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Canada's Hepatitis C News Bulletin

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FIRST NATIONAL ABORIGINAL HEPATITIS C CONFERENCE

April 30- May 3, 2002
Edmonton, Alberta
by Darlene Morrow



Opening Ceremonies

The conference was really well organized. The Nechi Institute and all their volunteers worked very hard and should be proud of their efforts. In addition, the conference was a very positive experience. People came to share their experiences and learn whatever they could about hepatitis C.

On May 1 there was a candlelight vigil. George Marcello passed the torch on to Ruth Morin (from the Nechi Institute, and wife of Fox) and Fox Morin who received a successful liver transplant.

There were also many opportunities for different organizations to share their resources. HepHIVE shared its newly released booklet, *Hepatitis C: Between You and Me*. This low literacy booklet was developed specifically for the aboriginal population, and is available to groups for free in BC (funded by the Aboriginal Health Division, BC Ministry of Health).

HepHIVE has also produced a video based on the booklet for people who are unable to read or prefer a video as a medium. This video was debuted at the conference and is also available at no cost to groups within

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HEPATITIS C AWARENESS CELEBRATION IN VICTORIA

There was both good and bad news from the Province's capital on Hep C Candlelight Memorial Day. We had representatives from HepCURE, HepCBC, AIDS Vancouver Island, and the BCHepC Collaborative Circle on the steps of the Legislature, along with a public address system, and candles. About 15 people attended. The sun shone, the wind blew, and it was wet and cold, the crowd was warm and friendly. The City of Victoria proclaimed May 1st as Hepatitis C Awareness Day, thanks to the continuing efforts of HepCBC. The government of British Columbia passed a proclamation declaring May as Hepatitis Awareness month as the positive result of many months of work by Bill Buckels, director HepCURE and the unanimous support of the BC Hepatitis C Collaborative Circle. Susan Brice, Chair of the Government Caucus Committee on Health, presented the provincial proclamation in the house on May 1st. Here are links to Hansard and the proclamation.

<http://www.legis.gov.bc.ca/hansard/37th3rd/h20501p.htm>

http://www.qp.gov.bc.ca/statreg/oic/2002/procs/oic_287.htm

We listened to the reading of both the provincial proclamation declaring May

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POLITENESS

by Dr. C.D. Mazoff, Ph.D.

(This is an open letter to the BC Hepatitis C Community, and to Health Canada)

In a perfect world, politeness would be wonderful.

In this world, however, the Federal Government knowingly poisoned the blood supply, ignored the findings of the official commission, and set up a scheme whereby lawyers "politely" walked away with \$52 million that should have gone to hepatitis C victims. These lawyers' "friends" are other lawyers, now called "honourable" (i.e., members of parliament) who set the whole thing up. If any of you out there think that these lawyers/politicians deserve applause or respect for "being so smart," then you are no friend of mine.

What does this have to do with anything, now, you might be saying? Well, the same people who pulled this off are setting policy for the rest of us with hepatitis C, and frankly it makes me weep.

In this world, Jarad Gibbenhuck could not get treatment, because doctors "politely" cringed behind the law (the one designed by the "honourable lawyers" who have designed an honourable policy and have hired their henchmen and women in Health Canada to carry it out "politely"). His family went bankrupt and was torn apart by the "polite" policies of this government. The Gibbenhuck's are now struggling to be allowed to give Jarad a controversial (yet harmless) herbal treatment which is so effective that it has allowed him to have a "normal" life for the **first time in his life**. Could it be that someone from the pharmaceutical industry "politely" phoned one of his "honourable" friends to make sure that their pensions and stock options are not threatened?

My friend Brian Brownrigg is not going to be around much longer because some doctor "politely" told him he couldn't qualify for treatment because Brian's enzymes were not within the limits "politely" set by government to maximize their private pension plans. Now it's too late for Brian.

Tell me: How many POOR ex-Prime Ministers and Presidents do you know? How many were this rich before they came into power? How rich are they when they leave? Is this because they have "politely" figured out ways to maximize their pen-

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REPRINTS

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

NEW

Peppermint Patti's FAQ Version 5 Available NOW!!

Peppermint Patti's FAQ Version 5 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 V5; the Advocate's Guide; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. 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.

THANKS!!

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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, 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.

Ad No. 21: Hep C Positive Man 40+ Independent, active, caring, compassionate, romantic, would like to meet Hep C positive woman 30-40+ with positive attitude and similar traits.

Ad No. 22: 44 year old man, employed, enjoys fishing, camping, hunting. Own home. Likes country/western music. Separated 2 yrs. Would like to meet someone with similar intents, age 35-45.

Ad 23: Hep C+ Lady 50+ Young looking, 5'6", 125 lbs, long hair, very attractive, seeks positive, upbeat man for mutual support, love, laughs, possible travel. Must love animals, the arts, spirituality. Please reply with sign. I am a Capricorn. Friends first. All replies answered.

**Got Hep C?... Single?
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<http://clubs.yahoo.com/clubs/ontariohepcsingles>

**VICTORIA HepCBC
GENERAL MEETING**

June 4th 7-9 PM, 541 Herald St.
Nominations to the Board requested
Contact: 595-3892



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\$20 CDN each, including postage. This is a GREAT Fundraiser for Support Groups! Call (250) 361-4808, or email info@hepcbc.ca to place your order

LIVER BIOPSY Do's & Don'ts

Since new people are always joining the list, I repost this information from time to time. Some people tell "horror" stories about their biopsies, but most sail through with little or no difficulty. There are several ways to do a liver biopsy, including the "standard" method without any x-ray or ultrasound guidance (this is the most frequently used method world-wide), ultrasound or CT-scan guided, laparoscopic, and via the jugular vein in the neck. The "rules" will vary somewhat, depending on the method used, but what is listed below will apply most of the time.

