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Canada's Hepatitis C News Bulletin

www.hepcbc.ca

THE CARAVAN OF HOPE FOR HEPATITIS C: MONDAY MAY 17TH, 2004 VICTORIA, BC

The Caravan of Hope arrived in Victoria May 17th, 2004, and met with Minister of Health Services Colin Hansen to review the current state of affairs in hepatitis C treatment choice and access. The Caravan of Hope also met with MLAs Randy Hawes and Lorne Mayencourt. Six of the Caravan of Hope's members were seated in the legislature gallery. At 3 p.m., a media opportunity and gathering of supporters took place on the legislature's front steps to speak out on hepatitis C.

The Caravan of Hope represents the estimated 65,000 British Columbians infected with hepatitis C and comprises a province-wide group of concerned citizens (Joan King, president, HepC-BC; Bradley Kane, coordinator, Princeton Support Group; Marjorie Harris, president, HepCURE); and various other BC hepatitis C non-profit organizations that have banded together in one voice to appeal to the government for greater access to care, treatment, and medicine for persons infected with the hepatitis C virus.

They commended the government for supporting our community by proclaiming May as Hepatitis C Awareness Month and May 1st as Hepatitis C Awareness Day (and our Candlelight Memorial for the second year in a row). They also recognized and applauded the government for the hepatitis C services that it has implemented to date.

However, they made it clear that these services are providing access to treatment for only about 650 people per year, and that at this rate it will take 100 years to treat those already known to be infected.

Of the 250,000 Canadians estimated to have hepatitis C, almost 30% live here in British Columbia, which only has 14% of the Canadian population. This is a glaringly

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HEALTH CANADA APPROVES PEGASYS RBV

On May 12, 2004 Health Canada approved Pegasys RBV (peginterferon alfa-2a) in combination with Copegus (ribavirin) for the treatment of adults with chronic hepatitis C, including those with compensated cirrhosis. The product will be available approximately one month from approval.

"We applaud Health Canada for approving Pegasys RBV," said Durhane Wong-Rieger of the Canadian Hepatitis C Network. "Many hepatitis C patients have waited many years for this new therapy. In fact, some have even delayed treatment in anticipation of its approval, because they felt Pegasys RBV was their best chance to clear the virus. But beyond the approval of new medications, we also need to consider quick provincial formulary approval across Canada so that patients who need this treatment do not have to wait any longer."

Approval of Pegasys RBV was based on the results of two pivotal Phase III clinical trials. Both studies demonstrated that virus genotype was the strongest predictor of whether or not a patient would achieve a sustained virological response (SVR) – the primary goal of treatment. These study results have had a profound influence on the way physicians in Canada and around the world treat hepatitis C.

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INSIDE THIS ISSUE:

TREATMENT

By Kathryn Antonsen

AT LAST: PEGINTRON VS PEGASYS

In this study, approved forms of pegylated interferon – PegIntron (peginterferon alfa-2b/Schering Corp.) and Pegasys (peginterferon alfa-2a/Hoffman-LaRoche, Inc.) – were administered along with Ribavirin in patients with hepatitis C genotype 1. Initial reports indicate that PegIntron, which is prescribed individually by weight, gave earlier positive results than Pegasys, which is given as a general flat dose. Virologic response at the end of treatment was 76 percent with PegIntron and 55 percent with Pegasys.

A major randomized clinical study (IDEAL-Individualized Dosing Efficacy vs. flat dosing to Assess optimaL pegylated interferon therapy) involving 2,880 patients is being conducted by Schering-Plough Research Institute (SPRI) to follow up these findings.

Concerns have been expressed that the initial Schering-Plough reports are based on a small, unrandomized study with patients whose disease variables varied widely. Surface reports from the study appeared incomplete (sustained viral responses not discussed) and did not offer a true picture of all clinical details.

Interest is high for results from larger clinical studies being conducted.

Sources: Independent Study Evaluates Virologic Response of Two Approved Forms of Pegylated Interferon in Combination with Ribavirin in Patients with Difficult-to-Treat Genotype 1 Virus (Schering Press Release); Luise, S., et al, Early and Late Kinetic of Virological Response During PEG-IFN Therapy in Chronic Hepatitis C. (EASL); Jules Levin, www.natap.org, Small, Unrandomized Study Compares Pegasys to PegIntron

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HOW TO REACH US:

EDITORS: *Joan King, Will Lawson, Smilin' Sandi*
PHONE: *TEL: (250) 595-3892*
FAX: *(250) 414-5102*
EMAIL: *jking@hepcbc.ca*
WEBSITE: *www.hepcbc.ca*
HepCAN List *http://health.groups.yahoo.com/group/hepcan/messages*

HepCBC
306-620 View Street
Victoria BC V8W 1J6

LETTERS TO THE EDITOR:

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

NEW!!!! Peppermint Patti's FAQ

Peppermint Patti's FAQ Version 6 is now available, and Version 5.6 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only $6 each, plus postage. Contact HepCBC: (250) 595-3892, info@hepcbc.ca

HepCBC Resource CD: The CD contains back issues of the *hepc.bull* from 1997-2003; the FAQ V6; the slide presentations developed by Alan Francis-cus; 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.

