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Canada's Hepatitis C News Bulletin

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MAY: HEPATITIS MONTH

PLEASE DO YOUR PART: SPREAD THE WORD

WHO WAS RUDY?

Born November 3, 1940, Rudy Lang, a resident of Kitchener, ON, passed away last month, unexpectedly. He was our friend.

Rudy was a quiet person, and went about supporting people with Hep C in his own quiet way, accompanied by his hedgehog Spiky and his ex-girlfriend Brenda. He was diagnosed with liver cancer back in 1999, and received treatment, and finally, a transplant in November of 2001. He had been infected by the blood supply, but I never heard him complain. He kept us entertained with his wacky sense of humour.

Rudy founded the HepCAN list, armed only with his treasured Atari. He was pax@golden.net. May he rest in peace.

ALBERT LOCKEY

We were sorry to hear that one of our subscribers, Albert Lockey, a resident of Surrey, BC, passed away on February 13, 2004. His wife Marian notified us. Our thoughts are with her.

FROM THE EDITOR

Greetings to all.

I would have liked to attend the Second Canadian Conference on Hepatitis C in Vancouver, but my work schedule wouldn't allow it. I found the First Conference in Montreal extremely beneficial, and would have liked to reconnect with my Hep-buddies. Something kind of magical happened when I told people I couldn't go: Several people came forward and offered to do reports on their experiences, and some of them got back to me with those reports. These people are some of our treasures: People with capacity and enthusiasm, who can help make a real change. We have too few of them. We are including their reports in this issue, and hope that, if you couldn't get there, you will feel like you did.

HepCBC had an Annual General Meeting last month, along with an election of Board Members. We are pleased to announce them:

Monique Chase, David FitzGerald, Laurie FitzGerald, Chris Foster, Joanne Galbraith, Joan King, Norma McLelland, RN, Arthur Ralfs, Kate Rhodes, Patricia Winram, and Dr. Denis Petrunia.

At this time, we would like to offer a special thank you and big hug to all of our wonderful volunteers.

One last thing: Can you do something for May, Hepatitis Month?

INSIDE THIS ISSUE:

HYPERTHERMIA PLUS PEG INTRON/RIBAVIRIN CLINICAL TRIAL UPDATE: MAY 2003

by Darlene Morrow

October 2003

I have been on smoothies and soft food since the end of August because of the problems with my mouth. They are due to the continued low white count. The drugs for my mouth are certainly making me throw up and the marijuana isn't helping. Maybe that was what was making me ill. I may try it again later.

October 10, 2003

I was really lucky on the flight home. There were lots of empty seats, and they gave me a whole row of three to stretch out on. I managed to sleep and wasn't broken when I got home. It was so great to see Bill!! And my kitties. And my house. And my country.

I decided to get second opinions on what was happening.

I went to see an oral specialist and she is working at getting my mouth problems under control. It seems to be working! I can't believe how quickly I can be out of pain.

I had a bone-marrow biopsy and they found Myelodysplatic Syndrome (bone marrow failure). It is the kind that makes too few cells. Hopefully this is a part of the side effects and will go away when I stop treatment. A repeat bone marrow biopsy will tell the prognosis, but I think I need to wait a year to give the marrow and the whole body a chance to heal.

I have been really sick and tired. Not much to say otherwise. The liver specialist didn't want me to go down to 65 micrograms of interferon/week but to stay at 100. I'll try.

November 2003

I am not able to take the 100 micrograms of interferon. My white count keeps dropping, so I have to stop the treatment for a

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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!!!!
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 Franciscus; and all of HepCBC's pamphlets. The Resource CD costs $10, including shipping and handling. Please send cheque or money order to the address on the subscription form on this page.

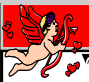
REPRINTS

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, 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, Nicole, Kelly, 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.

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Want a mate? Your Cupid ad could go here!

Got Hep C? Single? Visit:

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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 ONE

By Ken Thomson, BC Hepatitis C Collaborative Circle

Because there were three simultaneous tracks in this conference, I was unable to attend many sessions that looked very interesting. If you have notes on any of these sessions, please consider sharing that information with the rest of us.

In my next report, I will summarize sessions on genotype distribution in Vancouver's downtown east side, the Nova Scotia collaborative model, the future of hepatitis C, and legal and human rights issues.