Rule #1: It's *YOUR* body, so don't allow the docs to treat you in any way not to your liking. Remember: You're the boss and they work for you! If they don't like that concept, get another doc.

Rule #2: A liver biopsy is an invasive procedure (meaning your body will be penetrated by an instrument, namely the biopsy needle) so an INFORMED CONSENT is required. That means that you consent to the procedure only after the doctor doing it has informed you of the risks, benefits, and alternatives to the procedure. This must be done ahead of time, or at least before they give you any sedating medications. If you have been sedated, NO ONE, including you, can be sure you fully understand what is going on.

Rule #3: Ask for sedation or pain medication BEFORE the procedure, IN ADDITION TO the local anesthetic they'll use. If you've never had a liver biopsy, are very anxious about it, or have had a bad experience with a prior procedure, a sedative/relaxer, such as Valium or Versed, will help you relax and help you forget. A pain medication, such as Demerol or Morphine will help you feel much less pain. This can sometimes be a painful procedure, so be sure you get one or the other type of medication, or both. Also, how they give it to you matters! If given into a muscle (IM injection) it will take AT LEAST 20 minutes for the medication to work. If given into a vein through an IV tubing, it will work in 5 minutes or less. This is important because you don't want them working on you until after the medication takes effect! If the doc says the local anesthetic is enough, or doesn't wait long enough after the medication before starting, offer to trade places with him or her! Don't let them put you off if you feel strongly that you need these.

Rule #4: Be ready to help. During the procedure, you may be asked to hold your arm over your head, scoot to the side of the bed, hold your breath, and so on. This is to assist the doc in getting a good specimen. Even the best of them miss, so they may need to stick the needle in two or three or maybe more times (usually at least two). Remember that the goal of all of this is to get enough liver tissue for them to be able to do a good job of analyzing your liver.

Rule #5: Expect to have to lie on your right side afterwards. Although some places have you lie on your back, most places ask you to lie on your right side

after the procedure. The reason for this is that the weight of your body will put pressure on the puncture site to help stop any internal bleeding. Whether or not this really works is anybody's guess. I don't think anyone has really studied it to find out, but it seems like a good idea so they do it! Depending on the hospital, you may have to lie this way for a hour or more (often for 4 hours). If your hospital asks you to lie on your back, don't worry about it. The main thing is that they monitor you carefully so they detect any complications that may occur. The fact of the matter, is that almost everyone will have at least a little internal bleeding from a liver biopsy. But most of the time it's not enough to cause any concern.

Rule #6: If you had sedation for the procedure, then you have had something called "Moderate Sedation" and you MUST be carefully monitored during the biopsy and afterwards. Every hospital is obligated to do this by regulatory agencies. That means that they have to be sure that you can breathe on your own, and that your pulse and blood pressure are stable (they'll usually check these every 5-15 minutes, at least at first). How long it takes to be sure of this varies. It could be anywhere from half an hour to an hour or more. If there is any indication you NOT being stable, then they must keep you there until you ARE. Also, they will not let you drive yourself home, so make sure you make arrangements for someone to do that for you.

Rule #7: If you have any pain after the biopsy procedure is over, ask for pain medication. You may need some, especially if you didn't have any at the start. Most of the time, the pain is minimal afterwards, but everyone is different.

Rule #8: When all the lying and monitoring are completed, someone should be with you when you first get up. This will be the time when you may feel dizziness. Many people feel a little dizzy after lying for a long time after a procedure, so don't be surprised if you do. If the dizziness does not quickly pass, then the staff will need to evaluate you further.

Rule #9: Make sure they give you instructions on any precautions or restrictions to follow when you go home. These should be both in writing and verbal. The medication you had earlier will interfere with your ability to remember these instructions if you don't have them written down.

Rule #10: Make sure you know who to call if you have a problem after going home. Most people don't have any complications from a liver biopsy, but a small number of people do. These complications include pain, dizziness, bleeding, difficulty breathing, and infection. You will be monitored for these in the hospital, but it's possible they will occur after you go home

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WARNINGS

PLASMA THREAT

Those with advanced liver disease or liver transplant patients must not receive the blood plasma called PlasSD or SD, according to a new FDA warning. As well, any patient receiving these products must be checked for blood clots or failure of the blood to clot. Ten deaths were recorded between 1999 and 2001, which are believed to have been caused by these products. This kind of plasma is made from blood from many donors and is treated to destroy viruses like HIV and HCV, and contains substances that control clotting.

Source: "Doctors Are Cautioned Not to Give a Type of Plasma to Liver Patients," *New York Times* May 11, 2002, By Denise Grady

VIOXXR

VIOXXR (rofecoxib) is prescribed to relieve the pain arthritis and menstrual cramps, among other things. The drug causes fewer gastrointestinal problems than naproxen, but even so, a few patients, such as the elderly, can experience bleeding or possibly heart problems. Patients taking the drug should notify their doctor if they start retaining water, have breathing problems, feel weak or tired or have chest pain or weight gain. We with hepatitis C are advised not to take this drug.

