

hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

MAY: HEPATITIS AWARENESS MONTH



We hope individuals and groups across the world will take part in hepatitis C awareness events in their own community. You could start one of your own or help with one. We hope you will do something this month.

Larger events in the past have included concerts, candlelight ceremonies, press release events, skits performed in front of government buildings, letter writing campaigns, and ads on the radio or in the newspaper. Smaller efforts have included one person on a corner handing out pamphlets.

May 1st is the day our community has chosen especially for hepatitis C, but events have been held throughout the month.

We at the *hepc.bull* would love to hear what you did for Hepatitis C Awareness Month 2006.

8 Ways to Make A Difference

By Kathy Jensen, LCSW,
Community Outreach Director

The Hepatitis C Appropriations Partnership and the National Hepatitis C Advocacy Council have submitted a letter to President George Bush requesting a Presidential Proclamation demonstrating the administration's support of May 2006 as National Hepatitis Awareness Month. Many states, like Colorado, and cities, like Denver will also submit proclamations to their governors and their mayors. But how can you as an individual get involved? Here are some ideas. Lets make some noise.

- Ask your doctors, pharmacies, dentists, schools, libraries, banks, etc., to display Hep C Connection posters and handouts. Well send materials to you.

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ONTARIO MINISTRY OF HEALTH ORDEAL

In 1978 a blood transfusion saved my life. What I didn't know then was that the blood also carried a passenger; hepatitis C. The disease went undetected for over 20 years. Even then, it was only discovered when a specialist was doing tests to determine the cause of some internal bleeding. Needless to say, life has not been the same since.

Like many other people, before I became aware of my infection, I was totally unaware of hepatitis C. I didn't even know how it was transmitted. I was fortunate in one sense. The doctor who discovered the hepatitis was one of the treating doctors at the time I had the blood transfusion. We knew where I got the disease. In due course I was passed on to another doctor for treatment.

After running another battery of tests and a PCR, it was determined that I had genotype 3a, which has a relatively high success rate after treatment. Famous last words. At least I got to know the nice people at the blood testing lab very well.

The treating physician determined that 24 weeks of treatment with Rebetron would be appropriate. I know of some people who have had a relatively easy time with Rebetron. I was not one of those. To put it mildly, it was a trying ordeal. Among all of the other nasty side effects was the drug-induced diet. I lost about 40 lbs. The treating physician was quite concerned and ordered me to eat more; easy to say, hard to do.

After the 24 weeks of treatment a PCR showed that the virus was no longer in the blood. A PCR was scheduled for 6 months later to confirm that the treatment had been a success. It was not. Six months later came the news that the hepatitis was back. That's when the ordeal really began.

Due to various factors, treatment was delayed for a year. By this time, Pegasys had become available as an alternate treatment to the Rebetron, possibly with fewer and milder side effects, so the doctor prescribed 48 weeks of treatment with Pegasys, based on the fact that I had responded after 24 weeks but had relapsed. There were fewer and milder side effects, maybe, except for the headaches. The other side effects were a cake walk compared to the headaches. I had become used to some level of headache since, for me at least, headaches seemed to be part and parcel of the hepatitis. I rarely got headaches until the hepatitis started getting active. Then they began with increasing frequency. The ones that came with the Pegasys were much worse than anything I had experienced before.

Since I did not have a drug plan, my doctor and I were counting on the Ontario Ministry of Health to fund the treatment. Were we ever mistaken. Shortly before 24 weeks of treatment was finished my doctor received a letter from the Ontario Ministry of Health stating that they would not fund the 48 weeks of treatment, saying there was no documentation suggesting that relapsed Rebetron patients with genotype 3 would benefit from the 48 weeks of treatment. (Of course, there is no documentation supporting their stance either. I pointed that out to them.) They said that they rely on some experts, and that it was the opinion of the experts on which the Ministry based its decision. They actually cut me off funding before my 24 weeks of treatment was complete. A series of hasty letters resulted in the Ministry funding the full 24 weeks. There was a break in the treatment while we waited for the Ministry to fund the 24 weeks to completion. Whether this break made a difference in my next relapse is something we

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"I cannot afford to subscribe at this time, but I would like to receive the bulletin."

