



Special Edition

hepc.bull

BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

April 1999

Issue No. 11

Regression Of Cirrhosis, Hepatic Fibrosis In Hepatitis C Patients Possible With Interferon Therapy

WESTPORT, Jan 13 - Early-stage cirrhosis and hepatic fibrosis may be reversible in some hepatitis C patients who respond to long-term interferon therapy, according to investigators from the New England Medical Center in Boston.

Dr. Marshall M. Kaplan and others at the Massachusetts-based medical center report on two such patients in the December issue of *Digestive Diseases and Sciences*.

Both patients had early-stage (class A) cirrhosis and/or extensive fibrosis. "Neither patient had any signs of portal hypertension or of liver failure," according to the report.

After 23 and 30 months of treatment with interferon-alpha, liver biopsies in both patients revealed no evidence of cirrhosis or liver fibrosis, Dr. Kaplan and colleagues say. Both patients also demonstrated complete responses to interferon therapy, with "...normalisation of all liver function tests and disappearance of hepatitis C viral RNA."

This is not the first report of cirrhosis or fibrosis regression after appropriate therapy, the authors note. Based on their experience and that of other investigators, Dr. Kaplan and his team conclude that "...the presence of cirrhosis on a liver biopsy in a patient with chronic hepatitis C and conserved hepatic synthetic function should not be a contraindication for treatment with [interferon-alpha]."

Dr. Kaplan stressed in an interview with Reuters Health that the contraindication applies only to patients who are Child-Pugh class C and that those who are class A or B are potentially curable.

"A dogma in medicine has been that cirrhosis is not reversible and, by analogy, is therefore not treatable," he commented. "This paper is to say that this is not true."

Dig Dis Sci 1998;43:2573-2576.

ASPIRIN? THINK TWICE!

By Joan King-Diemecke

If you have cirrhosis, you may want to think twice about popping an aspirin or other NSAID. It is universally accepted that NSAIDs can have severe gastrointestinal effects and cause peptic ulcers to bleed. They may cause oesophageal bleeds, as well. According to an article (*Anti-inflammatory drugs and variceal bleeding: a case-control study*) in the February 1999 issue of GUT magazine, interviews were conducted at the University Hospital in Poitiers, France, with 200 patients with cirrhosis. Of these patients, 125 had been admitted for a first bleeding episode mainly related to oesophageal varices, and 75 patients had never had a bleed.

Twenty five percent of the patients who were admitted for bleeding had used NSAIDs during the week before the bleed. In contrast, only 8 of the 75 who had not had a bleed had used NSAIDs. Use of aspirin alone or combined with other NSAIDs was also more prevalent in the cases with bleeds (17%) than in the cases with no bleeds (4%). Analysis showed that NSAID and the size of the varices were the only variables independently associated with the risk of bleeding.

The study concluded: "Aspirin, used alone or combined with other NSAIDs, was associated with a first variceal bleeding episode in patients with cirrhosis. Given the life threatening nature of this complication, the possible benefit of this treatment should be weighed against the risk shown here. No firm conclusions could be drawn on non-aspirin NSAIDs used alone."

source: <http://www.gutjnl.com>
GUT 1999;44:270-273 (February)

Clinical Trial of VX-497

source: http://www.vpharm.com/press_rel/1998_press/21September1998-1.html

Abstract: Cambridge, Massachusetts, September 21, 1998 -- Vertex Pharmaceuticals announced today that it has begun Phase II clinical development of an investigational drug, VX-497, in patients with hepatitis C virus (HCV) infection. Vertex is expanding the scope of the VX-497 development program to explore the potential antiviral activity of the compound, in addition to developing it as a drug for autoimmune indications.

VX-497 is a potent inhibitor of inosine monophosphate dehydrogenase (IMPDH), a human enzyme that is essential for production of nucleotides—the building blocks of RNA and DNA. Blocking IMPDH may be an effective strategy for blocking the growth of certain cell types, such as lymphocytes, and the growth of viruses, because both lymphocytes and viruses depend on nucleotide synthesis for growth.