Source: http://www.hc-sc.gc.ca/english/protection/warnings/2002/2002_29e.htm April 19, 2002 Health Canada Advisory

TRANSMISSION WARNINGS

"RARE": GYNECOLOGISTS

HCV transmission from health care workers to patients is rare, but it does happen. A German team investigated an HCV+ gynecologist, who had operated on 2907 women between 1993 and 2000. The women were notified and offered free testing. 79% responded and were screened. The researchers made sure the virus of the patients infected matched that of the doctor. Of those tested, 7 had been infected by the doctor, so the transmission rate was 0.04%. The results were published. (*Arch Intern Med* 2002; 162: 805-10, 12 April 2002)

Source: <http://www.gastrohep.com/news/news.asp?id=1237> Risk of HCV transmission from infected gynecologists to patients is rare

TOP CARDIOLOGIST INFECTS PATIENTS

A top heart surgeon from Manhasset has infected at least 3 of his patients with Hep C, and is being sued by one of them. The plaintiff had valve replacement surgery in November of 2000 and became jaundiced soon after.

Source: www.newsday.com, *Seeking a Legal Remedy* by Roni Rabin

BEST RESULTS YET

The combination of Roche's Pegasys and ribavirin has shown the best treatment rates yet for those of us with hepatitis C, with a 61 percent sustained virologic response (SVR), the highest ever reported in a trial with a pegylated interferon. These results came from a phase III trial and were presented in April at the European Association for the Study of Liver (EASL) annual meeting in Madrid, Spain.

The study confirmed the evidence that treatment regimens should be based on genotype. The results for the more difficult genotype 1 were 51% SVR, and required 48 weeks of treatment. Non-genotype 1 patients achieved a 78% SVR with only 24 weeks of treatment and only 800 mg. of ribavirin daily, rather than the 1000-1200 needed by genotype 1 patients.

Source: PRNewswire April 18, 2002, *Highest Sustained Virological Response in Treatment of Hepatitis C Ever*

IMMUNITY?

According to this study, some people who spontaneously clear HCV may develop immunity that protects them if they are re-exposed, raising hopes for a vaccine. The study was done with active injection drug users (IVDU) in Maryland. The participants included 164 people who had never been infected, and 98 who had cleared the virus. They were followed for more than 2 years. All were counseled to curtail their drug use and were referred for treatment, but many continued to use. 21% of those not previously infected contracted HCV. Of those who had cleared the virus, only 12% became re-infected, and often resolved the new infection once again. Those who were co-infected with AIDS were 12 times more likely to develop a persistent case of hepatitis C. The researchers are not sure if the patients who cleared a second infection developed immunity.

Source: Reuters Health, Apr 26, 2002 *Immunity to Hepatitis C May Be Possible: Study*. by Merritt McKinney. Original article: Lancet 2002;359:1452, 1478-1483.

OMEGA IFN IMPLANTS?

BioMedicines has now enrolled all of the 90 patients taking part in a Phase II trial of omega interferon, a genetically-engineered, naturally occurring human interferon. Because the drug is well-tolerated, the weekly dose has been increased, to give higher response rates. The company hopes to use an implantable, subcutaneous delivery system, eliminating the need for self-injection.

PRNewswire, April 18, 2002, *BioMedicines, Inc. Completes Phase II Enrollment with Omega Interferon*, and <http://www.biomedicinesinc.com>.

HGF GENE THERAPY

A Japanese team of researchers has demonstrated how genes encoded for hepatocyte growth factor (HGF) could protect and regenerate liver cells when injected into mice. They used electroporation, stimulating the cells to become more receptive to the therapy. The mice were given plasmids with green fluorescence protein so genetic transfer could be confirmed.

"HGF in plasma was increased up to four-fold from pretreatment amounts, peaking 6-9 days after electroporation and quickly decreasing within 3 weeks," the team reported.

When challenged with a liver toxin, the pretreated mice had less liver cell damage than untreated mice, and ALT levels were lower and returned to normal faster.

Source: *Gene Therapy Weekly*, April 11, 2002 Page 2, *Gene transfer via electrical stimulus reduces toxin damage to liver cells*, by Sonia Nichols www.newsrx.com

GREEN TEA

Unfortunately, many of the livers of brain-dead accident victims which could be used for transplantation often come from accidents which are alcohol-associated. Alcohol causes fatty liver. Free radicals increase in fatty livers after they are transplanted, and these fatty livers lead to high rates of graft failure, so many of these livers must be rejected for transplantation.

Polyphenols in green tea extracts, free radical scavengers, are excellent antioxidants, and previous studies showed that green tea extract can prevent liver damage when there is an inadequate supply of blood, such as in an accident or surgery like transplantation or tumor resection.

In this study, rats were given doses of alcohol mimicking binge drinking in humans. The livers were remove and stored cold for 24 hours, and rinsed with a solution containing green tea extract before they were transplanted. Liver enzymes were 4 times higher in rats receiving fatty livers than those who received healthy livers. Alcohol caused severe cell death and decreased survival rates from 88% to 13%. The green tea extract increased the survival of fatty livers to 75%.

The researchers believe that, by using green tea polyphenols, many organs previously rejected could be used.