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"I want to volunteer. Please contact me."

"I want to join a support group. Please call."

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

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

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

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

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LETTERS TO THE EDITOR:

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

NEW!!! FAQ v7

Peppermint Patti's FAQ Version 7 is now available, and Version 5.6 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 125 pages of information for only \$6 each, plus postage. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

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

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

REPRINTS

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

THANKS!!

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

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



BE PART OF THE TEAM!

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

JUST ME AND MY HEP C

by Miss Sandy Berg

My "on again, off again" relationship with the very fickle hepatitis C virus began in 1988 with three blood transfusions—one of which was what everybody now calls "tainted." (Thanks a heap, Canadian Red Cross!) One of the donors who saved my life gave me that gift that never stops giving. In 1997 I received a letter—registered, yet—informing me that because of my transfusion history, I should report to my doctor and be tested for HCV. Totally unprepared for a "positive" result, and not even knowing what *that* could possibly mean, I answered my doctor's summons to come to her office to discuss my test results. Coincidentally, she had also tested me for my family's bug-a-boo, diabetes. I thought she was going to hand out my life sentence to that disease. Instead, the doctor said: "It's the hepatitis C blood work..." And then she said the words I will always hear in my head: "You have been exposed to the virus."

"That's it?" I enquired. "What does this mean?" But the doctor didn't assuage my fearful speculations.

"I'm ordering some more blood tests." And with that, she gave me an artificial smile of dismissal and showed me out.

I was feeling stunned. A huge sense of unreality was settling in. I could hear the doc's pronouncement reverberating in my head. I decided to research this mysterious visitor who had come to camp out in my life. How, I wondered, could I be so sick with some sort of progressive disease, and yet not notice "big" problems in my general health? Granted, I was experiencing a clutch of vaguely uncomfortable, non-specific symptoms, but nothing seemed to materialize blatantly enough to set the alarm bells ringing. This menu of inconveniences included various joint and muscle aches, headaches, dry mouth and eyes, a frustrating fatigue, itchy, blotchy rashes popping up on my body, nausea, dizziness, and periodic vomiting, which persistently plagued me. Am I, I wondered, just a hypochondriac looking for a place to happen?

Next, I'm told my whole family would have to have their blood tested for HCV. My young children didn't understand the "why", only that they had to have a "bad needle." My youngest, Tim, was nearly hysterical while the lab technician was trying to draw his blood. This was his first needle since his early babyhood vaccinations. Seemingly endless, tense days went by before all the results were in. By some miracle, my five sons and husband had not become infected. What a relief! Because, as anyone with young children knows, bodily

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fluids are everywhere. Unfortunately, the usual, simple precautions of normal hygiene like hand washing, covering open sores, brushing teeth, and washing the diapers in bleach and hot water were apparently no longer going to be enough. Additionally, my early research revealed that there was some chance conjugal relations with my husband could infect him. He, however, waved it off. We didn't use condoms. I was nervous, but other sources later stated that monogamous couples rarely infected each other. The risk rose proportionately with the number of bedmates involved. Nevertheless, I felt the full weight of the responsibility of being the one who remained constantly vigilant to protect others. Many changes in lifestyle were indicated in the available pamphlets I procured: Do not share toothbrushes, a nail clipper, or *anything* likely to have a blood trace on it. My own good sense led me to the myriad uses for disposable gloves—donning them whenever even the tiniest possibility of blood transfer presented itself. For myself, alcohol would forever be out of the picture. That was no sacrifice, as my imbibing was minute and sacramental in nature.¹

Frustratingly, my doctor was of little real help, but fortunately one phone call to the Victoria Hep C Support Group's office turned my life around. I can't remember who answered my call. It was a kind man whose smooth voice and calm manner reassured me immediately by answering many of my panicky questions. Sensibly, he invited me to the next monthly meeting at the church on View St.

My education in all things "Hep C" expanded widely. I met Joan King, C.D. (Squeeky) Mazoff and many of the other pillars of the HepCBC community in Victoria. They offered me materials from the resource library, which I borrowed, and I looked to the monthly *hepc.bull* for further edification on the various aspects of fighting the disease: drugs, trials, treatments, personal experiences, and for what progress was taking place where, and by whom. Best of all—I was not treated like a freak or a leprous outcast. Slowly, I began to relax a little, and gained some psychological and emotional control over my illness.