REPRINTS

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

THANKS!

HepCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, The Ocean 98.5 for their Public Service Announcements, Durhane Wong-Rieger, Bryce Brogan, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Brad Kane, Chris Foster, Darlene Morrow, Will Lawson, Judith Fry, and the newsletter team: Megan, Kathryn, Shannon, Jeanie and Diana. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

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

CUPID'S CORNER

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

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

Give us your name, tel. 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.

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

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

DIAL-A-DIETITIAN

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

NOTES FROM THE SECOND CANADIAN CONFERENCE ON HEPATITIS C: PART TWO

By Ken Thomson, BC Hepatitis C Collaborative Circle

Dr. Kevork Peltekian spoke about successes in Nova Scotia due to using a multidisciplinary team approach. There are a number of abstracts and poster presentations at http://www.nsheplink.dal.ca, which outline those issues and others such as the underreporting of hepatitis C as a cause of death.

Dr. Jenny Heathcote stated that the best treatment for genotype I was pegylated interferon with either 1000mg or 1200mg doses of ribavirin, depending on weight. She also stated that, for genotypes 2/3, 24 weeks of 800mg. of ribavirin has fewer side effects and almost as good results as 48 weeks of treatment.

She suggested that Eprex is useful for boosting hemoglobin and antidepressants are an important adjunctive therapy that should be considered in many patients. Because they can take 3 weeks to work, antidepressants should be started before treatment. The incidence of depression is highest during the first eight weeks of treatment.

Adherence was identified as an important issue. Davis, et al, (*Hepatology* 2003) were quoted as saying they found that patients who took at least 80% of the full amount of both interferon and ribavirin had an 80% EVR (Early Viral Response). Treatment needs to be tailored to the patient's lifestyle. For example, a university student would start in May. The prophylactic use of acetominophen (Tylenol) and anti-depressants, hepatitis nurses, addictions medicine counselling, and high fluid intakes are all measures that can help.

Patients with co-existing psychiatric diagnoses have an SVR rate similar to the general population if adequate supports are in place.

Statistically, reduced alcohol intake (improves compliance), a lower Body Mass Index, and treating at a younger age have an impact, with the chance of a sustained viral response falling by about 5% with every additional 10 years of age.

Dr. Heathcote presented an overview of treating specific populations. In summary, people with cirrhosis have an SVR of about 44% with PEG/ribavirin. Successful treatment reduces the risk of cancer and liver failure. If a transplant is ultimately necessary, re-infection is unlikely.

As a general rule, co-infected patients should avoid the 'd' drugs for HIV (such as ddC, ddI and d4T), abstain from alcohol, and treat the HCV first, if possible.

For people who have concurrent kidney failure, PEG may be safer, and viramidine may be a safer alternative to ribavirin.

Interferon cannot be used after a transplant.

People of African descent have a lower response rate.

It is essential to develop non-interferon therapies.

Injection drug users risk an infection rate of up to 50% within one month of commencing injecting.

People who relapse and are then retreated with PEG/ribavirin have response rates of 73% (INF mono) and 50% (Rebetron). People who were non-responders have rates of 33% (INF mono) and 11% (Rebetron).

Some of the barriers to treatment that were outlined were:

- There are only about 140 hepatology nurses in Canada.
- We need more scientists and research in basic and clinical science, public health, epidemiology, social issues, and health/economic policy.
- We need the affected community and advocates to effectively translate knowledge to policy makers.
- We need more education and patient support, a national information system, training for scientists and healthcare providers, improved infrastructure, and better insurance coverage.
- Access issues, side effects, and the need to administer by injection.

A final bright spot: previous spontaneous viral clearance or a low level exposure may induce some immunity. This means a vaccine may be possible.

Ralf Jurgens from the HIV/AIDS Legal Network spoke about legal and human rights issues. He stated that governments have failed to learn the lessons of the Krever Inquiry. He stated that people affected by hepatitis C need to be involved in the development, implementation and evaluation of programs designed to assist them.

He outlined several major issues of concern, beginning with discrimination. He stated that it would be useful to conduct a survey on HCV discrimination in Canada, partly because it is such a hidden issue.

Treatment and care issues include the lack of hepatologists outside of urban areas, poor treatment of people who use or have used injection drugs, and being denied treatment for HCV at the same time that there is a shortage of addiction and methadone maintenance therapy programs.

Some of the research concerns listed were the need for more funding, co-infection research and the fact that people who use injection drugs and prisoners are often excluded from clinical trials.

Compensation and disability benefits issues are complicated by inequities and differences between provinces.

Referring to prevention, he asked if anyone cares. Ninety-five percent of federal dollars for dealing with illicit drugs goes to reducing supply, a situation criticized by the Auditor General in 2001. Governments must develop specific plans with outcomes and accountability based on human rights and public health principles. To not do so is both fiscally and morally irresponsible.