Source: http://www.the-aps.org/press_room/eb/13.htm April 20-23, 2002, *Researchers Demonstrate That An Extract From Green Tea Could Aid in Alleviating the Shortage of Livers Available for Transplant*

SAFETY NEEDLE

The US FDA has approved Horizon Medical Products's LifeGuard Safety Needle for sale and distribution. The Safety Needle responds to recent changes in legislation which states that employees must, whenever possible, use safer medical devices so as to reduce the chance of needlestick injury which can result in bloodborne infections like HCV, HBV, and HIV. The new needle, designed for use in vascular port access procedures, is completely encapsulated when the needle is withdrawn from the port, a risky point in the procedure.

Source: PRNewswire, April 10, 2002 *Horizon Medical Products (HMP) Receives FDA Clearance On New LifeGuard(TM) Safety Needle* <http://www.prnnews.com> http://bioforest.biospace.com/news_story.cfm?StoryID=8448215&full=1&print=1

LIVING LIVER DONATION IN CANADA

The hepatitis C virus is causing the supply of livers available for transplant to be insufficient, not only in Canada. The Canadian Liver Foundation says that as many as 300,000 Canadians may be infected. Most of these patients, if they are even eligible for treatment, will not respond, and many will progress to liver failure or liver cancer. Right now there are 500 Canadians on the waiting list for a transplant, and only about 400 donors a year. Some wait for 2 to 3 years, and 20% die without receiving a liver. One option open now to Canadians is a living liver transplant. The first such operation in Canada was done in April 2000, and about 60 have now been performed at 4 different hospitals. There is a 10% chance of complications for the donor in an operation like this, and a 1% chance of death. The good part is that the liver regenerates, so even though about 2/3rds of the healthy liver is taken, it grows back, so that within one month, it is 90% as big as it was before the operation.

Source: <http://www.ctvnews.com/content/sitesections/1/864438.a> <http://www.ctvnews.com/content/sitesections/1/864438.a> May 10 2002 *'Living' liver donors on the increase in Canada*



TRANSPLANT IN SPITE OF PULMONORY HYPERTENSION

It is difficult to qualify for a liver transplant. A patient must generally be in good health, except for the state of the liver, so if a patient has other problems, such as heart, lung, or kidney problems, the chance of receiving a new liver is lower. In this study of 145 patients between 1997 and 1999, English researchers found that patients with severe pulmonary hypertension can survive liver transplantation when the cardiac index is preserved.

Source: *Liver transplantation for patients with pulmonary hypertension is feasible* www.gastrohep.com/news/news. Original article: *Liver Transpl* 2002; 8: 382-8 24 April 2002

MISMATCH BETTER?

Researchers from the University of Pittsburgh are suggesting that some transplant patients might do better with livers that are not a match. Such a liver would be rejected by the body, but it could reduce the recurrence of some conditions that can cause liver failure. Doctors pay attention to blood type and the size of the liver, but often don't test to see if human leukocyte antigens (HLAs) match. They just know that it doesn't seem to matter as far as rejection goes. Now they have noticed that survival rates are greater in those who receive mismatched livers, especially in Hep C patients, where twice as many patients have recurrence of the virus with HLA-matched livers. This is not true in cases of autoimmune disease. When there is no problem with disease recurrence, it is better to have a matched organ, to reduce rejection. Their theory has not yet been proven.

Source: *HealthScoutNews* Apr 30, 2002 *Mismatched Livers Could Be Match From Heaven*, By Ed Edelson, Reporter

GANCICLOVIR

Many recipients of transplanted organs find themselves battling cytomegalovirus (CMV), either their own, or what came with their new organ. This study investigated two methods of using ganciclovir after liver transplantation. One method was to use ganciclovir immediately upon detecting CMV, called prophylaxis. This was effective in preventing infection. The problem is that the risk is low, and treatment may be unnecessary. These researchers believe that preemptive therapy could reduce unnecessary prophylaxis.

"In summary," the authors write, "this study demonstrates that oral ganciclovir can be used effectively to implement preemptive therapy, and it highlights the advantages and limitations of routine use of a PCR test in a placebo-controlled study."

Source: *Reuters Health* May 02, 2002 *Preemptive Ganciclovir Prevents CMV Infection After Liver Transplant* Original article: *J Infect Dis* 2002;185:854-860.

BASILIXIMAB SAFE AND EFFECTIVE

A drug that has shown benefits for enhancing kidney graft survival is also effective for liver grafts. Basiliximab, a monoclonal antibody, is a drug proven effective to help the survival of kidney transplant patients. In this double-blind randomized placebo-controlled trial study, it is being proven safe and effective for prevention of rejection of transplanted livers. It is especially beneficial for HCV+ patients, who had a more than double problem-free transplant rate compared to those treated with the placebo.

Source: www.newsrx.com *Hepatitis Weekly* April 15, 2002, Page: 3 *Basiliximab appropriate for saving liver grafts in chronic hepatitis* by Sonia Nichols. Original article: *Liver Transplantation*, 2002;8(2):132-142.

**PLEASE NOTE:
THE hepc.bull STAFF IS GOING
ON VACATION. THERE WILL BE
NO JULY ISSUE. THE NEXT IS-
SUE WILL BE IN AUGUST**

FRANK DARLINGTON



Frank Darlington passed away peacefully on Monday night, May 20, 2002 at 10:45 PM, after a 2 month stay in the hospital. He will be missed greatly by his wife Arlene and his family, as well as by Joan King, David Mazoff and others who knew him.

Frank was infected by the blood system. He has been an activist all his life, very vocal against government abuses, and he loved rocking boats. His letters to the editor were frequent and to the point. He was an inspiration for us at HepCBC, and his wife Arlene has been one of our staunchest supporters, as well.