"VX-497 is a drug candidate with potential in a variety of autoimmune diseases, because of its selective activity on the proliferation of lymphocytes that orchestrate the immune response," said Vicki Sato, Senior Vice President and Chief Scientific Officer of Vertex. "In vitro experiments conducted in the past year with VX-497 have shown that blocking IMPDH also inhibits the growth of a wide variety of RNA and DNA viruses, including viruses that are closely related to the hepatitis C virus. This antiviral activity, together with the demonstrated effects of VX-497 on lymphocyte migration and proliferation,

(Continued on page 7)

REGRESSION OF FIBROSIS MAY NOT BE LIMITED TO RESPONDERS

According to Sobesky and Mathurin, (*GASTROENTEROLOGY* 116:378-386, 1999), regression of fibrosis may not be limited to responders:

"These investigators found that overall, **interferon treatment changed the natural fibrosis progression rate in patients with chronic disease independently of genotype and early response.** As Sobesky and colleagues suggest, treatment with interferon in chronic active hepatitis C should be a priority for patients with a high likelihood of progressive disease **even if they have no response, especially at 3 months.** The importance of this concept should be even more useful for the future evaluation of combination interferon and ribavirin in non-responders."

DONATION FORM

Please fill out & include a check made out to
HeCSC - Victoria Chapter. Send to:
Hepatitis C Society of Canada
Victoria Chapter
1611 Quadra St.
Victoria, BC V8W 2L5

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(A limited number of newsletters will be available free of charge at group meetings, as well.)

DISCLAIMER: Neither HeCSC nor the hepc.bull can 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 organisation.

SUBMISSIONS: The deadline for any contributions to the hepc.bull is the 15th of each month. Please contact: **Joan King-Diemecke** at (250) 388-4311, joan_king@bc.sympatico.ca, **Darlene Morrow** at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, hepcbc@home.com or **C.D. Mazoff** at squeeky@pacificcoast.net
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:
\$20 for business card size ad, per issue
There will be a maximum of 4 ads in each issue, and the ads will be published if space allows. Payments will be refunded if the ad is not published. Ads are also posted to the Web.

GASTRO '99

The Pan American Congresses of
Digestive Diseases and Endoscopy -
Vancouver, Canada -
August 30-September 2, 1999
<<http://www.lhsc.on.ca/casl/news.htm>>

COMING UP IN BC:

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

Chilliwack Contact: David, 792-3467.

Comox Valley Liver Disease Support Group
Meetings: Third Tuesday of each month, 7 PM, downstairs, Island Health Unit building. NEXT MEETING: Apr. 20th. Contact: Ingrid or Nicky, 335-1711 or Jeanne Russell ebus96@island.net

Cowichan Valley Hepatitis C Support Services is in desperate need of a meeting place. Contact: Debbie, 748-5450, dduncan@olink.net, or Leah 748-3432, r_attig@bc.sympatico.ca.

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: Apr. 25th. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Kelowna HeCSC Meetings: Last Saturday of each month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: Apr. 24th. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Nanaimo HeCSC Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Apr. 8th. Contact: Helen, 245-8759.

New Westminster Support Group Meetings: Second Monday of each month, 7:00-8:30 PM, First Nation's Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. NEXT MEETING: Apr. 12th. Contact Dianne Morrissett 525-3790.

Parksville/Qualicum 1-291 East Island Hwy, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551. dbamford@island.net

Penticton HeCSC Meetings: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: Apr. 14th. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca

Prince Rupert Contact: April, 627-7083.

Quesnel Contact: Elaine, 92-3640.

Richmond Meetings: Fourth Tuesday of each month, 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. NEXT MEETING: Apr. 27th. Contact: Carmel at Richmond Health Unit, 279-4069.

Sunshine Coast Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: Apr. 1st. Contact: Karen, 885-6413. karen_felske@sunshine.net

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: Apr. 8th. Contact: the CLF, 681-4588 or Herb, 241-7766. HMoeller@compuserve.com

Vernon HepCURE Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NEXT MEETINGS: Apr. 6th and 20th. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Vernon HEPLIFE Meetings: 2nd and 4th Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. NEXT MEETINGS: Apr. 14th and 28th. Contact: Sharon, 542-3092. sgrant@attcanada.net

Victoria HeCSC Meetings: Last Wednesday of each month, 1-3 PM and at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex) NEXT MEETING: Apr. 28th. Speaker: Dr. Yvonne Dollard, a natural health practitioner from Parksville HealthWorks. Contact: 388-4311. hepcvic@pacificcoast.net

White Rock Support Group: Meeting Room #2, Peace Arch Hospital. Contact Lisa Peterson at 538-8704.