On again, off again? I'm simply treading water. My last PCR was negative for measurable amounts of the virus. This can only be a good sign, I reason to myself. BUT... BUT...I still experience some suspicious and annoying symptoms. In my gut, I do not believe I'm "cured." After all, a liver biopsy in 1997-8 showed a liver in a state of chronic HCV infection, albeit, with only minimal damage. Does it just disappear?

I was sent to a liver doctor who tested and re-tested me to be sure I actually had

**IN LOVING MEMORY
KEN FRIZZLE**

It has now been a year (April 9, 2005) since my father passed away from HCV. It is amazing that I still feel shock whenever I think about it. How do you get over losing somebody? How do you ever feel whole again? At first I did not think I would get over it. My family doctor told me that her father had passed away when she was young and every time she thought of him she would cry. However, after some time had passed she found she could think of him and smile. I never thought that I would ever think of my father again without crying, however my doctor was right. I can now think of him and smile. I also love telling stories about him. It makes him real to me again. Sometimes, though, when I think about him, in the quiet and by myself, tears still come to my eyes. But I am glad they do. It means that I love and miss him and always will.

**WILL I EVER WAKE UP AND
NOT THINK "I HAVE HCV"?**

When I first found out I had HCV I could not wake up in the morning without the same thought running through my mind: "I can't believe I have Hepatitis C." Every morning my stomach would tighten and twist, and thus would begin my wonderful day. I know that not everybody will have this reaction, but I did, and I would bet I am not alone. I started to wish a day could go by that I did not think about it, or at the very least it would not be my first thought when I awoke in the morning. It is now two years later, and there is still not a day that goes by that I do not have at least a small thought about hepatitis C, however it is not my first thought when I wake up any more. And when I do think about it, my stomach does not tighten up and twist anymore. I have come to grips with the fact that I have it and have to live with it. Thinking of it each day is not necessarily terrible either. It reminds me to live a healthy, happy and full life as possible. It reminds me to be thankful for the life I do have. Life is what I make of it, and as long as I have a positive attitude, keep focused in living a healthy lifestyle and realize that I need to manage my disease, and be

thankful for what I do have, then I can stay focused and happy.

**DO YOU NEED SOMEBODY TO
TALK TO?**

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

**IS IT POSSIBLE TO AVOID
TREATMENT SIDE-EFFECTS?**

Anybody that has done a course of HCV treatment can tell you that the worst part is the side-effects. Not only are they hard on a person's quality of life, they can lead to discontinuation of treatment. A review in the *Gastroenterology and Clinical Biology* on February 20, 2006 looks at whether or not there are things that can be done to lessen these side-effects. Specifically they looked at: erythropoietin, G-CSF, vitamin E, glutathion, ursodeoxycholic acid, and antidepressants. They found that erythropoietin, G-CSF and antidepressants taken during treatment were the best for improving treatment.

www.hivandhepatitis.com/hep_c/news/2006/040706_a.html

VIRAMIDINE VS. RIBAVIRIN

It has been found in phase 3 trials of Viramidine that anemia is less common when using this drug as in comparison to Ribavirin (5% compared to 25%). However, the trial failed to show the drug to be superior to Ribavirin in achieving SVR. However, the trials were not weight based (like the dosing of Ribavirin is) and therefore further study will have to be conducted.

www.hivandhepatitis.com/hep_c/news/2006/032406_a.html

Hep C. One early test resulted in a false negative. My liver enzymes were out of balance, however. They jumped everywhere. Lately, though, my ALTs are within normal parameters.

So where am I now? I've done the Compensation dance, but how do I quiet the residual fears that push into my consciousness whenever I feel that familiar, dull pain in my upper right belly? Does the sleeping menace live on?

