organized the press conference, but the important thing was that George had the opportunity to make his cause understood.

In the middle of the speeches while I was deep in "my own little world," suddenly my wife and partner of 25 years, Valerie, appeared at my side and mentioned that she had to leave. I had been so "wrapped-up" I hadn't even noticed her, and it alarmed me a little that I had been so swept-away.

We were back on the road, waving and benefits of this worthy cause. walking at 2:30 PM. As we walked down Portage Avenue, past the University of Winnipeg, waving at buildings and busses, and talking to people and collecting donations, I marveled at this man who believes in his cause so much that he spends his life this way.

We arrived at Assinaboine Park at the peak of rush hour and said goodbye to our police escort. It was a peaceful end to a hectic and exciting day at Winnipeg's Garden of Life at the Assinaboine Park Conservatory where a celebration service in honour of George and The Canada 500 Day Walk was led by the Manitoba Interfaith Leader and

Party joined us. (Jon is a medical doctor and my friend Rev. Dr. Art (Atze) Veldhuis. The Garden of Life is a project by the Manitoba transplant program and tended by transplant recipients and donor families. We were joined by my father, Bill Sr., and Art's wife Rev. Oriole Veldhuis. Oriole and Art and I sang in our choir together years back, and it was just like "old times."

> I was just too exhausted, and so was George, for us to do much else at that point, and it was back to work the next day for me, so I hobbled off home.

> The days that followed were filled with events, and other towns... Selkirk, Portage La Prairie, Carberry, Brandon, Virden, Russell... I had talked to them all and they were all waiting, but I could not accompany George to them. Our time together was over. As I write this, I just received a call from the Yorkton Newspaper and they are waiting for George in Saskatchewan and will already be there by the time this goes to print.

> Of significance, too, is the meeting that George and I had with Judy Wasylycia-Leis, Winnipeg MP, and NDP Health Critic, who indicated that she or Svend Robinson of BC would be taking forward federal interests in the causes of organ donation and awareness.

> George, himself, met with Manitoba Justice Minister Gord MacIntosh to discuss improving the organ donor system in Manitoba. Unfortunately, I was out of time, and my employer has already given me a the better part of month off work and at work [in the form of earned-time and vacation] to work on The Canada 500 Day Walk, so I could not attend this meeting.

> As a matter of fact, as I said at the beginning, I was sorry in a way that I could not follow George's cause. But it was time to say goodbye to my adventure and go back to being a "Hepatitis C Guy" and let George Marcello bring his message to other Canadians... other Canadians who have the opportunity to share as I have in the joy and positive

> Here is what Manitoba Premier Gary Doer says in his official message:

> "Your message in support of a national registry for organ and tissue donations and about the importance of signing organ donor cards is of great significance.

> May I also extend my congratulations to all the participants and volunteers who have assisted with this campaign."

> Bill Buckels lives and works in Winnipeg Manitoba. He is founder of HepSEE WPG, and a father of great renown.

Page 10 Issue No. 32 hepc.bull **MARCH 2001** 

## **WORKERS** COMPENSATION

It was recently brought to my attention what would happen should you receive compensation while receiving monies from the Workers' Compensation Board, so I wrote them and I asked them the following questions:

- 1. "Will I have to forfeit any lump sum compensation I get because I am already receiving monies from WCB?"
- 2. "Will I have to repay WCB from my compensation payment?"
- 3. "Will my WCB payments be reduced because of a compensation payment?"
- 4. "I am receiving a widow's pension from the WCB. My husband's estate is about to have to be worth more than this. be awarded hepatitis C compensation. Is my pension at risk?"

now several type of payouts: from the Red | have to fight for what is right. Cross; from the Federal Government (1986-1990) and from the BC Government MLA demanding equal treatment to the (pre 86-post 90)

This is what they had to say: "The answer to all four of the questions . . . is Thank you 'No.'"