REPRINTS

Past articles are available at a low cost. For a list of articles and prices, write to the hepc.bull, via Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, hepcbc@home.com

THANKS!!

Victoria Chapter HeCSC acknowledges the personal donations, donations in kind and memorial donations received to date, and the following for discounts, donations of services, or equipment: Monk Office Supply, CFA 1070 Radio, Apple Canada, Pacific Coast Net and Island Internet, Inc., Mid-Island Realty, Questar Holdings, Unity Business Machines Ltd., Microsoft of Canada, Jim Pattison Group, Society Press & Graphics, Paradox Computers, CompuSmart, and Camp Church. We also wish to acknowledge an anonymous agency which has generously supplied us with government surplus computer equipment. Special thanks this month to David Klein & Bruce Lemer.

Dr. Peter Bennett's HELIOS CLINIC


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Reminder: Any change of address, phone number or postal code, please let your phone contact (in Victoria) or your chapter secretary know ASAP
HeCSC Victoria Tel. (250) 388-4311
hepcvic@pacificcoast.net

Epidemiology of HCV including Minority Groups and Parenteral Transmission

From a talk given by Jean Joly, MD
MRC Notes from the HCV Conference in Ottawa on
January 15, & 16, 1999
by Darlene Morrow

The distribution of hepatitis C is global. The transmission is through blood or blood derivatives, body piercing, health-care workers, sex, transplantation, vertical, and unknown.

1. Transfusions since the 1970's—the incidence following transfusion has been variable—approximately 3%. In a Canadian study 9.2% post transfusion were positive for hepatitis C (570 participants in this study).
2. Transplantation is another effective way of transmitting the disease.
3. The most efficient method of transmission is by IVDU. Hepatitis C is much more efficient than HBV or HIV. There is a 90 percent prevalence over 5 years in IVDU. And the probability of succeeding here with prevention is very low.
4. There is poor practice used in body piercing in general. And body piercing has been around in one way or another since at least the time of Caesar.
5. Occupational transmission is through needlesticks, cuts, etc. The probabilities of acquiring infection this way is approximately 1.8%. The range is between 0 and 7 percent. A total of 200 - 300 of these infections have been looked at in a variety of studies and found that the hollow needle is associated with a much greater risk.
6. Sexual transmission is certainly a risk. Male to female transmission is 4 to 1.
7. Household contacts—a very small proportion of unrecognized HCV. Perinatal transmission does occur, but it is HIV dependent. It is between 14-23% from mother to child. This increased vertical transmission has been shown to be lower in a few small studies where birth was by Caesarian section.

I would say that the transmission of HCV is 60% from IVDU, 20% from sexual, 10% from occupational, and 10% unknown. *(We seriously question the sexual transmission statistics given here and which both Health Canada and the CDC in the USA put much lower—ed. The statistics are apparently tied to the lifestyles of the cohort)*

The incidence of HCV

British Columbia

- renografts - 3.3%
- prisons including both male and female - 25%
- male prisoners - only 40%

Alberta

- prisons including both male and female- 25.6%
- homosexual population- 6.4%

Worldwide

The highest incidence is in Egypt with 25 percent. However all studies are based on blood donors and

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NEWS FROM THE CRD, VICTORIA

1998 was the first time we have seen a drop in the number of hepatitis C cases identified in the CRD. In 1995, there were 427 cases, in 1996, 528 cases, in 1997, 624 cases, and in 1998, 572 cases were reported.

Capital Health Region's Street Outreach nurses can be accessed 7:30 to 9:30 PM at the Needle Exchange for free hepatitis A and hepatitis B vaccines for hepatitis C infected persons who are street entrenched only. Their office phone number is 384-1372, where you can leave messages. (These nurses can also help if you are taking interferon, and because of prior IV drug abuse, you do not wish to inject yourself.)

All other HCV positive persons who are Hep B or Hep A negative can access the vaccine free of charge through their family physician or probably walk-in medical centres who can order the vaccine for them. Because of sheer numbers, EDC is not administering vaccines to HCV positive persons at this time, and folks are encouraged to go through their doctors. Please note, the CRD does not hand out vaccines to people to take back to their doctors. The doctor's office must pick up the vaccine with their regular vaccine orders on behalf of patients.