¹*True to the 1999-2001 study of 133 Hep C positive people by N. Lindsey, MS, et al., Behavior Modification Following a Diagnosis of Hepatitis C Infection, changing lifestyle is the key to decreasing morbidity and mortality from Hep C in the US (i.e., taking the recommended actions to avoid further infections actually does reduce Hep C deaths.)*

Courage, kindness, determination, and strength are the memories that I have of a man with hepatitis C. Hepatitis C is the silent killer that took this man away prematurely from this earth, from the ones he loved and from those who loved him.

Our family first learned that my dad had hepatitis C when he went to upgrade his life insurance. He took all the tests required of him to be approved for a new life insurance that would financially take care of his family if he died. He wanted to know that if he were to die, his family would be provided for. He cancelled his original life insurance assuming his new one would be valid any day. Then the phone call came from the life insurance agency that he was denied life insurance due to the fact that he had hepatitis C.

Hepatitis C was something that no one in our family had heard of. At first we really weren't that worried. You see my dad was a real fighter and he always seemed to be able to conquer any difficulty. Since this wasn't the first illness that he had dealt with, we thought that he would be all right. My dad had lived with excruciating back pain for over a decade at this point. He had endured five operations on his back and dealt with living a life of being handicapped since he was 33 years of age.

My dad contracted Hep C through a blood transfusion during one of his surgeries back in 1984. He spent the next thirteen years in and out of the hospital fighting hepatitis C and all of the illnesses that it brings on. Watching someone you love deteriorate from hepatitis C is one of the saddest things to witness.

Hep C has the nickname of being a silent killer for a reason. People don't seem to really understand the depth of this disease. Statistically we are still trying to get the real numbers of how many people die from hepatitis C. Even though our family knows that my dad's death is directly related to hepatitis C, his death certificate states that he died of liver cancer, as this was the end result of his having hepatitis C.

His life was cut short much too soon. Help us fight this disease. If you know of any one who has hepatitis C or has died because of hepatitis C, call us or write to us with your story. Together we can gather all the facts and help cure people of this disease.



Fatima Jones



Artur Detorres with grandson Kyle Jones

WHAT ABOUT LIVER CANCER?

A small but real percentage of those of us with hepatitis C may go on to develop liver cancer, as in the case of Artur Detorres. It is one of the possible consequences of hepatitis. It usually only occurs in those who already have cirrhosis.

There are 4 types of liver cancer. The type most associated with hepatitis C is hepatocellular carcinoma (HCC).

What are the Symptoms?

Some of the symptoms of liver cancer are similar to those of hepatitis C infection, so just because you have these symptoms doesn't mean you have liver cancer.

- Pain or discomfort on the right side, especially in the upper belly or around the right shoulder blade
- A hard lump on the right side just below the rib cage
- Unexplained weight loss
- Loss of appetite
- Nausea and occasionally vomiting.
- High temperature.
- Jaundice - Yellow skin and eyes, dark urine and pale stools.

How is it Diagnosed?

• *Blood tests.* An alpha-fetoprotein test (AFP) may be slightly elevated in patients with Hep C, and very high levels of AFP is a good indication of liver cancer. Unfortunately, this is only seen in a few patients

• *Ultrasound*

• *Intraoperative ultrasound* is used during surgery to locate specific areas of cancer within the liver.

• *CT scan* - This determines the number and size of tumors in the liver and whether they can be removed.

• *MRI* provides exact, detailed images of the liver and tumor.

• *Biopsy* through fine-needle aspiration.

• *Angiography* - A catheter is inserted into an artery in the leg into the artery that supplies the liver. Dye is injected and X-rays are taken.

• *Paracentesis* - Abdominal fluid is removed by placing a needle into the abdominal cavity (not into the liver), and is tested for cancer cells.

• *Laparoscopy* - With the patient under anesthesia, a small camera is guided into the abdomen to see if the tumor has spread outside the liver.



How is it Treated?

The treatment depends on size and type of cancer and if it is primary or secondary.

* *Surgery* can remove the tumor or part or all of the liver. A liver transplant may be performed only if the disease has not spread outside the liver and if a suitable donated liver can be found.