Impact of antiviral therapy on work capacity (Colina Yim)

Work productivity and functioning decrease most in the first three months of treatment with PEG/ribavirin. Eighty-one per cent of missed days occurred during that time.

In a study of 161 patients, 24 per cent missed work days. Most missed less than 30 days. There was an even split between the need for time off, job modification, and going on disability benefits.

CCOHTA – Assessment of interferon-based therapies (Don Husereau)

Pegylated interferon w/ribavirin was compared to interferon w/ribavirin for the frequency of serious adverse events. Peg/ribavirin had higher psychiatric (3.3 vs. 3.0%), serious infection (2.6 vs. 1.1%), and other adverse events (11.1 vs. 7.1%). The frequency of gastrointestinal adverse events was lower (2.0 vs. 2.3%).

The conclusion was that, compared with interferon/ribavirin, peg/ribavirin can increase the need for urgent medical attention. Accordingly, managers and policy makers should balance the need for increased short-term hospital use with a perceived decrease in long-term health costs.

A couple of doctors in the audience questioned what they saw as a possible attempt to limit the use of the newer medication. It was pointed out that reducing the number of liver cancers because of treatment was also an important factor to consider.

Treating co-infection (David Wong)

There is an increased risk of severe hepatotoxicity with antiretroviral treatment. Some of the potential mechanisms are mitochondrial toxicity (NRTIs), direct hepatotoxicity (full dose Ritonavir), hypersensitivity reactions (NNRTI), immune restoration in association with chronic hepatitis C (or any viral hepatitis), and increased HCV load with HIV suppression.

Up to 75 per cent of patients will experience increased ALT on HAART. Relatively few will develop severe hepatotoxicity. HIV accelerates fibrosis progression. The risks for rapid progression are infection after age 25, alcohol consumption, and a CD4 count under 200.

In Ontario, up to two thirds of HCV cases are genotype 1. The treatment discontinuation rate is 20–30 per cent. The treatment team may influence outcomes. The 80/80/80 rules seems to apply. The 12-week response rate is similar to HCV mono-infection.

HIV viral load and CD4 count both drop with treatment. The CD4 count drops but the CD4/CD8 ratio is maintained. Ribavirin and ddC, ddI, d4T, and AZT increase the risk of toxicity.

Co-infected patients have a high rate of co-morbid conditions. Treatment may be less well tolerated but individual characteristics and support are important. A multidisciplinary approach is needed. [This shows the need for enhanced community and peer support.]

In an ideal world, treat HCV first. In the real world, the stage of HIV infection, risk of opportunistic infections, and CD4 count need to be considered. A general rule-of-thumb is, if the CD4 count is over 350, treat the HCV first; if the CD4 count is below 200, treat the HIV first.

MOMMA'S NOTES:

The 2nd Canadian Conference on Hepatitis C was called "New Knowledge, New Hope" – a catchy name, designed to make you think something was going to be different. Well, I do not really feel that it was anything like that.

For one thing, we had to fight like "h" as consumers just to be there. Many of you know what we went through for that. Few were given the financial help to fly, take a bus, or get on the ferry. However, many of us felt it was important enough to fight back and get there by hook or by crook, and that is what many of us did. Thanks to some financial support from HepCBC, the Action Committee of People with Disabilities, and VANDU, four people from ACPD and SOLID were able to get to Vancouver and attend this conference.

For another, very few hepatitis C groups have any funding. Groups are operating out of people's houses, and paying out of their own pockets for paper and for internet access to receive and provide information. It seems that, while there may be new knowledge, there is no new hope.

What was great was seeing so many people I have known for several years, meeting those I knew by name but had never been able to put a face to, and meeting those I had always wanted to meet but never could afford to because they live across Canada.

I was particularly taken with a workshop by Syrus Ware, which provided good, well presented information. But one of the new groups paid to work in the prisons got up and as much as said she was lying, and that the report about the availability of clean syringes in prisons as provided by PASAN was untruthful. It made me wonder what was going on. How can a group working with prisoners provide incorrect information? Syrus never blew her cool and just kept saying she appreciated hearing that what she had presented was incorrect. However, I am not quite as nice. It reminded me of the commercials that tell us health care is improving, so I got up and said so. I never had so many people thank me in my life.