CONFERENCE ON CO-INFECTION

Title: The Shifting Epidemic: HIV and Hepatitis C Co-infection

Speakers: Jenny Heathcote, James Kreppner, Martin Schechter

Moderator: Michael O'Shaughnessy
Co-sponsored by the NHRDP and the CTN.

Date: May 4th

Time: 10:30 am- 12:30 pm

Place: Victoria Conference Centre.

Mike O'Shaughnessy, of the Canadian HIV Trials Network, has agreed to provide passes for our members to attend the workshop at this conference. They are devoting one morning to Hep C and HIV co-infection. James Kreppner is a co-infected person. Dr. Heathcote is a Hep C specialist, and Dr. Schechter will be talking about the epidemiology.

If you would like tickets, you may sign up by calling the HeCSC Victoria office at 388-4311. You may leave a detailed message.

SOME CLINICAL TRIALS IN BC

(Please contact the following nurses at 604-876-5122)

1. Phase III Open—label randomized, multi-center parallel dose efficacy and safety study comparing PEG interferon alpha 2a (IFN) to an induction regimen of Roferon A in the treatment of HCV. Please contact Susan for more info.
2. A study of viral load in HCV measured at 12 hour intervals for 5 intervals before and after the start of treatment with interferon alpha 2a. Please contact Natalie for more info.
3. A study of induction consensus interferon in HCV patients with failed response to interferon alpha 2a and ribavirin. Please contact Susan for more info.
4. Treatment of chronic HCV in patients with coagulation disorder. Please contact Susan for more info.
5. Study comparison of PEG IFN alpha 2b plus ribavirin versus IFN alpha 2b plus ribavirin for the treatment of chronic HCV in previously untreated adult patients. Please contact Natalie for more info.
6. Ribavirin plus Intron A combo in non-responding or relapsing chronic HCV patients following IFN therapy. Please contact Natalie for more info.
7. A study of maintenance IFN alpha in HCV patients with an inadequate response to IFN and ribavirin. Please contact Natalie for more info.

VICTORIA VOLUNTEERS

If you are interested in volunteering to visit our sick members who are home-bound or hospitalised, please call Trish at 479-5369, or email her at plunkett@islandnet.com

We need items and books for our GARAGE SALE, which will take place in **July**. Please contact Jean Day, 370-1587.

Volunteers are needed for our Run For Life on **July 18th**. Please contact 388-4311.

URGENT: We need 20 to 30 volunteers for **RIBBON DAY**, Sunday, **May 23**, to hand out ribbons and information at the malls. Please contact 388-4311.





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 checks payable to **HeCSC Victoria Chapter**, and mail to **HeCSC, Attn. Squeeky, 1611 Quadra St., Victoria, BC V8W 2L5**. 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 check for a donation of \$2, if you can afford it. Mail to the same address as above.

Disclaimer: The hepc.bull and/or HeCSC cannot be held responsible for any interaction between parties brought about by this column.

That Dreaded Sea of Hepatitis

Peaceful, carefree, young and innocent.
We rushed to the waters, curious.
Kind, beautiful, handsome and eager.
No burdens.

Aliens? Mystery? Fate? No matter!
We surf on through this Hep Sea, fearful.
Pounding waves crash. Monster wave coming.
Nowhere to hide.

Friend in torment, struggling bravely.
Grabbed by the undertow.... stolen!
Anguished heart crying, we drift alone.
Arms empty.

Gathering to us, friends and loved ones.
Good food, hugs, and memories sharing.
Talking, comforting, hot tears stinging.
Hearts can mend.

Away this ebbless Sea waits a garden.
Trilling songbirds, and flowers wondrous.
Smiling friends with open arms, welcoming.
Peaceful rest.

...Audrey R. Knight

February 3, 1999

Tortilla-Black Bean Casserole

2 cups chopped onion
1-1/2 cups chopped green pepper
1 (14 oz.) can whole tomatoes, undrained (cut up)
3/4 cup picante sauce
2 cloves garlic, minced
2 tsp. ground cumin
2 (15 oz.) cans black beans, rinsed and drained
12 (6-inch) corn tortillas (can substitute flour tortillas)

GARNISH: (Any are optional)

1 cups shredded low-fat Monterey Jack cheese (8 oz.) or more
(can mix cheddar cheese also)
2 medium tomatoes, sliced thin
2 cups shredded lettuce
Sliced green onions
Sliced, pitted black olives
1/2 cup reduced-calorie dairy sour cream or plain yogurt

In a large skillet combine onion, green pepper, undrained, cut-up tomatoes, picante sauce, garlic, and cumin. Bring to boiling; reduce heat. Simmer, uncovered for 10 minutes. Stir in beans (rinsed and drained).