Jason Grebely, from the Pender Community Health Centre in Vancouver, put forward the concept that the potential exists to cure HCV in one-third of the injection drug users in Vancouver. While genotype 1 accounts for 68% of cases in Canada, genotype 3 is more prevalent among injection drug users. In Vancouver, genotypes 2 (10%) and 3 (29%) make up 39% of cases. Because of the higher treatment response rates associated with these genotypes and the shorter duration of treatment needed (24 weeks), the potential exists to cure a significant percentage of patients, improve health outcomes and reduce the number of potentially infective people.

He spoke about PATH (Pender Assisted Therapy), which is directly observed therapy for the treatment of HIV within a MMT (methadone maintenance therapy) program. 80% of patients have achieved viral suppression, independent of ongoing cocaine use. The program is a multidisciplinary 'one stop shop' with addictions, primary care and infectious disease expertise. It employs physicians, nurses, counselors and a research team.

Their experience with HCV treatment is limited but encouraging. Six patients, all longstanding injection drug users, have completed treatment. Four (66%) have achieved SVR (Sustained Viral Response). A nurse administers the weekly dose of pegylated interferon and dispenses the ribavirin on a daily basis. This approach allows for increased frequency and intensity of addictions counseling, increased understanding of reinfection issues and an increased understanding of the degree of patient support required.

I have only a few notes from the **Disability Issues** session. Legally, it can be full of gray areas and loopholes. No province mandates that employees be entitled to paid sick leave. You can be fired for being sick or off work, but if your absence is caused by a disability and the disability can be accommodated without undue hardship to the employer, you may have some protection. Alberta is one province where hepatitis C has been ruled by a tribunal as being a disability.

The problems and barriers in this area include a low understanding of the duty to accommodate disability, stigma, discrimination, and the lack of confidentiality of health information.

NEWS

By Shannon Price and Kelly Cox

HCV IN CANADA'S PRISONS

At the Hepatitis C Conference in Vancouver last month, Francoise Bouchard, director of health services for Corrections Canada, explained the need for government to track, study, and try to stem the spread of hepatitis C and other infectious diseases in prisons. Bouchard discussed the steps that Corrections Canada is taking, but acknowledged that hepatitis C is still on the rise.

Source: Hepatitis C Conference in Vancouver Hears of Efforts Underway in Prisons
http://www.cdcnpin.org/scripts/index.asp

TRANSMISSION VIA ACUPUNCTURE

Lack of proper sterilization techniques used by a Montreal woman practicing acupuncture illegally for the past 25 years has led to health authorities having to track down 1,144 patients and ask them to be tested for hepatitis C.

At least two similar cases are known, in which patients may have been exposed to hepatitis C or HIV.

Acupuncturists who belong to the province's professional organization are required to discard needles after one use.

Source: The Canadian Press, 2004, Blood tests urged in wake of illegal acupuncture in Montreal
http://www.mytelus.com/news/article.do?articleID=1551254

RIBASPHERE APPROVED

Ribasphere, a generic ribavirin, has been approved and is being marketed by Three Rivers Pharmaceuticals. The purpose is to make medicine for Hepatitis C more affordable for all individuals. See NATAP, at *www.natap.org*, for cost and contact information.

ARTIFICIAL LIVER MACHINE

Doctors in China have developed a bio-artificial liver machine that is much smaller than earlier models. This machine can imitate metabolizing and detoxifying liver functions and determine which treatment a patient needs. It can also perform plasma replacement and hemodialysis. These new machines may be out clinically as early as April.

Source: Xinhua
http://english.peopledaily.com.cn/200401/08/eng20040108_132135.shtml

MEDICATION MAY HELP CONTROL DRUG CRAVINGS

A BC doctor found out that a bi-polar medication, Seroquel, helps control hard drug cravings. Seroquel acts on the same part of the brain as illicit drugs (such as cocaine and crystal meth), and helps people feel content. Although this medication works, it cannot replace support and counseling for people addicted to drugs.

Source: Canadian Press, January 25, 2004, Kelowna, BC (CP)

VANCOUVER'S NEW SAFE INJECTION SITE

Although there are many advocates for Vancouver's safe injection site, there are also many critics, especially in the U.S. Some concerns are that this site encourages drug use and prolongs suffering and disease. Advocates for the site believe that it deglamorizes drug use and provides a safe environment with first aid and access to treatment services. The site's goal is to reduce transmission of HIV and Hep C by getting the drug users off the streets.

Source: CMAJ " November 11, 2003; 169 (10)
http://www.cmaj.ca/cgi/content/full/169/10/1063

SUMMER FRUIT SALAD

1 cup mixed berries
1 mango peeled, pitted and cubed
1 nectarine pitted and sliced
2 tablespoons orange juice

1. Mix the fruit in a bowl. Sprinkle with the orange juice.
2. Serve for breakfast over yogurt, as a side dish with lunch or dinner or for dessert over sorbet.