Ken Winiski and Robert Nickerson gave a great presentation on anti-oxidants. I wasn't much impressed with the dietician, though, as I also have "the Hep diet" and recommendations put out by the dieticians of Canada. So I thought she really lacked and was somewhat contradictory to our own Mary G. at the Jubilee Hospital, who helps so many of us watch our nutrition, assists us with our vitamin and protein intake, and provides general support for our good health. Nobody ever stops to think that, if you are on welfare, you have to get the Nutritional Supplement or you could not afford to eat the basic diet anyway.

Unfortunately, I cannot cover all the presentations I attended. However, I do want to comment on Ken Thompson's presentation about people still waiting for treatment, treatment being denied, the current difficulties in having treatment covered if it did not work for you the first time, and the slowness of British Colum-

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(CONFERENCE NOTES—ontinued from page 3)

bia and Canada to approve Pegasys/Copegus. I am sure that there will be an article from Ken in this issue, so you will see what I mean.

I did not see much change in treatment options for people from when Chris Laird and I camped out at the B.C. Legislature in 2000. I do not see much change from when Penny Priddy announced in 1999 that Pharmacare was going to cover Rebetron. I do not see much change in the way treatment approval is given – it is still under special request authority from Pharmacare and still looks at 1.5 elevated ASTs and ALTs. Nothing has changed. Less than 5,000 have been treated in B.C., yet we have 40,000 infected. No epidemic is declared. No pandemic. But twelve people die from SARS and the whole country is thrown into a tizzy.

Even though HepCBC is not part of the AIDS community, many of the groups attending and presenting were AIDS groups, and most of the booths were by AIDS groups. I cannot understand why there is so much more money available for an AIDS strategy than for a hepatitis strategy. I in no way want to imply that there is enough HIV/AIDS funding, but the lack of dollars in hepatitis funding is disgusting, even though we have five times the infection rate. Somehow, we have not begun to incorporate into our own awareness that we need a separate strategy and a separate organization because we are unique. Heart patients do not go to a cancer clinic for information or treatment, but we have few, if any, places to go that are specific to our disease.

Several things I thought were really lacking in the conference were the following:

Vancouver is in the unique position of having the first legal safe injection site in North America, but not one day trip was scheduled for the delegates to visit it. Some did go anyway, and VANDU did a walkabout of the downtown east side, but little else went on in relation to this. Representatives from the site should have been presenters. (Vancouver is also unique in having VANDU. Few, if any, cities have a drug-users' union. Thanks to VANDU, we were able to come together for a meeting and dinner at their offices.)

Vancouver has one of the largest drug-using populations in North America, mostly concentrated in one area. It seems to me that there was a distinct effort made to keep everyone very busy, so that they did not see the third-world squalor some Canadians live in. After all, it is not a good thing that the site of the 2010 Olympics should be home to the poorest postal code in Canada – perhaps in North America.

This was a very busy conference. It started most days at 7:30 a.m. and went to 5:30 p.m. or later. It was too busy for people with health issues to be able to take it all in. Also, there were three discussions going on at any one time, so it was impossible to know exactly what went on in most of them.

The area the conference was held in was very large. I ended up having to use my walker, because I was exhausted from walking back and forth from one venue to another.

Dr. Mel Krajden had an extremely good presentation and I only wish that somehow these were available in hard copy for those of us who couldn't write it down as it came up on the screen. He said he would put it up on the website. Maybe one of you could chase it down.

One of the issues I raised with Dr. Krajden was the problems many seem to have post-treatment. Some seem to recover very well, but others do not feel well at all despite having a zero viral load. Many of us have developed other illnesses or diseases. (For example, it seems to me I am hearing from more people with hepatitis or in treatment who have broken teeth, and more about osteoporosis being a common diagnosis among those with hepatitis C.) Yet there seems to be no reasonable explanation or study of these effects. The answer seems to be consistently, "We don't know." Well I wish someone would hurry up and do some research and find out.

I wish there had been more specifics on poverty, housing, and accessing extra needed dental and medical help.

I also wish there had been hard copies of all the presentations so that we could share the information at home. We do not always have the means to share the information we need. Computers are great for a lot of things, but I am an old-fashioned girl – I like paper copies.