In a 9x13x2 inch baking dish, spread one-third of the bean mixture over the bottom. Top with half of the tortillas, overlapping as necessary, then half of the cheese. (You may want to use more cheese.) Add another one-third of the bean mixture, the remaining tortillas and bean mixture. You can add some cheese on top before baking. I have put the cheese on before and after, it's good both ways.

Cover and bake in a 350 degree oven for 30 - 35 minutes, or until heated through. Sprinkle with the remaining cheese. Let stand for 10 minutes.

If desired, top with tomato slices, shredded lettuce, green onion, and olives. Serve with sour cream or yogurt. Cut into squares and serve. Makes 10 to 12 side-dish servings or 6 - 8 main-dish servings.

Nutrition info: (per side dish): 232 calories, 6 grams fat, 14 mg. cholesterol, 16 grams protein, 35 grams carbohydrates, 586 mg. sodium, 7 grams fiber, RDA: 14% calcium, 18% iron, 45% vitamin C.

I have been making this casserole for years!!! Can't remember where I found it, but I sure am glad I did. Now I will tell you a few variations I've made over the years of buying the wrong ingredient or this or that. I have used flour instead of corn tortillas, have used both at once. I have used chicken in this. If you have leftover chicken breasts you've grilled, baked, or boiled, you can cut it up and add it to the bean mixture or sprinkle on one of the layers. The possibilities are endless with this one! Have fun and enjoy!

A salad that goes nicely with this is cut up cucumber, red onion, and fresh tomatoes, marinate in a good Italian dressing. Let stand for an hour or a few hours. Serve chilled with the casserole.
Anonymous

Ad No. 10

Respectful, respectable man (49) but looks younger who is very active and loves life. I'm 6' tall, 210 lbs. and considered nice looking, emotionally and financially secure and non-symptomatic. I won't let Hep C rule my life and am looking for a positive female to share a long-term happy life together. Vancouver area.

Ad No. 11

Would like very much to begin a new friendship via letters, or in person, with an HCV positive man. I am an upbeat, kind-hearted, enthusiastic female, late 40's who delights in seaside walks and derives great pleasure in nature's endless array of offerings! A good sense of humour a definite plus. BC please.



Remember when?:

* When someone talked about blue-green algae, you thought it was about pond scum, not the Spirulina dietary supplement.

* If someone mentioned Alpha-Lipoic Acid you thought it was Timothy Leary's latest experiment.

* St. John's Wort was probably what John got for not praying enough

* Interferon sounded like the name of a Klingon starship Kirk wanted to phaser out of existence.

* Phase III Clinical Studies was probably a mid-semester exam only worth cramming for and promptly forgetting.

* An "injection site" sounded like a new housing development

* A nap was a seldom available luxury, not a sometime requirement

* 12 steps was a two story house

*Bill Ruttman
Lansdale, PA
billr0003@erols.com*

Gut



Pesach

SQUEEKY'S CORNER

Since the election of our new steering committee, the Victoria chapter has become even more productive than before, and our outreach to the community has outgrown our meagre means. We are all ill with Hep, and we are all volunteers. And we are tired. So, we took the position that the national office of HeCSC should support our work and help us to expand it nationally, since no one else is providing our service. To this end, over the past few months, we sent several letters to Tim McClemon telling him clearly what we wished to do, asking for help. As has been the general policy from Toronto to Victoria for the past two years, head office ignored our request, and shelved it yet again. In fact 2 former Directors who resigned because of issues such as this have told me that 2 years ago the BOD voted to make the hepc.bull the national bulletin—but it was forgotten, as usual.

Our steering committee met to discuss this last turn of events, and we decided that you, the membership, should know what is going on, and that you should choose how you want YOUR SOCIETY to operate. Below you will find a letter from Judith Fry, Ron Thiel, David FitzGerald, Ken Crews, Jean Day, Joan King, and me David Mazoff, to Tim McClemon, in response to his non-response to our letter. Copies of our letter and the responses were sent to the Board of Directors, and to Jeremy Beaty. In that they have refused to do the honourable thing, we are bringing this matter before YOU, the Hepatitis C Society of Canada.