For breakfast, serve over French Toast or Griddle Cakes; for dessert, serve over low-fat ice cream or frozen yogurt.
Substitute an equal amount of peeled, sliced apples or pears for the blueberries and add 1/4 cup chopped walnuts.

Source: www.foodfit.com/recipe.asp?rid=18

(TREATMENT—Continued from page 1)

DOES SURGERY ACCELERATE THE SPREAD OF LIVER CANCER?

This study was conducted to investigate whether surgical removal of cancerous liver tumours (hepatocellular carcinoma [HCC]) would increase the risks of cancer spreading or reoccurring.

By testing blood for the tumour indicator (hAFP mRNA), the presence of circulating malignant cells can be confirmed. Eighty-one patients who underwent surgeries for curative treatment gave blood samples before, during and after the procedure. All clinical variables, tissue types, and staging of cancer, blood samples, and postoperative results were included in the analysis.

Findings of this study indicate that surgical treatment is not confirmed as a risk for cancer spread or reoccurrence.

Source: Sheen IS, et al, World J Gastroenterol. 2004 Jan;10(1):31-6. Does surgical resection of hepatocellular carcinoma accelerate cancer dissemination? PMID: 14695764
http://www.ncbi.nlm.nih.gov/

LOW DOSE DAILY MAINTENANCE

236 male patients with chronic hepatitis C (1b genotype) were treated with interferon (IFN-alpha2b) and ribavirin for a 6- or 12-month period. 117 patients (49.5%) responded to therapy and were divided into two groups for further study. One group went on to receive low daily amounts of interferon alone for 12 months, while the other group did not.

After 6 months, 83% of patients who received interferon maintenance still showed sustained responses, while only 37.9% of the patients who discontinued treatment remained negative.

The results showed that combined interferon/ribavirin treatment given over longer time (12 months) is more effective when followed with a low daily dose of interferon.

Source: Tarantinno G, et al, Low daily dosage of interferon for 1 year after HCV-related end-therapy response. A randomized-controlled study, Liver Int. 2003 Dec;23(6):413-9. PMID: 14986815

CIRRHOSIS IS REVERSIBLE

Antifibrotic and antiviral treatment was provided to 64 patients with HCV-caused cirrhosis. Interferon-alpha (drug with antifibrotic effects) was given with or without ribavirin to prolong a virologic response. It was questioned whether this would contrib-

(Continued on page 5)

UPCOMING CLINICAL TRIALS VANCOUVER, BC

Dr. Frank Anderson's office is participating in the following studies:

1. High dose Pegasys and Copegus in HCV patients who did not respond to previous Pegylated Interferon alfa-2b/Ribavirin combination therapy.
2. Pegylated Interferon plus Viramidine versus Pegylated Interferon plus Ribavirin in naive patients. Those with Normal ALT are included!
3. Low dose Pegylated Interferon maintenace therapy in cirrhotics who were non responders to previous Interferon and ribavirin combination therapy.

If any people are interested, the office would be happy to screen them and see if they are eligible. Call 604-876-5122 and leave a message for Natalie stating which study they are interested in. If enrolled in the program they would have to come to our office for all visits. If there are a few people from the same area we could possibly coordinate carpooling.

(TREATMENT—Continued from page 4)

ute to a reversal of the effects of cirrhosis.

Five of 64 patients responded, with one of these showing relapse. Another treatment group of 4 HCV infected renal patients showed reversibility of cirrhosis in 3 cases.

Source: Pol S, et al, Hum Pathol. 2004 Jan;35(1):107-12. Reversibility of hepatitis C virus-related cirrhosis.

IS ULTRASOUND USEFUL IN LIVER CANCER?

This study sought to determine whether contrast ultrasound techniques (dynamic flow imaging) could be used to confirm the effectiveness of treatment for hepatocellular carcinoma (liver cancer).

Treatment involved using radio frequency waves to terminate vessels that supply blood to tumours. Most tumour nodules tested (45 of 48) were successfully assessed using dynamic flow imaging, while positional depth limited results in 3 cases.

By confirming the presence of these vessels and the success or failure of treatment, clinicians can now treat patients with greater accuracy and confidence.

Source: Hotta N, et al Hepatogastroenterology. 2003 Nov-Dec;50(54):1867-71. Usefulness of contrast-enhanced ultrasonography with dynamic flow imaging to evaluate therapeutic effects for hepatocellular carcinoma PMID: 14696421 http://www.ncbi.nlm.nih.gov/

(PEGASYS —Continued from page 1)

Viral genotype as the strongest predictor of treatment response was also validated during a presentation of soon-to-be published Canadian consensus guidelines on the management of viral hepatitis at the 2nd Canadian Conference on Hepatitis C in Vancouver in March 2004.