* *Chemotherapy* uses anticancer drugs to kill cancer cells and shrink tumors

- Hepatic arterial infusion - Anticancer drugs are sent to the tumor through a tube inserted into the hepatic artery
- Hepatic arterial infusion pump - This sends the drug to the liver continuously.
- Chemoembolization - A tiny catheter is inserted into an artery in the leg and up into the hepatic artery. An anticancer drug is injected along with tiny particles which block the flow of blood so the drug stays in the liver temporarily or permanently.

* *Radiation therapy* uses high-energy rays to kill cancer cells. It affects cancer cells only in the treated area.

* *Freezing* with a cold probe, or injecting alcohol into the tumor

* *Laser therapy, microwave therapy*

* *Palliative therapy* is used to reduce pain and control symptoms

- Pain medications
- Radiation to relieve pain by shrinking the tumor
- Nerve block - Alcohol is injected around certain nerves to block the pain.
- Paracentesis - Removes excess fluid to relieve pain.
- Massage
- Acupuncture
- Acupressure
- Relaxation techniques are used, such as listening to slow music or breathing slowly and comfortably.

(Continued on page 5)

(LIVER CANCER—Continued from page 4)

How can I prevent it?

* *Get hepatitis A and B vaccines.* Progression of liver damage is greater in those infected with more than one type of virus.

* *Consider interferon treatment.* Studies show most people who have responded to treatment experience slower or no progression of liver disease. Of 40 year old untreated HCV-positive males, when they reached 70 years of age, 34.4% would have developed liver cancer. In untreated females, the results would be 22.0%.

* *Avoid aflatoxins,* a fungus that grows on peanuts, corn, soybeans, etc. There is a relationship between constant exposure to aflatoxins and liver cancer. Not all countries monitor their food supplies for this fungus.

* *Get an alpha-fetoprotein test yearly.* High levels can indicate liver cancer, and it is good to have a baseline figure.

* *Get an ultrasound yearly.* It can show lesions at an early stage, when treatment can be more effective.

* *Get a biopsy.* This is the only way to know what the state of your liver is.

* *Avoid diabetes and weight gain:* Get exercise. Eat wisely. Diabetes is associated with fatty liver, and so is hepatitis C. Fatty liver can go on to produce fibrosis and scarring.

* *Don't drink or smoke.* Alcohol is one of many toxins, and is known to damage the liver. Tobacco is associated with cancer, including liver cancer.

* *Avoid other toxins.* When possible, avoid drugs, both prescription and non-prescription.

* *Get your ferritin levels checked* (iron overload). Iron collecting in the liver can damage the organ.

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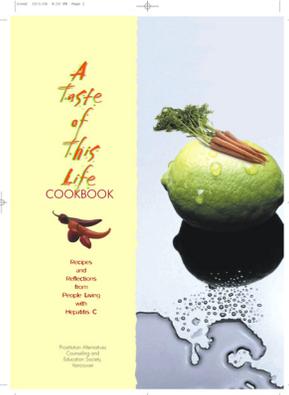
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**P. A. C. E. Society
Prostitution Alternatives Counseling & Education is pleased to make available our cookbook:**

**"A Taste of This Life"
Recipes and Reflections
from People Living with Hepatitis C,
and our pamphlet:**

**"Hepatitis C Basic Information"
"When hearts and minds join and stories are shared, MYSTICAL things happen"**

We see sex workers as our greatest asset and those living with Hepatitis C as the experts. We dedicate our project to all those who face similar barriers.

**Join us and indulge in:
"A Taste of This Life"**

**To view visit our website at:
www.pace-society.ca
or contact us at pace-admin@telus.net**

(AWARENESS—Continued from page 1)

- Write a letter to the editor of your community newspaper or submit an article; volunteer to be interviewed about your personal story.
- Submit a short article to your church bulletin, civic organization, or other newsletters that you receive.
- Attend a hep C support group in your area and network with others.
- Send a note or email to your legislator and tell them about your concerns and issues related to living with hepatitis C.
- Open up to family, counselors, friends, and educate them.
- Offer to give a talk at your neighborhood school, church service, etc.
- Make a donation to the Hep C Connection to support our education and outreach efforts.

Thanks for all your help to increase public knowledge. Share your success stories with us by contacting Kathy Jensen at 720-917-3960 or kjensen@hepc-connection.org

PegCARE

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

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

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

PegCARE: 1-800-603-2754

PEGASSIST

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

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

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

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

COMPETITION!