I was also told to advise our members rempel@citytel.net that "these payments do not affect compensation entitlements and that the Workers' Compensation Board is not interested in claiming any part of the payment."

I hope this helps.

C.D. Mazoff Executive Director, HepCBC

# PRE 1986 - POST 1990

I have been made aware that people that some of you were uncertain about who were infected with Hep C from blood products are not included in the Red Cross or Government Compensation deals.

> It is also my understanding that approximately 20 to 25 people may fall into this gray area. At this moment I have only been able to get the name of one individual. I am asking others to contact me so that we will not be left out.

In Ontario the government has offered \$ 25000 with no waiver being signed. In Quebec and Manitoba this amount is \$ 10000. In B.C. they are talking about \$ 5000 if we are lucky with a waiver being signed. This does not seem fair. Our lives

In the meantime the lawvers will be making millions of dollars off the sick. I also reminded them that there are This just does not seem to be fair. We all Pre 1986/post 1990

> Please write to our premier and your other groups in Canada.

Bruce Rempel



## COMPENSATION

#### **BRITISH COLUMBIA**

1986-1990

Bruce Lemer/Grant Kovacs Norell Vancouver, BC

Phone: (604) 609-6699 Fax: (604) 609-

Before August 1, 1986 or 1990-1991 David A Klein/ Klein Lyons Legal Assistants: Lisa Porteous and & Candace Wall

Vancouver, BC (604) 874-7171, 1-(800) 468-4466, Fax (604) 874-7180

William Dermody/Dempster, Dermody, Riley and Hamilton, Ontario L8N 3Z1 (905) 572-6688

The toll free number to get you in touch with the Hepatitis C Counsel is 1-(800) 229-LEAD (5323).

#### ONTARIO AND OTHER PROVINCES

Mr. David Harvey/ Goodman & Carr

Toronto, Ontario

Phone: (416) 595-2300, Fax: (416) 595-0527

### TRACEBACK PROCEDURES:

#### INQUIRIES-CONTACT:

The Canadian Blood Services Vancouver, BC 1-(888) 332-5663 (local 207)

This information is for anyone who has received blood transfusions in Canada, if they wish to find out if their donors were Hep C positive.

RCMP Task Force TIPS Hotline (Toll free) 1-(888) 530-1111 or 1 (905) 953-7388 Mon-Fri 7 AM-10 PM EST

#### CLASS ACTION/COMPENSATION

If you would like more information about class action/compensation, or help with a lookback, contact: Leslie Gibbenhuck Tel. (250) 490-9054

E-mail: bchepc@telus.net

She needs your name, address, birth date, transfusion dates, and traceback number.

National Compensation Hotline: 1-(888) 726- 2656

#### ADMINISTRATOR

To receive a compensation claims form package, (877) 434-0944.

www.hepc8690.com info@hepc8690.com

your claim (86-90), please contact the administrator. They should answer all of your questions. If, however, they do not, then please contact Bruce Lemer who has promised me that he would answer your questions at no charge.—C.D. Mazoff

## **HOLE IN THE PACKAGE**

One of the gaping holes in "the package" concerns secondarily infected people. The deal applies only to children or spouses. Any another family member or caregiver who was infected cannot apply for compensation. I have one such case in Halifax now, and hopefully she will do some press interviews to bring this to light. The government knew that Hep C could be transmitted to caregivers since the late 70's. I have documented cases of, I assume, nurses in an Ottawa hospital who were infected. They and their patients were diagnosed using surrogate testing, as laid out in the Canadian Medical Journal in 1979.

The biggest single reason these people are infected is the Government. Despite what please call the Administrator at 1(888) 726-2656 or 1 they claimed in court, Hep NonA/NonB (first called Hep C in 1974), was well known and well tracked in Canada from the mid 70's. The dangers of passing it on were well known and documented, and how to prevent its spread was well known. What wasn't well known was the existence of the disease and how it could be caught. The Government was silent as \*\*Should you have any questions about the status of a tomb on these issues.