PIVOTAL STUDIES PROFOUNDLY INFLUENCE THE WAY PHYSICIANS TREAT HEPATITIS C

A pivotal study published in the March 2, 2004 Annals of Internal Medicine found that patients infected with the "easier-to-treat" hepatitis C genotypes 2 and 3 could reduce the length of treatment with Pegasys RBV from one year to six months and lower the dose of Copegus from the standard dose of 1000 or 1200mg to 800mg and still achieve an SVR of 84%. This landmark study provided the evidence of the importance of tailoring Pegasys and Copegus combination therapy according to genotype. Today, this approach is considered by many physicians to be the standard of care.

"What is also gratifying is that this comes with an improved tolerance," said Dr. Morris Sherman, a hepatologist at Toronto General Hospital. "The side effects that are often the most troubling, namely flu-like symptoms and depression, occur less frequently with Pegasys RBV than with interferon alfa-2b plus ribavirin. This means fewer patients will have to stop therapy because of side effects."

Another pivotal study, published in the September 26, 2002 issue of *The New England Journal of Medicine*, showed that Pegasys RBV is a more effective treatment for chronic hepatitis C than interferon alfa-2b plus ribavirin. Specifically, the SVR rate in the Pegasys RBV-treated patients was 56% compared to 44% in the interferon alfa-2b and ribavirin group. Only Pegasys RBV has shown increased efficacy compared to interferon alfa-2b plus ribavirin in all patient sub-types in a large, randomized, prospective trial.

ABOUT PEGASYS RBV

Pegasys (peginterferon alfa-2a) in combination with Copegus (ribavirin) may provide superior efficacy compared to standard interferon combination therapy in hepatitis C patients of all genotypes.

The benefits of Pegasys are derived from its new-generation, large – 40 kilodalton (KD) – branched-chain polyethylene glycol (PEG) design, which allows for constant viral suppression over the course of a full week. Pegasys is the only pegylated interferon available as a ready-to-administer solution in a pre-filled syringe. Each weekly subcutaneous injection contains 180 mcg of pegylated interferon alfa-2a (40KD) which is the approved standard dose for all patients, regardless of body weight. Pegasys also distributes more readily to the liver (the primary site of infection) than standard interferon.

A PATIENT'S PERSPECTIVE

John Bartzis has just completed a full course of Pegasys RBV treatment through a worldwide expanded access protocol (clinical trial).

"I feel fortunate to have had the chance to go through this therapy and am pleased to report that it has been successful," he said. "I feel healthier, I have more energy, and I think it's important for other Canadians who suffer with hepatitis C to have hope, and to know that if it can work for me it could work for them too."

John also said, "The fact that I only had to inject this medication once a week made a huge difference when faced with the prospect of completing almost one full year of therapy it made it easy. And the [fixed dose] pre-filled syringe helped remove the guesswork."

LETTER TO THE EDITOR

Hi there!

Just so you know, I am Sky, and I would like to let you know how treatment turned out for me.

I was a genotype 3a. For six months, I took shots once a week and five pills a day. I was on "death-row" for a year! I lost so much hair, I had bald spots. My eyes had that "she is sick" look. I couldn't even hold my head up! And I was a pain in the ass to everyone around me. Trust me, I thought I was dying! I finished my treatment around Halloween.

I have felt awesome for 3 months now. I thought it would never happen! I am feeling so energetic, and I am getting stronger as each day passes. In the last month I have been getting "my looks" back too! My hair is growing back thick as the grass in my yard! Ha ha! I am now calm, good natured, and back to normal! Since November 19th, I have been managing a store.

Once in a while my knees feel stiff, and my "thumbs" lock up during the night. It's like a kind of arthritis that the medication left me with. At least I feel better everywhere else!

Good luck to you. Hang in there. It's awful, but it's worth it!

God bless you!—Sky

ONCE UPON A TIME IN OTTAWA: A FAIRY TALE?

Once upon a time in Ottawa, there was a hearing on post-transfusion infection that cost millions in legal and court costs.

Justice Krever wanted to name names and lay blame, so millions more were produced, for court costs and still more lawyers. He won, but didn't bother to do what he had spent millions fighting for.

Then the government and the lawyers and the national organizations signed a deal and the government set up a $1 billion plus fund for the victims. Months before the victims saw a cent, the lawyers got paid out of the victims fund compensation fund, and the national organizations saw another fund of millions created to allow them to operate. Everybody was getting money, it seemed, except the victims.

How to manage the fund now became the question. "First we need an administrator," they said, and hired Crawfords at a cost of millions of dollars a year--paid from the victims' fund.

Then Crawfords hired PricewaterHouse-Cooper to do the actual accounting--and paid them from the victims' fund.

Then the Canadian Blood Services said they had to do tracebacks for the victims, but didn't seem to think they should have to pay for it, so millions more were allocated to them--from the victims' fund.

Crawfords then spent $3/4 million from the fund to have software designed, and paid out money to Royal Trust and TD Asset Management to invest the money at a total of millions more over the life of the deal – all paid out of the victims' fund.

Crawfords felt they needed the services of investment consultants Towers Perrin and actuary Eckler Partners, so they hired them and paid them--out of the victims' fund.