My biggest peeve was with the hotel where we had the big gala banquet. People do not understand when I get upset about the wasted food in a place like the Hyatt. Several of us tried to take the leftovers so we could get them to VANDU or Mother Hastings, or somewhere else they would be used. I just cannot understand how a hotel could toss out what looked to be over $3,000 worth of uneaten roast beef, prawns, bread, fruit, and many other morsels I could never afford on my budget. This was a time I cried shame. I hope it never happens again, and frankly, I hope the Hyatt re-examines its policies on food donations.

All politics and shortcomings aside, though, it was a very good conference. A conference on hepatitis needs to include those who are living with this dragon because all the clinical trials in the world do not explain it at all. We as consumers need to attend more of these conferences. This is how our concerns will become heard. We need to put forth our concerns that we are being ignored and being treated like third-class citizens who are given last consideration for treatment.

Carol Romanov
Advocate: ACPD Victoria

ARTHUR'S PERSPECTIVE

From March 27--30, I attended the 2nd Canadian Conference on Hepatitis C, sponsored by Health Canada and held at the Hyatt Regency in Vancouver. The conference was intensive, with presentations and exhibits from 8:00 a.m. until around 7:00 p.m., and with breakfast and lunch available outside the conference rooms. This provided good opportunities for meeting people and networking.

The conference program consisted of plenary sessions, posters, exhibits, and three "tracks", each focussing on one of three specific issues: medical management and research, prevention and public health, and advocacy, community development and support. As a hepatitis C sufferer, nearly all the talks looked interesting to me, but since the tracks ran concurrently, it was impossible to attend all of them. Having a scientific background, and hoping to hear about the latest developments, I attended mostly the presentations on medical management and research.

There was a surfeit of information, and the rapid pace of the power-point presentations made it difficult to keep up, so I eagerly await the issuing of the conference proceedings. However some points did stand out. There was much talk about treatment with interferon-alpha, interferon-alpha with ribavirin, and pegylated interferon-alpha and ribavirin, this last now being the standard. Unfortunately, the success rate with treatment for genotype 1, the most common in North America, is still below 50 per cent, and as some readers may know personally, the side effects are notoriously bad. Good data were presented to show that, unless

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(CONFERENCE NOTES—Continued from page 4)

there is at least a one-hundredfold drop in viral load by the twelfth week of treatment, in the case of genotype 1, there is little point in continuing on with the full 48 weeks of treatment. This policy is due to the low chance of success (only two or three per cent), coupled with the bad side effects and the expense.

Of considerable interest is who gets treatment in our publicly funded system. This issue was discussed primarily from the clinical point of view, i.e., how severe the disease is and what the chances of success are. The standard is the liver biopsy for fibrosis, and Dr. Frank Anderson emphasized that probably everyone with hepatitis C should have a liver biopsy. If fibrosis is severe enough, then treatment should be given. There was also mention of retreatment for non-responders and relapsers. Non-responders have a low chance of successful treatment, while it is better for relapsers.

There was no discussion on the economics of treatment beyond the catchphrase, "You can pay now or pay later." Right now in B.C., only a small fraction of hepatitis C patients qualify for treatment, and it seems obvious that this is primarily in order to save money. It is a legitimate scientific question in the area of pharmaco-economics to ask whether this strategy of saving money in the short term to balance a provincial budget is a good one for the longer term. Although treatment is expensive, acute care hospitalization at a later date might be even more expensive, and that's to say nothing about quality of life issues. This becomes an even more cogent issue when viewed in the light of data presented by Jenny Heathcote showing a steady decline in treatment response with age.

One scientifically interesting, but perhaps depressing, talk was given by Thomas Michalak on the detection of residual HCV in patients after successful treatment. Successful treatment is defined as a sustained virological response (SVR) six months after treatment has ended. This means no detectable viral RNA in the bloodstream. However the clinical tests for viral RNA are not actually the most sensitive. Michalak, using research laboratory tests, detected HCV in 100 per cent of cases he looked at after successful treatment. It should be noted that the clinicians, particularly Mel Krajden of the B.C. Hepatitis Centre, equate an SVR with a cure and that such patients exhibit a full recovery. Although I have no medical training, this situation reminds me of that with chicken pox. Traditionally, people get chicken pox as children and are then immune, but years later the same virus can resurface and cause shingles.