(POLITENESS—Continued from page 1)

sion plans and stock options while redirecting the public coffers to their "friends"?

Has anyone here ever heard of a thing called history? Has anyone every read any?

Oh, excuse me. Now I'm being rude. In fact, some of you may be feeling threatened because I'm pushing you against the walls of your own consciences. THIS, however uncomfortable it may seem to you, PALES IN COMPARISON to how Canadians with hepatitis C are being abused by corrupt governments and the people who carry out their policies.

I suppose, then, you'll all say, "David is ranting." No, I'm speaking *difficult* truths.

How many people in BC this year will get treatment? How much Federal and Provincial money will go into drug development for hepatitis C? How many, like Frank Darlington, will die?

On the other hand, I wonder what certain politicians' bank accounts, stock portfolios and land holdings will look like a mere 3 years after they leave office?

I'm wondering how many paid employees of politely compliant ASO's (AIDS Service Organizations) as well as those in Health Canada's Hepatitis C Division will be able to take a nice holiday this year or put a down payment on a house with the money they "earn" doing (?) hepatitis C work?

On the other hand, I wonder how many people with hepatitis C who have given their all to helping others with hepatitis C have had to, or will have to, sell their homes or will go bankrupt or will stop helping others because they have been politely and purposely pushed out of business by the Health Canada-AIDS Back Scratchers' Club.

I have just heard, through the grapevine, that the next round of hepatitis C funding is already earmarked for AIDS organizations, and not for the small, independent hepatitis C organizations that do all the work.

While more and more money goes to organizations with Gay or Lesbian executives, whose clientele comprises mostly co-infected or active drug users, what ever happened to the straight middle class? Why aren't people with hepatitis C being paid to do hepatitis C work?

Speaking of which, how many straight middle class executives who now find out they have hepatitis C are going to go into a needle exchange for support? None! More and more of them, however, have been calling me. There are lots of them out there in the closet. They don't want anyone to know.

My problem is how do I continue to provide information to this group of citizens when the government has not seemingly taken them into account?

ACPD (Action Committee of People with

(Continued on page 7)

THE "CARE, NOT CASH" WAS A BOGUS, EMPTY AGREEMENT

Compensate the pre-86-post-90 hepatitis C victims

Don't get me wrong, I believe all Canadians deserve good health care, but this was Allan Rock's deal.

Since 1999, BC has received \$23,375,000 in quarterly payments from the federal government through Allan Rock's "Care, Not Cash" for the pre-'86/post-'90 hepatitis C victims who were left out of the '86-'90 compensation package. BC is to receive \$66-Million over 20 years.

By the end of May, the administrator for this BC/Red Cross Package will have determined who qualifies as a pre-'86 victim and who doesn't, of the 5,000 applications from across Canada. Why was money transferred by Health Canada to the provinces for 4 years before victims were identified?

Pre-'86 victims on BC disability II have been turned down for bottled water, nutritional supplements, vitamin supplements and a home-maker, all prescribed by their doctor. I, for one was too ill to appeal.

This March the court approved the BC/Red Cross deal. BC is dividing only \$6.5-M among 1,000 applicants. That's only \$6,500 each, and payments will be stretched over a ten year period. The BC Class Action lawyer has to be paid out of this fund too. This money was gained from a Red Cross building flip in Vancouver on which the province put a lien. (The Canadian Blood Services is now working out of the same building.)

From this BC/Red Cross Hep C compensation deal, some HIV victims got to skim \$14-million from the top, which will give them about \$240,000 each.

If Hep C victims are on disability, they must put this money in a trust fund or they'll lose their benefits. They can take money out for such things as a homemaker or to maintain their health. But they cannot use it for a 'newer to them' car even if they live in the country. They can hitch hike.

Is Gordon Campbell going to live up to his 1998 words in the legislature when in opposition? Campbell quoted Mike Harris of Ontario and Justice Krever, and insisted all victims of the blood system should be compensated equally. Ontario gave each pre-'86/post-'90 victim \$25,000 financial assistance without dragging them through the courts. You'd think Gordon Campbell would have done the same.

Hopefully the new health minister in Ottawa, Ann McClelland, will see fit to compensate all the blood injured equally. As she and Allan Rock were both Justice Ministers, I'm sure they'd agree that would be just and fair.

Susan White

(AWARENESS DAY—Continued from page 1)

Hepatitis Awareness Month and the City of Victoria proclamation declaring May 1st Hepatitis C Awareness Day, by Marjorie Harris and Joan King. Joy McPhail gave an excellent short speech, wishing us well and assuring us that she would be encouraging the Government to follow through on its fine words. She said that she would personally keep reminding people of the devastating effect of the disease, the escalating costs that had to be addressed, and the need for action to give support to those affected. She congratulated us on the proclamations, reaffirmed that she would do everything she can to protect services for the hepatitis C community, and offered to work with any Hepatitis C Awareness programs planned for May.

Each person attending spoke from the heart, sharing his/her personal experience with hepatitis C. We remembered friends and loved ones who had succumbed to the effects of hepatitis C with a moment of silence, and then the crowd joined in and sang three of Bill Buckels' resoundingly great Hep song parodies, to the restrains of his plaintive guitar, while we held up our candles. The event was video taped and the HepSong parodies will eventually make it up on-line. It was both sad and celebratory, and a model of what such an event should be.

And that is the good news.