To Tim McClemon
Executive Director
HeCSC

From: Dr. C.D. Mazoff
Co-chair, Victoria Chapter
(for the steering committee)

This morning, Tuesday March 16th, I called you to ask why your response in writing to our telephone conversation was so evasive and non-committal.

As you remember we discussed the following issues and you agreed to each one on the phone.

1. That the bulletin would go national, that one member of the BOD would sit on the editorial committee and that using our bulk mailing permit this would save everyone a lot of money. We would get regional editors and increase the size of the bulletin, as opposed to the idea of sending out the hepc.bull as is in bulk to local areas which would then insert local information there and mail out individually.

2. I laid out a proposal for a first contact package, consisting of the most recent FAQ, a subscription to the bulletin, and our pamphlet and more. You agreed this was a very good idea. I explained the finances of the operation, how printing 100 FAQ's cost \$3.50 a unit but that printing 1000 would lower the cost to below \$2. That we would sell them for \$7 and give \$1 to Patti for each, leaving a profit of \$4. You agreed. You agreed to combine the two subscription fees (National and hepc.bull) and raise the combined fee to either \$25 or \$30.

3. You agreed to our request for a postscript laser printer (1200 dpi) and new and proper equipment for Joan who has done more than most without reward, or recognition in any tangible form from National. The quality of the bulletin is beyond question and producing it on her small monitor and clunker only makes the job harder. You agreed to honour her.

4. I laid out the details and costs of the pamphlet series, and that we have secured printers and that everything is in place. I mentioned that costs would go down from \$0.40 to \$0.10 per unit should we increase the run to a national level. You mentioned that you wanted Health Canada to look them over. Well if health Canada was so bloody concerned, why did they let the tainted blood into this country, lie to the public, not educate physicians, or produce information themselves—which is why we exist (I thought).

5. So the bottom line, in your response to our request, was more stalling. I had mentioned to you on the phone as well, how when we wanted to put the HepCAN online—a service that should have been provided a long time ago by Head Office—you balked and stalled over a measly \$90 for 9 months—and \$90 instead of \$360 because I talked the service down, not you. So, while you can't decide for however long you want, people out there walk around in darkness because of your timorousness, and the lack of action of Health Canada.

6. I also mentioned to you the necessity for coordinating strategies, and especially information technology. I reminded you that we have great expertise with computers and that we have set up a database that would better benefit our members by allowing us to trace the progress of their illness and the efficacy of treatment, as well as provide local physician contact and evaluation. You said, as usual, "great idea."

7. The point is that 2 years ago, I offered to come to Toronto and set up the computers and you refused; and my understanding is that you do not wish to share "your" information with us—just as you do not open your books to us, just as you want money from local chapters but give us NONE OF THE \$250 000 you get each year from the government. We know that it has been spent on a lot of air fare and hotel bills. Personally, I take a bus, and crash at friends. That way I can print out more bulletins.

We expect a proper response to this letter.

Dr. C.D. Mazoff
Co-Chair HeCSC Victoria
for the Steering Committee

Happy Easter

First Reply:

David:

Sorry that you don't like the letter. I don't know what else to say. I'll respond when the Steering Committee has reviewed the letter and responded. I don't react well to "demands".

Sorry,
Tim

Second Response:

David

I did not agree to any of these proposals. They are all good ideas but I do not have the ability to embark upon them because of the cost implications. I appreciate your ideas and suggestions but I cannot act upon them immediately. They need consideration by the Board because of the cost, period. If you call that stalling, then so be it. These are the constraints I work under.



Emperor Cretin

We Who Are About to Die Salute You!!



COMPENSATION WOES?

◆ Have your hospital records been lost?

◆ Do you think you contracted Hep C from Gamma Globulin shots?

◆ Contact Bruce Lemer for a free initial consultation. He may be able to help. (604) 609-6699

JOE'S STORY

Hi, I've stored up many Hep C newsletters because I had a "what's the use" attitude. Tonight I read. I read Darlene's story. I'm glad for you and your family. The thing I'm afraid to lose is the love. After a while, an ill person can drain the life's love from those around them. I work with people who have diseases that do just that—suck the life out of love—not all, but many. I don't want to be an energy drainer. I want to give. What I write here to you is my way of re-involving myself and counting my blessings.