The standout talk of the conference was given by Jenny Heathcote of the Toronto Western Research Institute in the closing plenary session. She reviewed the status of treatment and research. No new treatment appears to be likely in the near future. Promising results on a protease inhibitor were derailed in phase 2 trials because of cardiac problems. (In phase 1 trials a new drug is given to healthy volunteers to make sure it's safe, in phase 2 trials, it is given to small numbers of patients to see whether it actually works, and in phase 3 trials, it is given to large numbers of patients in "double-blind" studies to generate meaningful statistics.) Work is also ongoing on both therapeutic and preventive vaccines.

As a long-time yoga practitioner, I was disappointed that the presentation on yoga and exercise during the "Nutrition, Exercise and Complementary and Alternative Therapies" session was cancelled due to illness. This session, moderated by Smilin' Sandi, was one I attended for my personal benefit. My own approach to health centres on nutrition, exercise, and yoga, so I would like to have seen more on this, especially on other disciplines with which I am unfamiliar. For instance, I would like to have seen something on what traditional treatments like Traditional Chinese Medicine and ayurveda can or cannot do about hepatitis C. In addition to presentations, some hands-on demonstrations might be appropriate since many of the conferees were, like myself, HCV-positive. Perhaps these topics, like the pharmaco-economics one, will be addressed at the 3rd Canadian Conference on Hepatitis C. Of particular interest to the HCV-positive individual might be the nutrition advice given by Diana Johansen. This can also be found at: http://www.dieticians.ca/resources/HepatitisC_Guidelines.htm

Apart from a couple of caveats, the 2nd Canadian Conference on Hepatitis C was an excellent affair. In addition to the wealth of information, it was an excellent opportunity to meet and network with other people in a non-stigmatizing environment. In retrospect, I wish that HepCBC had at least a table at the conference, and

I thank Smilin' Sandi for doing double duty by distributing HepCBC materials for us as well as attending to her own responsibilities.

I look forward to the third conference and hope to remedy that omission. Finally let me remind the reader that there was much more at the conference than I could take in. It would take at least three perspectives to get a good idea of everything that transpired.

Arthur Ralfs, HepCBC

RIDING THE DRAGON

It comes in the darkness,
seething dreams, and fright!
Flies in the sunrise,
on the hard edge of night.
It clouds over spirits,
in shadows and pain!
Strangling the souls,
with Hell's winged might!
It fills up the hallways,
cries echoing through minds!
Tears blur the vision,
and cold shaking at night.
Screaming the terrors,
and in horror, we fight!
Ride hard on the waves,
no substance, or light.
Riding the dragon,
full into the pain!
Faith brings us LIFE!
This much we gain!

© Del GG

Del's Story
Originally written September 22, 2001
Last Updated January 26, 2004
http://creativeintensity.com/smking/heppers.htm#Del

At the 2nd Canadian Conference on Hepatitis C, Del Grimstad from Comox Valley, Vancouver Island, shared his personal journey on access to care and treatment, followed by a discussion on access to treatment by low income or homeless persons with HCV. Del is a married father of two and a Canadian Forces veteran, having served 20 yrs. He volunteers for NIAS as Hep C support.

(HYPERTHERMIA UPDATE—Continued from p. 1)

week. I am trying to do it once a month and taking 80 mcg. the rest of the time.

January 3, 2004

I had my fiftieth birthday today!! I just refused to give in to the fatigue and all. Bill had organized a wonderful surprise for me and had all kinds of birthday cards and messages from people. It was wonderful. Terry and Melody had our lawn plastered with pink flamingos and old buzzards as a present - it was great. We had a super day and ended it with dinner at the Cannery – we haven't been there in years. It was wonderful. I even had a glass of wine.

January 5, 2004

Had a great birthday dinner with Mom and Joan. Lots of fun. Also had another glass of wine. Joan gave me a wonderful digital camera and Mom gave me a fantastic watch. And I got flowers from both of them. Nothing like flowers to cheer you up.

Flew to Holland. I was really wiped out. The flight was late and I almost missed my connection, plus I was up for over 30 hours. Awful. Mom and Joan were at the airport, but I was too tired to even talk with them. I recovered a bit over the next few days.