On the sad side, Vancouver Island News sent a reporter/cameraperson despite an on/off/on again series of messages initiated by HeCSC. Due to the contrary publicity surrounding the event, turn-out numbers were most disappointing, not enough, apparently, to justify the showing of the footage taken by our local TV station, because, after a lot of hard work organizing the event and getting the word out through the media, the Victoria Chapter of HeCSC sent out a fax telling people that the event had been cancelled. We hope that someone can figure out why they should want to dump on anyone else's parade, but dump they apparently did... This just seems to accent the schisms that the Circle was formed to heal. It makes one want to despair, but I guess we should just take it as a spur to move forward and increase our efforts to convince people that the Circle is not a threat, but an opportunity to get our various acts together and to support each other. We have got to talk with each other. Hope burns eternal.

Marjorie Harris, et al.

(ASK THE ADVOCATE—Continued from page 8)

Some employable spouses may be excused to look after a disabled partner.

No reviews for people with developmental disabilities/"mentally handicapped" and some people with mental illness in the invisible disability group.

Security deposit refunds will not be considered income of any kind, but will be seen as an asset.

New cash on hand rules apply to applicants not recipients at annual review.

Single parents will have to provide court documents that marital assets cannot be sold.

Dietary allowances will remain, but tied to specific diagnoses.

This part is a little vague: They are planning a transition phase for people who will be facing a reduction in benefits, but the details are not formulated. (The person sharing this got shut down fairly quickly, as it's "still being worked on". The suggestion is that benefit levels will remain in place for up to 5 months after the 1st of September, and when a person receives their "new" designation, for which they will likely have a 60 day window for application after the letter informing them that they no longer qualify in their current category once the new legislation is in place, and after which (i.e., the 60 days), their benefit level may continue for up to three months (just long enough to claim their spot under the best bridge in town, ideally one with a view). How long the benefit level remains in place will be dependent how long it takes to process their application. (This is when things got really confusing and melt down occurred).

Oh yeah - no Christmas bonus for adults. So much for "Do unto others..."

Anonymous by request

ISVHLD 2003 INTERNATIONAL SYMPOSIUM OF VIRAL HEPATITIS AND LIVER DISEASE

Sydney Convention & Exhibition Centre
Sydney, Australia

6-10 April 2003

Contact:

ISVHLD 2003 Congress Managers
GPO Box 128
Sydney NSW 2001
Tel: + 612 9262 2277
Fax: +612 9262 3135

E-mail: isvhld@tourhosts.com.au
Internet: www.tourhosts.com.au/isvhld

(ABORIGINAL CONFERENCE—Continued from page 1)

BC. Send requests to hephive1@shaw.ca

The National Association Friendship Centers (NAFC) has also published a high literacy booklet called Hepatitis C Information Manual, as well as several tear-off sheets—the one on tattooing was particularly good. These can be obtained by sending an email to naf-cgen@nafc-aboriginal.com.

Data was presented at the conference by Dr. Forrester, an epidemiologist with the Center of Infectious Disease Prevention and Control in the Blood Borne Pathogens Division of the Bureau of Infectious Diseases on the incident rate of acute hepatitis C in the aboriginal population in relation to the non-aboriginal Canadian-born population. The statistics were analyzed from 1999 and 2000.

The study found that the incidence rate in the Canadian aboriginal population averaged out to be 8.5 times higher than that of the Canadian-born population.

When risk factors between the two groups were compared, there was no difference. IDU was by far the biggest contributor at 67%. The next largest group was those with no known risk factors (sporadic transmission) at 13%.

We were also informed that there is a master's student from McGill University working on his thesis with Health Canada to investigate this large sporadic group. Hopefully a common thread(s) will be found so that we can identify the source of transmission, thereby enabling us to prevent the spread of HCV through this route.

However, we are still left with the fact that Canadian aboriginals have an incidence rate of acute hepatitis C that is 8.5 times higher than that of the non-Aboriginal Canadian born population. Clearly education is tantamount in importance. We need to involve the entire community in our efforts.

One project currently underway with the National Friendship Centers Association is to turn the hepatitis C information into stories. This would allow the elders to educate the young in a format that is inherent to the aboriginal population.

I'd just like to end on a comment made by one of the presenters. He said we all bring gifts to the table and Hep C was a gift that some of us bring. I had to really think about this one, but I like the way Randy explained it. We take the things that come to us and through our own journey of understanding and living with this disease. We have a choice. We can share what we've learned (our gift to others) and fight to make a better life for those that follow. Our children and grandchildren will have a better life because of what we're doing. That's a pretty special gift, and somehow that makes it easier for me to keep pushing ahead.

(Continued from page 5)

Disabilities) is overwhelmed with requests for advocacy work to help those with hepatitis C, and they have little funding. HepCBC desperately needs an office, as do Mid Island Hepatitis C Society and HepCure. There is money, but we won't get it.

HepCBC gets more hits to its websites than all the stakeholders put together. We own the FAQ and the *hepc.bull*. We are struggling to keep them alive.

Let me politely ask my friends in Health Canada this question: "When you have put us out of business, who will provide the services we do?" The fact of the matter is that you really don't give a damn, do you?

I am more than willing to sit down with Health Canada, and with Betsy McKenzie, in particular, and work out cost effective measures that do not compromise the integrity of the hepatitis C community, and which would benefit all Canadians with hepatitis C. Health Canada refuses to deal with me, saying that I am not polite. I think what they're really saying is that I won't kiss their A\$\$ets.