If you could use copies of papers backing this up, let me know at bdevenne@sprint.ca, 1-902-864-6376. I can fax or mail you a copy.

Bruce Devenne

Page 11 hepc.bull Issue No. 32 **MARCH 2001** 

## **COMING UP IN BC/YUKON:**

**Armstrong HepCure** Office and library, by appointment. Contact: Marjorie, 546-2953, amberose@sunwave.net, www.junction.net/hepcure

Castlegar/Grand Forks/Trail Contact: Robin, 365-6137

Chilliwack BC HepTalk Meetings: 2<sup>nd</sup> and 4<sup>th</sup> Wed, of each month, 7-9 PM, Chilliwack . Contact: HepTalk@fraservalleydir.everyl.net, or 856-6880.

Comox Valley HeCSC Meetings: Third Tues. of each month, 6-8 PM, St. George's United Church on Fitzgerald. Next meeting March 20<sup>th</sup> Contact: Jayne, 336-2485 or Dan, 338-0913, Rhagen@mars.ark.com

Cowichan Valley Hepatitis C Support Contact: Debbie, 715-1307, or Leah, 748-3432.

**Cranbrook HeCSC**: Meetings: 1st and 3rd Tues. of each month, 2-4 PM, #39 13th Ave South, Lower Level. Next meetings March 6<sup>th</sup> & 20<sup>th</sup>. Contact: 426-5277, hepc@cyberling.bc.ca

**Creston / Golden / Invermere** Educational presentation and appointments: Contact Katerina 426-5277

**Downtown Eastside Hep C Support Group** Meetings: Each Mon., 4:30-6:30 PM, Carnegie Center, 401 Main St., Vancouver. Contact: Carolyn, momma@vcn.bc.ca

**HepCBC INFO Line.** Free medical articles or other info. Contact: David, (250) 361-4808, info@hepcbc.org, www.hepcbc.org

Kelowna HeCSC Meetings: First Sat. of each month, 2-4 PM, Rose Avenue Education Room, Kelowna General Hospital. Contact: Doreen, 769-6809 or eriseley@bcintemet.com

**Kimberley Support Group** Meetings: First Mon. of each month, 1-3 PM. Next meeting March 5<sup>th</sup>. Contact Katerina 426-5277

**Kootenay Boundary** Meetings: 2nd & 4th Tues. of each month, 7 PM, 1159 Pine Ave, Trail. Next meetings March 13<sup>th</sup> & 27<sup>th</sup>. Contact: Brian, 368-1141, k-9@direct.ca.

Mid Island Hepatitis C Society Meetings: Second Thurs. of each month, 7-9 PM, Central Vancouver Island Health Centre, 1665 Grant Street, Nanaimo. Next meeting March 8<sup>th</sup>. Speaker: Yvonne Dollard, Iridologist/Herbalist/Nutritional consultant.. Contact: Sue 245-7635, Floyd 741-1595, or mihepc@home.com

Mission Hepatitis C and Liver Disease Support Group Meetings: Third Wed. of each month, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting March 21st. Contact Gina, 826-6582 or Patrick, 820-5576.

Nelson Hepatitis C Support Group Meetings: ANKORS Offices, 101 Baker St., Contact: Ken Thomson, 1-800-421-2437, 505-5506, info@ankors.bc.ca, or Ken Forsythe 355-2732, keen@netidea.com

New Westminster Support Group Meetings: 2nd Mon. of each month, 7:00-8:30 PM, First Nations' Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. Next meeting March 12<sup>th</sup>. Contact: Dianne Morrissettie, 525-3790.