I had appointments and blood work at Utrecht. Everything is going well. I am back in the study. It seems that two companies are fighting for the right to fund it. I wonder if we will ever really know what is going on.

I just got sicker and sicker in Holland. I seem to have picked up something extra.

January 19, 2004

I flew back home and got lucky with seating again – three of them to stretch out on. What a difference it makes. I wasn't quite so tired when I got home.

Things progressed as usual otherwise, but I was sick for about three weeks and can't seem to get back to normal. I saw the haematolgist again, and she is sure that my problems are not the result of the treatment. We went through my list of questions, and she had answers for everything. The best that she could give me was that the treatment could be aggravating the condition but not causing it. She did, however, agree to do a second bone-marrow biopsy to confirm the diagnosis after I have stopped treatment.

February 2004

I am feeling a little better but have had to stop the interferon again. The neutrophils have been at 0.5 or 0.6 for quite some time, and the haemoglobin is really low. I am getting worried. I am switching to the prescribed 65 micrograms of interferon, in hopes that that will alleviate the problems.

March 27, 2004

Well, I had a transfusion today. Changing doses doesn't seemed to have helped. The haemoglobin is just too low and I am so tired of being tired. The haematologist wants to put me on Neupogen to increase my neutrophils. It is very expensive, and we are trying to get it through the Cancer Agency.

April 7, 2004

I have taken my last shot of interferon and swallowed my final ribavirin capsule. Yippee!!!

I have been on treatment since March 23, 2003. That makes 54 weeks of treatment on ribavirin and 50 weeks on interferon. The standard period of treatment here is 48 weeks, so I figure I am still ahead of the game.

In that time, I had to stop the interferon a number of times, particularly during the last six weeks. (I had to stop every two weeks because my white count and haemoglobin were too low.) The liver specialist here told me that I had to take the doses that I had missed. Unfortunately, I couldn't make the last two. I even went as far as to have a transfusion to get the haemoglobin up and have been taking shots to get my white count up (at $400/week). It worked, but my blood work still showed signs of a new infection setting in, and I was so sick and weak from it all that I had to call it quits.

The virus is still not detectable, but the real tests will come at six months off the medication and again at one and two years. If I am undetectable at six months, the odds are 95 per cent that I will remain undetectable for five years. If I am still undetectable after one year, the odds are 98 per cent for a cure; at two years the odds are 99.9 per cent – assuming they know what they are talking about.

It has been unbelievably difficult and everyone has been so kind and patient. I am sure it will take awhile to feel better, but at least I can start the road to recovery. I can hardly wait to have my life back again.

***

I just want to thank everyone for their continued support. Thanks to Smilin' Sandi for her moral support and help whenever she could, and to the Dars for all the e-mails. A special thanks to Doris for all her help, and a huge hug for Vic for remaining undetectable!! I am so happy for the both of you.

Also thanks to all who helped out with meds. Thanks to Wendy for putting my message out there. The outpouring from the community was very touching. People I have never talked to or even met were willing to go out of their way to help me. You all know I couldn't have done it without you.

Most of all, thanks to my big sister, Joan. She managed over me when I was at my worst, sent out e-mails and letters, and made a million phone calls on my behalf, to say nothing of sharing her house with me for so long. And catering to the whims of a grouchy, sick person. But most of all, for the hugs and love.

I am off to Europe for three months from mid-May to the end of August. The e-mail address below will find me anywhere.

Wow!! The sun is shining today and that's good sign.

Love to everyone and lots of hugs.
Darlene Morrow
Email: Darlene@watercolour-art.com
Internet: www.hepcvsg.org or www.geocities.com/darmorr

RCMP TASK FORCE REPORT

03-22-2004

To whom it may concern:

The RCMP Blood Task Force would like to update you on the court appearances for those who were charged with criminal offences relating to the Canadian blood system.

The legal counsel for the Canadian Red Cross and Dr. Roger Perrault appeared in Hamilton on March 19, 2004 in Superior Court. Tentatively, a Pre-trial is scheduled for the first week of May. In the interim, the parties are scheduled to return to Superior Court at 10 a.m. on May 21, 2004. The Superior Court in the City of Hamilton is located at 45 Main Street East.