And, to those members of Health Canada who are reading this, you are more than welcome to write a letter in the next issue of the bulletin explaining all of this to us all. That would be polite.

Dr. C.D. Mazoff
Moralist at large

One more thing, as a former professor, I'm giving you all some homework: Go out and rent the video Gandhi and WATCH it. Contrary to popular myth, neither Gandhi nor Jesus were "polite."



**VICTORIA HepCBC
GENERAL MEETING**
June 4th 7-9 PM, 541 Herald St.
Nominations to the Board requested
Contact: 595-3892



Please attend this important meeting. If you like the things that HepCBC has provided you with—*hepc.bull*, *Peppermint Patti's FAQ*, *Advocate's Guide to Hepatitis C*, HepCAN list, pamphlets, counselling, computers—then we need YOUR help to ensure that these services continue.

Health Canada will not help us—only if we sell out, and if that's what you want to do, it's your choice. So **SHOW UP** at the meeting and either help us pack it in, or help us keep on keeping' on!!!

Hello!

Great newsletter!!

Excellent, valuable, helpful, interesting content and very, very well written!

A support group friend attended the HCV conference in Texas, at the end of last year, and brought me the Oct. issue of *hepc.bull*. WOW! I've had my ear to the wind, so to speak, since I was diagnosed with Hep C in 1994. I've attended International Conferences meeting here in the San Francisco Bay Area for the last five years. I haven't seen any other newsletter I like nearly so well.

I work in a teaching hospital (San Francisco General Hospital) which is also the county/public hospital. So I have access to a medical library -- where I used to go on my lunch hour or after my shift, to read the journals which might feature studies in which I could glean some tidbit of information ...it got so tiresome. I'm so glad somebody else seems to be doing it who can report to me the little gems they've found. I also help to take care of many patients who have hepatitis (C and or B, and some of them have HIV, also). Often, I am the first person to offer them information about hepatitis. I'm also, now, one of the two nurses (we teach in tandem) educating the entire nursing staff in the department of psychiatry about hepatitis. (We're a large department, serving nearly 100 acute patients all the time.)

So, my subscription to your news bulletin will mean more information for many people, in addition to myself.

Thank you.

Cheri

To the Editors:

I'm very bitter towards the doctors and the B.C. Hemophilia Treatment Centre refusing my requests for a tranjugular biopsy. All my tests indicate that I should have this procedure. I've been told by two doctors that, without the biopsy, they could not consider me for drug treatment. This is a classic case of a "Catch - 22" situation. What really gets me upset is the fact that other hemophilia treatment centres in Canada promote this safe procedure. A person working for the Vancouver Hemophilia Treatment Centre told me that they don't do this procedure on hemophiliacs. In the year ending 2001, the Province of Ontario Hemophilia Centres had performed 40 plus tranjugular biopsy on their hemophiliacs. Only one hemophiliac needed to stay in the hospital longer than the others, staying two days instead of one

day. The two doctors that I mentioned above were all set to perform this procedure until they spoke with the Vancouver Hemophilia Treatment Centre. And it's not only me. I have spoken with three other B.C. hemophiliacs who are in the same boat. One made arrangements to travel to another province two years ago and had this procedure performed.

Anonymous from BC

Has anyone else run into this serious problem? Have you been able to do anything about it? —Joan

**Congratulations to Grandma
Joan, on the birth of her**



grandson, Oliver

**DR. GABE MIRKIN'S
FAMOUS BEAN-EGGPLANT-
TOMATO CASSEROLE**

- 1 Onion, chopped
- 2 Cloves garlic, minced
- 1 Green pepper, chopped
- 2, 28 oz. Cans plum tomatoes, chopped
- 2 T. Fresh oregano or 1 t. dried
- 1 T. Fresh thyme or 1/2 t. dried
- 1 Bay leaf
- a Pinch of cayenne, or to taste
- 1 Eggplant
- 2 Cans kidney beans (or 3 c cooked beans)

Bring the onions, garlic, pepper, tomatoes with their juice, and the seasonings to a boil and simmer for 10 minutes. Dice the eggplant and add it to the pot. (You can peel the eggplant if you wish, but it tastes just fine with the peel left on). Stir in the beans and simmer for 20 minutes. Freezes well.

Servings: 4 - 6
Calories: 233
Total Fat: 1
Fiber: 12

I had the opportunity to take part in a meeting with the Ministry of Misery on Monday the 13th, and here is the latest bad news. This situation is deplorable.

They claim that there are now 7000 in the DB1 category (Disability Benefits, which, under the old act, included those who didn't have a lot of extra medical needs, supposedly) and expect of course many will move to the "persistent multiple" category which will be part of the E&A Act (Employment and Assistance Act) Bill 26, which replaces the BC Benefits Act - not the E&A for PWD's Act (People with Disabilities Act). They expect this category to grow to 11,000 people and the question is, "From where will the vast majority of these 4,000 people come?" From the current DB2 perhaps? This provides extra medical costs for disabilities likely to last more than 2 years, recurrent, cyclical, etc. I daresay YES.

I was uncharacteristically optimistic when I suggested on our web site that "persistent & multiples" (this sounds like a diagnosis, sort of like PMS, but means Persistent and Multiple barriers to employment -- new act spin doctoring) would receive \$596.00. It is planned that they will receive \$501.00 as do employables. Their "good" news is that P&M's will get medical, will qualify for the earnings exemption, and will not be time limited to 2 of 5 years. They "may" have an employment plan and will not qualify for the subsidized bus pass or likely for any other ancillary DB2 benefits, i.e. car insurance subsidy, gas tax rebate, park pass, ferry pass, fishing license reductions - although, their only response to this question was, "Those are dealt with through other Ministries, so we don't know." But in Campbell's government, I suspect that anything that can be cut will be cut.