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

(MINISTRY ORDEAL—Continued from page 1)
will never know.

My doctor tried appealing to the Ministry of Health. This had no effect. I tried an appeal on my own behalf. This also had no effect. The Ministry official I spoke to actually said that there was no appeal from a Ministry ruling. I suspect they thought I would quietly go away and wait to die. Not so. I had tried several organizations at the provincial and federal level that purport to offer assistance to those with hepatitis. I can only say that I was greatly disappointed with the level of support I got from these organizations. The most I got was a "Good Luck." I then contacted my local MLA. He asked me to write a letter outlining my case and he would give it to the Minister of Health.

I e-mailed Joan King if she knew where I could find some information to appeal to the Ministry. Joan was kind enough to send me some documents and a very important link: <http://www.natap.org/>. Though it is primarily an HIV site, they have quite a few abstracts from documents relating to the treatment of hepatitis. It proved useful for the information, but nothing in it was enough to change the mind of the Ministry of Health. Even when I cited one document stating that it was prudent to treat those with genotype 3 for 48 weeks, the Ministry failed to take that document into account. I also pointed out to the Ministry the economical advantage to treating the disease rather than to let it just develop. After all if they do not treat now then they will eventually have to pay for any transplants, cancer treatments, or treatments for other diseases that may arise from the initial hepatitis attack. The Ministry knew all this, but insisted that they rely solely on the advice of their specialists. As a result of this, they still refused to authorize payment for the treatment. They would rather absorb future costs than pay for present costs. Or perhaps they are hoping that I will die and thus no longer be a problem to the smooth operation of their little bureaucratic empire.

When I sent the letter to my MLA I foolishly thought that the MLA and an appeal to the Minister of Health would cause the Ministry of Health to change their opinion. The political appeal had no effect. I should have realized that the Liberal Party of Ontario would be of no help. Despite promises for Hep C funding by the Minister of Health in 2004, they did nothing. It was just another in a string of broken promises.

A PCR was done after the 24 weeks and it showed that I was again clear of the virus. We thought maybe it did work this time. It was not to be.

During a routine physical, just a month and a half after the PCR, my AST and ALT levels had risen to over the 100 IU/L level. The results were sent to my treating physician and another PCR was ordered. The

hepatitis had returned. Based on this the doctor applied for approval of 48 weeks of treatment with Pegasys, pointing out to the Ministry that I had relapsed after only 24 weeks last time, and that perhaps 48 weeks would be the appropriate treatment period. The Ministry of Health of Ontario again turned down the application. They cited the same reasons given before-- no documentation supporting the requirement of 48 weeks of treatment for genotype 3 relapsers. I did e-mail my local MLA to ask him to intervene with the Minister. I got a brief e-mail over a month later requesting some other information which was supplied immediately. I am still waiting again. Again it has been over a month and no reply. It is obvious to me now that the political system has failed me. Judging by what I hear from others this is just par for the course. People with serious illnesses and disabilities are treated as second-class citizens and are quietly and efficiently brushed under the carpet.

I decided to appeal to the Ontario Ombudsman. I have sent the documentation that the Ombudsman's office requested. They received the information on 23 of March of this year. Hopefully this will be of some help. I can only hope so. This has all the appearance of becoming a long-term struggle for my rights. I do not take kindly to being thrown on the scrap heap. I intend to fight as long as I have strength to do so.

I have learned several things from this ordeal. If I had to do this again, I would certainly choose a different approach. I suggest that anyone that finds themselves in a similar situation do the same. I think you actually need a multi-faceted approach to achieve a successful result. You will also need the help of your friends and loved ones since this is an exhausting process to do by yourself, as I found out. It also helps to have a positive outlook and a good sense of humour. As I stated earlier, I foolishly believed that the political process and appealing to your local MLA might result in a positive outcome. I now know this is wrong. Perhaps if your local MLA is a cabinet minister instead of a back-bencher, then you may get some results. Cabinet ministers may occasionally need the support of other ministers to put forth their agenda. They can use this "good will" to achieve a favourable result. Back benchers have no such clout.