Then there was the fund's legal council. The one-time class action lawyers were hired, with the chance to make still more millions--from the victims' fund.

Crawfords needed lawyers and medical experts across the country to participate in appeals, and accountants to do the annual reports, so they were all hired and paid--out of the victims' fund.

Finally the day came when the victims themselves started to draw money from their fund, only this money was in thousands, tens of thousands, and occasionally hundred-plus thousands, not in the millions.

In 2008, the government, concerned about the financial sustainability of the fund, sent in independent auditors who examined it from every possible angle. If the fund kept spending money like it was, they announced, it would go broke long before the government's anticipated date.

So the government and everybody involved except the victims took a long hard look at the contract.

The only people in the contract with any legal responsibility for the financial sustainability of the fund were the victims, so they kicked the victims out of the fund and lived happily ever after.—*Bruce DeVenne*

(CARAVAN OF HOPE—Continued from p. 1)

disproportionate burden of hepatitis C infections in our province.

Many people with hepatitis C are running out of time and need to access treatment within the next 5–10 years. This means increasing the treatment rate by 10–20 times – from 650 persons per year to 6,500–13,000 per year. The considerable investment that this will require pales in comparison to the costs of maintaining the status quo.

The group suggested that the federal transfer of "Care Not Cash" money be dedicated directly to hepatitis C care now. They asked that the B.C. government also invest proactively in dealing with this devastating epidemic. They also asked that the federal government fund B.C. in accordance with the number of cases we have, and that it supply that money now, not over time.

Our Imminent Needs—Some Key Points:

- The Canadian Institutes for Health Research estimates that, by 2008, hepatitis C will cost Canadians $1 billion annually.
- With only 14% of the population, BC has almost 30% of the cases in Canada.
- Between 30% and 70% of infected patients have yet to be informed of their infection Therefore, they are unable to take steps to protect their health and that of others.
- We have treated less than 6% of infected patients to date. Every dollar spent on treatment can result in four dollars of medical cost savings.
- Approximately 20% of HCV-positive persons either now have or will soon develop expensive, life-threatening conditions such as cirrhosis, liver failure, and liver cancer.
- The need for liver transplants will increase by 246% over the next few years.
- We need a coordinated, cost-effective multidisciplinary approach that utilizes community-based organizations and peer supports in addition to specialists, nurse-practitioners, primary care physicians and other health professionals.

With this approach, we can substantially reduce the current side effect caused by treatment discontinuations/failure rates of 20%-24%. Under current Pharmacare criteria, a treatment failure is a death sentence for many patients. Every treatment failure that is prevented can save up to $20,000 in medication costs alone.

Treatment to cure hepatitis C can be complicated and difficult to tolerate. Cross-education and expedited referral pathways need to be in place to deal with treatment complications such as neuropsychiatric disorders, malnutrition, dental problems, addiction issues, and financial issues in a timely manner so as not to jeopardize treatment outcomes. Some of these interventions require specialized expertise. Much of the basic information, education, and support can be provided very cost-effectively by community-based organizations and peer supports.

On the other hand, at this stage of research, treatment aimed at cure may not be the best choice for many HCV-positive people. We need to take action to ensure that these people stay as healthy as possible for as long as possible while other medications are developed.

In addition to increasing the investment in liver clinic pilot projects (Kelowna, for example, has a four-year wait list), we need to improve capacity in other communities throughout the health regions.

A ten-minute appointment in Vancouver can cost a Trail resident over $1000 in expenses for three days' travel, loss of income, accommodation, food, childcare, etc. Patients report being exhausted for weeks afterwards. We need to better use Telehealth, local community resources, support, patient and provider education, and health promotion.

Hepatitis C is both preventable and treatable.

Contacts:

Marjorie Harris, President, HepCURE; Director, Canadian Hepatitis C Network; (250) 546-2953; Armstrong, BC.

Bradley Kane, Coordinator, Princeton Support Group; (250) 295-6510; Princeton, BC.

Joan King, President, HepC-BC; (250) 595-3882; Victoria, BC.

Ken Thomson, Chairperson, BC Hepatitis C Circle; (250) 422-1280; Kootenay Region, BC.

INFECTED?

If you think you have been infected with Hepatitis C from the Canadian Blood Supply, you must do the following to be compensated:

(1) If you are a member of the bleeding disorder family and were infused with blood or blood product within the window of 1 Jan. 1985–1 Jul. 1990, then you automatically qualify for compensation.

If you are a member of the general public, you must have a traceback done to locate the infected infusion.

(2) In both cases, contact Crawfords at 1-977-434-0944 and ask them to send you an application kit.

(3) Have the doctor treating your hepatitis order the required tests and fill out the appropriate papers for the level for which you qualify.

Level 1 one requires acceptance by the administration and the presence of hepatitis C antibodies in you blood. You will get $10,000.

Level 2 requires you to have a PCR blood test done. If it shows the hepatitis C virus in you blood, you will get $20,000.