The bus pass subsidy is to remain, and there is no planned increase. They are "looking at ALL paid volunteer initiatives" so Community Volunteer Program & Training Initiative Benefits will likely have new restrictions on them. I mean, let's face it, review is synonymous with cuts in this world. The Therapeutic Volunteer Program initiatives, for diagnosed mental health consumers only, are being reviewed in many health authorities, as well.

Volunteering will not be a condition of benefits for continuous designates. Darnn, there goes my sheltered workshop/workfare theory. *(Continued on page 6)*

TOO BAD....

by Bruce DeVenne

Following my last article, I received a call telling me that Crawford's would not recognize unemployment as income when figuring your best three years of earnings. I found this strange, since, with people in construction and other season related work, this is looked at as part of their income, they depend on it, and Ottawa considers it taxable income. Well, the truth is stranger still. Whether or not unemployment counts as income, according to the deal signed on your behalf by the class action lawyers and others, depends on where it is applied. If you are figuring your pre-claim earnings, and it will, therefore, increase your claim, it's not counted. On the other end, it does count. If you received unemployment or CPP disability during a claim year, it is deducted from your post claim check, decreasing the check you receive.

They didn't miss a trick in keeping every cent they could in the pot. The whole thing works out like this:

You pick your best three of earnings, and deduct any unemployment you may have collected in that time span.

- Average the three years out, and apply the inflation rates to bring it up to the years claimed.
- Deduct all taxes, CPP, UIC payments, etc., the same as you would a pay check
- Then deduct another 30%. Why??? Just because you are now down to about 55% of what you started with.

The CPP pension and UIC payments that didn't count as income before, therefore reducing your claim, now count, and are deducted from your claim amount. They use UIC twice as reductions in your claim: once to reduce the original total, and again to reduce the final check--once denying it as income, and then, recognizing it and using it as income.

Too bad they don't use calculations like this when paying Lawyers etc.



VOLUNTEER APPLICATION FORM

NAME: _____

ADDRESS: _____

CITY: _____

PC: _____ PROV: _____

TEL: () _____

FAX: () _____

EMAIL: _____

ABILITIES OR AREA OF INTEREST:

Library Printing Copying Phoning
Fundraising Counseling
Research Refreshments
Special Events Publications
Computer Help Errands
Grant Applications Board Member
Other

Experience:

Time available:

SEX M F

Date of Birth: ___/___/___

Mo Day Year

Contact: HepCBC
2741 Richmond Rd, Victoria, BC
V8R 4T3
Tel. 595-3892 or Email:
info@hepcbc.ca

COMPENSATION

LEGAL ACTION

Hepatitis C Class Action Suit Line:
1-800-229-LEAD (5323)

1986-1990

Bruce Lemer/Grant Kovacs Norell

Vancouver, BC

Phone: 1-604-609-6699 Fax: 1-604-609-6688

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

www.kpmg.ca/microsite/hepatitisc/english/forms.html

Klein Lyons

Vancouver, BC 1-604-874-7171,

1-800-468-4466, Fax 1-604-874-7180

www.kleinlyons.com/pages/class_actions/Hepatitis_C.htm

Mr. David Harvey/ Goodman & Carr

Toronto, Ontario

Phone: 1-416-595-2300, Fax: 1-416-595-0527

Ernst & Young Law Office (Ontario)

1-800-563-2387

Lauzon Belanger S.E.N.C. (Quebec)

www.lauzonbelanger.qc.ca

Goodman and Carr LLP

pre86hepc@goodmancarr.com

www.goodmancarr.com

Other:

William Dermody/Dempster, Dermody, Riley

and Buntain

Hamilton, Ontario L8N 3Z1

1-905-572-6688

LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC

1-888-332-5663 (local 207)

Lookback Programs, Canada: 1-800-668-2866

Lookback Programs, BC: 1-888-770-4800

Canadian Blood Services Lookback/Traceback &

Info Line: 1-888-462-4056

Hema-Quebec Lookback/Traceback & Info Line:

1-888-666-4362

Manitoba Traceback: 1-866-357-0196

RCMP Blood Probe Task Force TIPS Hotline

1-888-530-1111 or 1-905-953-7388

Mon-Fri 7 AM-10 PM EST

345 Harry Walker Parkway, South Newmarket, On-

tario L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656

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

Toronto Compensation: 1-416-327-0539, 1-877-434-0944

Quebec Red Cross Compensation: 1-888-840-5764

1986-1990 Hepatitis C Class Actions Settlement
6/15/99 www.hepc8690.ca/

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-888-726-2656 or 1-877-434-0944.

www.hepc8690.com info@hepc8690.com

MISCELLANEOUS

Excellent Website!!: HCV Tainted Blood, Canada:

<http://members.rogers.com/smking/tainted.htm>



DIAL-A-DIETITIAN

732-9191 (Vancouver Area)

1-800-667-3438 (Toll-free

elsewhere in BC)

Are you in the 86-90 Window?
Are you having any problems?

Contact: Terry Waller
(250) 642-6766

(Terry is not a lawyer but a concerned victim)

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