You will definitely need the support of your friends and loved ones. The battle is a very tiring process. Many of us already know how exhausting just an ordinary day can be. The extra stress and aggravation will definitely have an effect on you.

It is important for you to realize that the Ministries that were initially set up to help citizens no longer view that as their goal. To these faceless and soulless bureaucrats you are just a statistic. You do not exist except as

a number and a statistic to deal with. They will reject anything that causes them to deal with facts or realities that exist outside their comfort zone. They do not care that the quality of your life may be greatly diminished by the decisions that they make.

I believe the first thing you need to do is gather all of the documentation you need before you begin the appeal of the ruling. Make sure that any documentation is directly related to the genotype of your hepatitis. If you are either a failed or a relapsed patient, make sure you try and find as many documents supporting your stance as possible. NATAP is the first place you should look. Most other sources of documentation are not readily available to the lay person. When you do start the appeal process it is probably a good idea to make your situation known to the media. It would probably also be a good idea to seek assistance from the opposing political parties while you seek help from your local MLA. I am not certain that this will work either, but it certainly is a better possible strategy than the one I chose. I would also seek the help of the federal Ministry of Health. The federal government gave the provinces money to help those with Hep C. In Ontario, at least, this money was just added to the general funds of the Ministry of Health and is not, therefore, available for the use of those who suffer from this disease. You may find that opposition parties may have spoken on this matter. It appears that the agencies that have misspent these funds may have done so inappropriately. You may have recourse to the auditor-general of your province. Again it may require some assistance from an opposition politician to access this route.

At least with media and opposition party support, you may be able to shame the Ministry to actually change their mind. As a last resort, you can always turn to the Ombudsman in your province for assistance. Who knows, it may actually work.

Timo Ahonen

PS: On April 11th, I heard back from the Ombudsman's office. They said they are unable to do anything since it would be up to my doctor to supply the evidence documenting that 48 weeks of treatment was justified. I told them that I could not find any information supporting either argument. Based on that, there was nothing the Ombudsman could do. It's another one of those Catch-22 things. It was worth a try but, truthfully, I didn't expect much. If they let people go without cancer medicines in Ontario, you can't expect them to fund hepatitis drugs. I guess I'll just have to try and sit tight until something other comes along, or...



PUT YOUR MONEY WHERE YOUR MOUTH IS!

By Ernie Zivny

It has been over a year since Mr. Steven Fletcher stood in the House of Commons and said that a Conservative government would compensate the victims immediately. Mr. Fletcher was talking about the pre-86/post-90 hepatitis C victims of tainted blood.

We are now past the anniversary, April 20, 2006, when Mr. Fletcher's proposed legislation was passed and approved unanimously by all parties of the House to compensate all victims of tainted blood infected through the Canadian blood system. We are still waiting. Does this mean that we are to remain The Forgotten Ones?

The Liberals discriminated against the pre-86/post-90 hepatitis C victims when they denied us compensation. They saw fit to compensate the 86-90's; they saw fit to compensate all those infected with AIDS through the tainted blood system, with no window, at the same time discriminating against the pre-86/post-90 hepatitis C victims by denying us compensation.

Victims of hepatitis C-tainted blood are dying; some are living in poverty through no fault of their own because of not being able to work due to the severity and side effects of hepatitis C. Some people living with hepatitis C require special diets, but the Ontario Liberals saw fit to reduce the special diet supplement, for those who depend on the supplement, to a mere \$10.00 per month.

This just shows how important sick people are to a Liberal Government and our health care system. If they would only remember what our mothers taught us: An ounce of prevention is worth a pound of cure.

A few short weeks ago Mr. Fletcher's office told me that they were discussing an interim payment. This may be a step in the right direction, however it does not bring us closer. I don't know what is so hard about doing what so many politicians have said when they wanted our votes: It is the right thing to do. Compensate all victims.

In the meantime the government lawyers are getting paid quite handsomely while victims die and suffer. All we want is to be treated like the rest. Give us the same as the AIDS victims, with interest. Are we any different from the AIDS victims? We got the same tainted blood. Both kill and debilitate their victims.