Level 3 requires a biopsy of your liver showing an accepted level of damage. The protocol is listed on the applications. Members of the bleeding disorder family can qualify for this level under a different protocol because of the unique risks of a biopsy to them. They can also opt for a transjugular biopsy, which is less risky, but I have heard is not as accurate either.

This level will qualify you for loss of services in the home or replacement of lost wages. You can also opt to waive the right to either of the above and instead take a one-time $30,000 payout. However, I think that would be risky, because if you were to get sick and be unable to work, you couldn't change your decision.

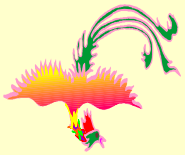
Level 4 was set up to compensate in stages. The sicker you got, the more money you were supposed to get, and there was to be no problem with having enough money. Well, here are a couple of surprises: Level 4, although your liver has deteriorated and you are sicker, gives you a different number after the word "level", but no more money. Also, "wage replacement" really means about 40% of your lost wages if you're lucky.

Levels five and six both offer lump-sum payments, and Level 6 also makes allowance for medical care.

For more detail on specific requirements and amounts at each level go to http://www.hepc8690.ca/content/claimants/essential/compensationSchedule-e%20.pdf.

If you have any questions or problems, just yell.

Bruce DeVenne
88 Sycamore Lane, Lr. Sackville NS, B4C 1E9
Ph: 1-902-864-6376
Fx: 1-902-864-8512
E Mail bdevenne@ns.sympatico.ca



THE MAIDEN AND ME

By: Lisa Krekorian-McDiarmid

Something is stirring,
its coiled source yet unknown,
Thoughts compete loudly
eroding pillars of bone.
Yesterdays' vile rumours rise
into absolute truths,
Henchmen awaiting,
ripe blade amongst noose.
The witch hunt, the trickery-
The Maiden of Lauren,
Atrocities denied;
Armenian Genocide reborn again.
Acceptance occluded
by plaques of betrayal,
Dissolving resentments as serenity hails.
Pleasant memories serve as hope,
While forgiveness restores.
Hospice strength in one vessel,
Allowing Phoenix to soar.
The Flames turn us to ashes,
the Maiden and me,
No longer ours is to question,
the world we have seen.
Our Visions once foreboding,
we are tied evermore,
Having placed principles
above personalities,
Spirits One with our Lord.

Hi, Joan. I would like to offer this poem for the Bulletin. I was formally diagnosed with HCV in June '97. This poem in essence describes my doctor's and my own journey with acceptance of so many issues surrounding disease, spirituality and recovery. If you'd like to use it, I offer it as a small gift in thanks for what hepcbc.ca, and all other related Hep C sites have given to me. Sincerely, Lisa

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, Ontario 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 1-877- 434-0944.
www.hepc8690.com info@hepc8690.com

MISCELLANEOUS

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

COMING UP IN BC/YUKON

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

Campbell River/ Comox Valley Hep C Support and information, call 830-0787 or 1-877-650-8787 P.O. Box 52, Port Hardy, Dan Webb (250) 902-2238 or 1-866-902-2238 niacph@hotmail.com

Castlegar Contact: Robin 365-6137

Comox Valley Contact: AIDS Vancouver Island Hep C Community Support (250) 338-7400 Del : dggrimstad@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432.

Cranbrook HeCSC-EK Support Group Monthly meetings- Call for details. Katerina (250) 417-2010, hecsc-ek@shaw.ca or Leslie (250) 426-6078, ldlong@shaw.ca

Kamloops Hepatitis C Self-Help Support Group: 1st & 3rd Thurs. monthly. 1 p.m. AIDS Society, 437 Lansdowne St. Call (250) 372-7585 or Susan (250) 554-7055, ask@telus.net

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine Riseley (250) 768-3573, eriseley@shaw.ca or Lisa Mortell 766-5132 lmortell@silk.net or toll-free 1-866-766-5132.

Kootenay Boundary: For individual support & info contact Brian Reinhard (250) 364-1112 reiny57@yahoo.ca

Mid Island Hepatitis C Society Friendship and support group, 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Sue for info 245-7635, mihepc@shaw.ca

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Contact Vivian 265-0073

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St. Contact Alex Sherstobitoff, 1-800-421-2437, 505-5506, info@ankors.bc.ca http://www.ankors.bc.ca/

Boundary Hep C Support. Contact Ken 250-442-1280 ksthomson@direct.ca

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations Urban Community Society, 623 Agnes Street, New Westminster. Contact Dianne Morrissettie 604-517-6120 dmorrissettie@excite.com

Penticton Hep C Family Support Contact Leslie 490-9054, bchepc@telus.net

Powell River Hep C Support Group Next meeting: Contact the Health Unit 485-8850 .