The legal counsel for Dr. Roger Perrault, Dr. John Furesz, Dr. Wark Boucher, Armour Pharmaceutical Company, and Dr. Michael Rodell appeared in the Superior Court in Toronto on February 10, 2004. The Superior Court in the City of Toronto is located at 351 University Avenue, Toronto, Ontario. They are scheduled to return to Superior Court at 9:30 a.m. on March 26, 2004.

The RCMP Blood Task Force will continue to provide updates relating to court appearances.

The toll free line and the web site are still available for those who wish to contact the Blood Task Force.

1-888-530-1111
www.recmp-grc.gc.ca/html/bloodtaskforce_e.(English)
www.recmp-grc.gc.ca/html/bloodtaskforce_f (French)

Sincerely,
D.O. Hvidston, Cst, BTF Liaison Officer
B.W. Fair, Insp., OIC RCMP Blood Task Force

I WAS PROUD ONCE!

I came to this country at the early age of four.
I was told it was a long and hard journey for our family
to come to this beautiful land.
I wasn't alone, Mom, Dad and three kids and one ready
to come out the door.
We came to arrive in the coldest city in the land,
however only a few years later, we were only blocks from the sand.

Both my parents were very wise, and always taught us between right and wrong.
I truly feel their strength and wisdom was also passed on.
It was fun growing up in a small town,
Dad playing guitar and Mom singing along.
I played sports like any other youth at that time,
with all my friends, Scott, Mark, Jeff, Roger, Tony and Don.

At that age, I never told my brother and sisters how much I really loved them;
we only fought and argued with one another.
I asked my Dad a long time ago, “Why do we choose the paths we take?”
He told me, “If we didn't, you, your sisters and your brother would not be here, if not for your mother.”
Then I started to understand. Life was not just about cookies and cake.

As I grew up, I started to notice some changes.
People who were classmates and friends
now started to be strangers.
I was always told by my mom not to bother.
Friends like that were not friends at all.
People are people, but they sometimes have no idea how much damage can be caused by anger.
I'm glad I got through that period of my life,
because it only prepared me for that one day to stand tall.

That day came once I marched on graduation parade and saluted my Mom and Dad.
I truly thought things would be different in the CAF Navy, but that wasn't to be as I soon realized.
But then again, I could have been sick and fatigued.
That's why I'm so sad.
I waited three years and served almost eight to only find out I would really be surprised.

Now, I find myself not knowing what will become of me, as I look to the sky.
All the symptoms were there to be found,
but under God above,
they weren't noticed and now they won't even call.
I pray for those people who hid this illness from me,
and I ask God to forgive them and not to ask why.
As you know we are all humans and live in one world,
so I pray one day we can all get along
and tear down the walls that separate us all.

A once proud sailor,
Ex-Leading Seaman Anderson TC 439
of HMSC Margaree, HMCS Ottawa, FMG Halifax & HMCS Preserver

Troy's Story
Originally written Dec. 8, 2003
Last Updated Jan. 16, 2004
London, Ontario, Canada
http://creativeintensity.com/smking/heppers.htm#Troy
tanderson007@rogers.com

Troy, 38 yrs. old, is a Hepatitis C victim from tainted blood in 1985 and has been denied military disability in spite of his military medical records indicating extremely high liver enzymes.

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 1-888-726-2656 or 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

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

Mission Hepatitis C and Liver Disease Support Group 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Contact Gina 826-6582 or Patrick 820-5576, missionsupport@eudoramail.com

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

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 Group 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/

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. Contact for info, 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) chcn.alexander@sympatico.ca http://www.canhepc.net/

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

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, Hep-SEE Chapter Contact Jeanie for information/appointment 705-735-8153 hepseebarrie@rogers.com

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 Hepatitis A Vaccine and group info

Hamilton Hep C Support Group Contact: Norman Frankum (905) 379-2072 nfrankum@hamiltonhepc.net http://www/hamiltonhepc.net/

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

Niagara Falls Hep C Support Group Last Thurs. monthly, 7 PM, 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 Contact Karyn (705) 497-3560

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

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

Trenton ON support. Contact Eileen Carlton 394-2924

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.

HepC Edmonton 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

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!

The hepc.bull needs people to summarize and "translate" articles, and HepCBC needs people to staff our office and answer phones. The HepCAN list needs a moderator trainee.

Please contact Joan at
250-595-3892 or
info@hepcbc.ca