Ernie Zivny
Membership Development
Circle C Support Group (Sudbury On)

'Because'



Peace begins in all our hearts
As love does come and never departs.
Rise and feel the warm sweet sun,
With an end to night we jump and run.

Twilight gleams within clouds above
Hear fluttering wings of a snow white dove.
White and free she glides overhead
To praise the Lord and raise the dead.

My heart belongs to only you
I shall always be completely true,
No strings attached to bind or keep
But just a trust so very deep.

Trust is one way in which we feel
The warmth, the closeness when we're real.
A gentle kiss upon the cheek and eye
Tickles like the gentle butterfly.

Long to love and love to long
Become that beacon oh so strong
That others see the light and come
From the millionaire to the good street bum.

The sound of music is just so magic
Unlike the sirens, which indeed are tragic.
Which sound upon the city street
Makes you stop and stomp your feet?

We have some time and then we go
Not to the land of white bright snow
Not to the heat of Dante's fire
But to the object of our heart's desire.

Cherish all which lives and is...
Depend on others so you may give
Gifts freely given with no remorse
That is what life is about of course....

Life goes on and on and on
We shall not feel empty or forlorn
Time is time and that is that
New life is like changing an outdated hat.

Peace begins within our brain
We learn to pray as it starts to rain
We begin to praise if we stand tall
We are just humans after all.

Some say flying is just like dying,
Some distorted memory.
I say dying is just like flying,
Some reported revelry.

Lift up your eyes to the universe now
Think not that this is IT
Wonder never fails to show,
Water it well and it shall grow.

Peace Brothers and Sisters, Always!
S.Tara Balduf (Ane Palmo)

COMPENSATION

LAW FIRMS



1986-1990

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

Pre-1986/ Post-1990

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

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

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

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

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

Other:

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

LOOKBACK/TRACEBACK

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

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

Manitoba Traceback: 1-866-357-0196

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

CLASS ACTION/COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296
Health Canada Compensation Line: 1-888-780-1111
Red Cross Compensation pre-86/post-90 Registration: 1-888-840-5764
Ontario Compensation: 1-877-222-4977
Quebec Compensation: 1-888-840-5764
ca/en/ms/hepatitisc/forms.html

ADMINISTRATOR

1986-1990

To receive a compensation claims form package, please call the Administrator at 1-877- 434-0944.
www.hepc8690.com info@hepc8690.com
<http://www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf>

Pre-86/Post-90

Hepatitis C Settlement Fund—KPMG Inc.
Claims Administrator
2000 McGill College Avenue, Suite 1900
Montreal (Quebec) H3A 3H8
1-888-840-5764 (1-888-840-kpmg)
HepatitisC@kpmg.ca
<http://www.kpmg.ca>

MISCELLANEOUS

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

COMING UP IN BC/YUKON:

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

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

• **Comox Valley** 355 6th St. Courtenay; Contact Phyllis 338-7400 phyllis.wood@avi.org Drop In; Harm Reduction

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

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

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

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

Castlegar Contact Robin 365-6137 eor@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

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

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

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

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

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

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

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

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

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

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

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

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

Prince Rupert Hepatitis C Support Contact Ted 624-7480 Ted.Rogers@northernhealth.ca

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

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

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

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

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

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

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

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

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

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

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

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

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

OTHER PROVINCES:

ONTARIO:

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

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. May 11: Durhane Wong-Rieger: "Optimizing Life with Hepatitis C" Contacts: Smilin' Sandi smking@rogers.com Sandi's Crusade Against Hepatitis C <http://creativeintensity.com/smking/> <http://health.groups.yahoo.com/group/hepc-info/> 1-800-841-2729.

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

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

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

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

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

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

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

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

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

Unified Networkers of Drug Users Nationally undun@sympatico.ca

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

info@hepcyorkregion.org www.hepcyorkregion.org



QUEBEC:

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

ATLANTIC PROVINCES:

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

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

PRAIRIE PROVINCES:

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

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

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

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

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

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

Life with Hepatitis Society of Central Alberta Meets weekly. Chris or Laverne, 309-3652, orthomas@shaw.ca

If you have a Canadian HCV support group to list here, please send details to info@hepcbc.ca Please inform us of any changes by the 15th of the month —Joan

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