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Prince George Regional Hospital, room 1356 (former Chapel) Contact Gina 963-9756, gina1444@yahoo.ca or Ilse 565-7387 ikuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Contact Ted Rogers (250) 624-7480, Ted.Rogers@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Contact Brad 295-6510, kane@nethop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy 557-2487, wmm@island.net, www.island.net/~wmm/ http://health.groups.yahoo.com/group/CANhepc/

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

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, 3862 Broadway (behind Panago). Contact Deb 877-0042 or Doreen 847-2132, deb@plnw.org

Sunshine Coast—Sechelt: 1st Wed. monthly, 6:30 pm at Sechelt Indian Band Health Unit. Contact 604-885-9404

Pender Harbour – 3rd Thurs. monthly, 6:30 pm at Pender Harbour Paper Mill. Contact Myrtle 604-883-0010 or Bill, pager 604-740-9042

Vancouver: Healing Our Spirit—Offering HCV and HIV education, support to Aboriginal People in BC. 100 - 2425 Quebec St. Contact 1-800 336-9726, info@healingourspirit.org www.healingourspirit.org

VANDU Vancouver Area Network of Drug Users Each Mon., 2 PM, Bus fare & snack. 50 East Hasting St. Bus fare & snack. Contact Cristy or Ann 604-683-8595 (ask for VANDU). Space limited. vandu@vandu.org www.vandu.org

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

YouthCO AIDS Society HepCATS #205-1104 Hornby St., Vancouver. Info, contact Caitlin Padgett caitlinp@youthco.org Support, contact Matt Lovick 604-688-1441 or 1-877-YOUTHCO www.youthco.org

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

Victoria Support & Info Contact The Needle Exchange 384-2366

Victoria HepCBC & INFO line —Contact (250) 595-3892 info@hepcbc.ca, www.hepcbc.ca

Works Without Words Yukon Hep C Support Group Every Thurs. at 7 p.m., Grace Community Church, 8th & Wheeler St.. Contacts: Harry & Debbie 867-667-2402 harry.mckenzie@klondiker.com Brian: 867-668-4483 P.O Box 31216, Whitehorse,YK.

QUEBEC:

Arundel Contact Andy Aitken chcn.alexander@sympatico.ca Canadian Hepatitis C Network

http://www.canhepc.net/

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

AND OTHER PROVINCES

ATLANTIC PROVINCES:

Fredericton, NB Contact: Bob, 453-1340

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

Cape Breton Island, N.S. The Hepatitis Outreach Society Support Group 2nd Tues. monthly 150 Bentick Street, Sydney, N.S. 7:00 - 9:00 PM. Call Cindy Coles 1-800-521-0572, (902) 733-2214 Fax (902) 733- 2043 hoscb@ns.sympatico.ca

ONTARIO:

Barrie Hepatitis Support Contact: Jeanie for information/ appointment 705-735-8153 dragon-slayer2001on@yahoo.ca

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contacts: Smilin' Sandi smking@rogers.com "Sandi's Crusade Against Hepatitis C" http://creativeintensity.com/smking/ Ken Ng, 905-723-8521 ext. 2170 1-800-841-2729 (2919) re: testing, free Hep A and Hep B Vaccines and group info. Next Meetings: June 10th.. July 8th Speaker: Colina Yim, RN, MN Toronto Western Hospital "The Impact of Antiviral Therapy on Work Capacity in Patients with HCV" Aug. 12, Sept. 9th Speaker: Dr. Durhane Wong-Rieger, PhD "Living Well with Hepatitis C"

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

Unified Networkers of Drug Users Nationally undun@sympatico.ca

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact: Carolyn (519) 880-8596 lollipop@golden.net No meetings in July or August.

Niagara Falls Hep C Support Group Last Thurs. monthly, 7 PM excluding July and Dec., Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact Rhonda (905) 295-4260, hepcnf@becon.org

AIDS Committee of North Bay Bi-weekly HCV Support meetings Shannon (705) 497-3560

Peel Region Hep C Support Group www.peel-hepc.com Contact (905) 799-7700 healthline-peel@region.peel.on.ca

St. Catharines Contact Joe (905) 682-6194 jcolan-gelo3@cogeco.ca

Hepatitis C Network of Windsor & Essex County Contact Andrea 250-5399 or Michelle 256-1878 hepcnetwork@mailcan.com http://hepcnetwork.cjb.net

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

PRAIRIE PROVINCES:

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

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

Fort McMurray, Alberta Hepatitis C Support Network 1st Wed. monthly 12:00- 2:00 p.m. Lunch included. #205, 10012A Franklin Ave. Contact: Lyn (780) 743-9200 Fax (780) 943-9254 wbhas@telus.net

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 7 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Phone (403)527-7099 bettyc2@hivnetwork.ca

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

Note* Some support groups do not have meetings in the summer months or other seasonal holidays-Contact the group for clarification.

If you have a Canadian HCV Support Group to list on this page, please send the name of the group, day, time, place, contact name/phone, and email address to smking@rogers.com PLEASE inform me of any changes, or of any special events/speakers, etc., in your area, well in advance of the date. —*Smilin' Sandi*

BE PART OF THE TEAM!

We need people to summarize articles, and HepCBC needs office staff. The HepCAN list needs a moderator trainee. Please contact Joan at 250-595-3892 or info@hepcbc.ca