Parksville/Qualicum 102a-156 Morison Avenue, PO Box 157, Parksville, BC V9P 2G4. Open daily from 9AM to 4 PM, M-F. Contact: 248-5551, sasg@island.net

Parksville/Qualicum MIHepCS support and contact: Ria 248-6072

Penticton Hep C Family Support Group Meetings: 2nd Wed. of each month, 7-9 PM, Penticton Health Unit, Board rooms. Next meeting March 14<sup>th</sup>. Contact: Leslie, 490-9054, bchepc@telus.net

Powell River Hep C Support Group "Living With Liver Disease" sessions, Second Wed. of each month, 7-9 PM, Public Health Unit, 4313 Alberta Ave. Next meeting March 14<sup>th</sup>. Contact: Cheryl Morgan 483-3804.

**Prince George Hep C Support Group** Meetings: Second Tues. of each month, 7-9 PM, Health Unit Auditorium. Next meeting March 13<sup>th</sup>. Contact: Gina, 963-9756, gwrickaby@telus.net or Ilse, ikuep-per@pgrhosp.hnet.bc.ca

**Princeton** Meetings: Second Sat. of each month, 2 PM, Health Unit, 47 Harold St. Next meeting March 10<sup>th</sup>.Contact: Brad, 295-6510, citizenk@nethop.net

**Queen Charlotte Islands/Haida Gwaii**: Phone support. Contact Wendy: 557-9362, e-mail: wmm@island.net

**Quesnel**: Contact Elaine Barry. Meetings last Mon. evening every other month. 992-3640

**Richmond: Lulu Island AIDS/Hepatitis Network:** Meetings/dinner every Mon. evening. Contact Phil or Joe at 276-9273.

**Slocan Valley Support Group** Meetings: Contact: Ken, 355-2732, keen@netidea.com

Smithers: Positive Living North West Meetings: Every 2nd. Wednesday of each month. 7-9 PM, 3731 1st Avenue, Upstairs. Next meeting: Mar. 14<sup>th</sup>. Contact: Deb. 877-0042 or 1-866-877-0042, plnwhepc@bulkley.net, or Doreen, 847-2132, aws@mail.bulkley.net

Sunshine Coast—Sechelt: First Wed. of each month. Next meeting March 7<sup>th</sup>. Contact: Kathy, 886-3211, kathy\_rietze@uniserve.com—Gibsons: Last Thurs. of each month. Next meeting March 22<sup>nd</sup>. Both meetings—Health Units, 7 PM. Contact Bill, pager 740-9042

Vancouver CLF Meetings: Cancelled. Call 681-4588 to start an evening meeting. **Help Line:** 657-6757 or 1-800-856-7266

**Vancouver HepC VSG** Meetings: Last Wed. of each month, 10:30-12:30, BCCDC Building, 655 West 12th Tom Cox Boardroom- 2nd floor. Next meeting March 28<sup>th</sup>. Contact: Darlene, 608-3544, djnicol@attglobal.net, or info@hepcvsg.org.

**Vernon HeCSC HEPLIFE** Meetings: Second and fourth Wed. of each month, 10 AM-1 PM, The People Place, 3402-27<sup>th</sup> Ave. Next meetings March 14<sup>th</sup> & 28<sup>th</sup>. Contact: Sharon, 542-3092, sggrant@netcom.ca

Victoria HeCSC Meetings: Last Wed. of each month, St. John's, 1611 Quadra St, 1-3 PM, and Begbie Hall, Royal Jubilee Hospital, Room 306, 6:30-8:30 PM. Next meeting: March 28<sup>th</sup>. Contact: 388-4311, hepcvic@idmail.com

**Victoria Support and Discussion Group** Meetings: First Wed. of each month, 7-9 PM, Next meeting March 7<sup>th</sup>. Contact Hermione, Street Outreach Services 384-1345, hermione@avi.org

Victoria HepCBC Support Groups Small support groups for men or women. Men, contact Guy at 382-9888, kidstum@home.com Women, contact Joan at 595-3882, or jking@hepcbc.org

**Yukon Positive Lives** Meetings: Third Wed. of each month, Whitehorse. Next meeting March 21<sup>st</sup>. Contact 456-2017, positivelives@yknet.yk.ca or Heather, fromme@marshlake.polarcom.com, www.positivelives.yk.ca

### **OTHER PROVINCES**

#### ATLANTIC PROVINCES:

Atlantic Hepatitis C Coalition, QEII Health Sciences Centre, Bethune Building, Rm 223, 1278 Tower Road, Halifax, TEL: 420-1767 or 1-800-521-0572, FAX: (902) 420-1768, rahcc@ns.sympatico.ca, www.ahcc.ca Meetings:

• Antigonish: 2nd Wed. of each month, 7-9 PM, St. Mar-

- Antigonish: 2nd Wed. of each month, 7-9 PM, St. Martha's Health Centre, 25 Bay St, Level 1 Conference Room
- Bridgewater: Last Wed. of each month, 7-9 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room
- Halifax: 3rd Tues. of each month, 7-9 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110
- Kentville: Second Tues. of each month, 6:30-8:30 PM, KingsTech Campus, 236 Belcher St, Rm 214
- Truro: Last Tues. of each month, 7-9 PM, Colchester Regional Hospital, 25 Willow St, Conference Room
- Yarmouth: First Tues, of each month, 7-9 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1— Main level

Cape Breton Hepatitis C Society Meetings: Second Tues. of each month. Contact: 564-4258 (Collect calls accepted from institutions) Call toll free in Nova Scotia 1-877-727-6622

Fredericton, NB HeCSC Meetings: 7 PM Odell Park Lodge. Contact: Sandi, 452-1982 sandik@learnstream.com

Greater Moncton, N.B. HeCSC Contact Debi, 1-888-461-4372 or 858-8519, monchepc@nbnet.nb.ca

#### **ONTARIO:**

Durham Hepatitis C Support Group Meetings: Second Thurs. of each month, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby, Contact: Smilin' Sandi, smking@home.com http://members.home.net/smking/index.htm, Jim (905) 743-0319, Ken Ng, (905) 723-8521, or 1-800-841-2729 (Ext. 2170)

**Hep C Niagara Falls Support Group** Meetings: Last Thurs. of each month, 7-9 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thurold. Contact: Rhonda, 295-4260 or hepcnf@becon.org

**Kitchener Area Chapter** Meetings: Third Wed. of each month, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener: Contact: Carolyn, 893-9136 lollipop@golden.net

**Ottawa Support Group** Meetings: 7-9 PM, 309-1729 Bank St, 3<sup>rd</sup> floor: Use rear door off parking lot. Contact: Ron, 233-9703, ronlee@attcanada.ca

Windsor Support Group Meetings: Last Thurs. of each month, 7-9 PM, 1100 University Ave. W. Contact 739-0301 or Ruth or Janice (Hep-C), 258-8954, truds99@hotmail.com

#### PRAIRIE PROVINCES:

Edmonton, AB Hepatitis C Informal Support Group Meetings: Third Thurs. of each month, 6-8 PM, 10230-111 Avenue, Conference Room "A" (basement) Contact: Cathy Gommerud, yzcat@telusplanet.net or Jackie Neufeld, 939-3379

Edmonton, AB Meetings: Second Wed. of each month, #702-10242 105 St. Contact Fox, 488-5773, 473-7600, or fox@kihewcarvings.com

**HepSEE WPG Winnipeg** Meetings: Last Wed. of each month, 7-9 PM, Young United Church, 222 Furby St., Rm AB, Main Floor. Contact: Bill, 489-1405, bbuckels@escape.ca

#### **OUEBEC:**

**Hepatitis** C **Foundation of Quebec** Meetings: Dawson Community Centre, 666 Woodland Ave., Verdun. Contact Eileen: 769-9040 or fhcq@qc.aibn.com

Page 12 hepc.bull MARCH 2001 Issue No. 32