This disease, and consequently the combo treatment (by the way, the newsletters from Darlene and Hep C really helped me fight for my rights) have left me in some despair. My first genotype was 2b. After 6 months of interferon 3 million units 3X/week and 1000 mg of ribavirin daily, I dropped from a viral load of 28 million to 350 thousand and stayed there. Then the virus must have mutated, because my genotype now is 1b. I spent 3 months more on 5 million units of interferon 3X/week with 1000mg of ribavirin daily to my final 4 months of treatment on 10 million units of interferon 3X/week and 1200 mg of ribavirin daily. That all ended in September of 1998. But my side effects continue, especially unexplained neuropathy. A 10 day prescription of Biaxin finally rid me of the rashes (developed on ribavirin) just three weeks ago.

During treatment I really thought I was going insane and eventually became quite depressed, but in a peculiar way. Not only did I have the classic incessant crying (which is not me at all), no energy, arthralgia, myalgia, and insomnia alternating with hypersomnolence (I literally would sleep 48 hours without eating and drinking), I also became very aggressive, paranoid and suspicious, and suffered what I call horrible temper tantrums. I was not fit for the company of the ones that loved me. I scared them as well as myself. Paxil, 20 mg per day, was a miracle. How I made it is beyond me. Physically, my hemoglobin dropped from 16 to 10, my WBC dropped below normal, and my platelets dropped to the point that my MD warned me to avoid physical activities, such as stair climbing and running for fear of bleeding into my joint cavities. I could not walk up steep grades without gasping for air, sometimes I literally had to get down on my hands and knees. The muscle and joint pain was almost more than I could tolerate, and would have been except for the narcotic oxycodone (percocet without the Tylenol).

Tonight, March 7, 1999, I am alive, and have energy enough to write and to fight. I just needed to flashback and remember. I think it was worth the effort, although my viral load never went below 350,000. Somewhere in all my rambling is a message of hope and of love. Although I am now beginning to suffer from the chronic fatigue that plagued me in mid-1997, before

TX CHAT FROM the [HepCAN LIST](#) Reprinted with the kind permission of Sharon Grant and Gordon Kerr

Sharon Grant wrote:

I'm looking for information again, this time on transplants

- criteria to meet for transplant
- length of time in hospital and where it is done in B.C.
- length of time laid up and at home before you can resume your life
- type of tests and drugs used post-transplant and times of these tests
- how long the new liver will work
- when it goes are you able to get replacement transplant
- what is the time frame before transplant and the tests and visits needed before you get that great PAGER.

Please send any or all information you have, and if anyone who has had a transplant and wouldn't mind telling us about, it would be great. Thanks.

Hi Sharon,

Hopefully I can help you out a bit on this as I'm on the transplant list in Vancouver. First of all, you can contact the B.C. Transplant Society at (604) 877-2100 in Vancouver, or toll free at 1-800-633-6189 from out of town. Lynn Mori is the liver transplant co-ordinator, or her secretary Cecilia may be of help.

First, your liver specialist would refer you for pre-transplant evaluation if he or she feels that your liver is compromised to the point that a transplant becomes an option. The transplant team—consisting of the clinical co-ordinator, clinical nurse, dietician, intensive care nurse, clinical psychologist, social worker, transplant surgeons, and transplant physicians—assess your condition over a period of time, in my case every three months for a year, and determine if or when you are ready to be activated on the list. You also see an ophthalmologist, anaesthesiologist, and a dentist (to minimise the danger of post transplant infection which is crucial, as the body requires immunosuppressant drugs to reduce the possibility of rejection).

Aside from the condition of your liver, other factors are taken into account. Your emotional stability is a factor, as well as the ability to follow the program. You must abstain from any alcohol or drugs of any kind, of course, and stick to the dietician's recommendations for nutrition.

treatment, I now know my enemy and that helps. My heart goes out to you Darlene, as well as to all the others who are suffering. I needed to reach out to someone who knows. I am afraid but I am a fighter, a most wonderful fighter. I want someday to be more active in a cause that really connects me to people. I've done so much wrong, it's time for doing some right.

Thanks for being there.

Joe

You must be able to have a reasonable amount of support from friends or family as post transplant you will be unable to drive to the hospital, or go to the drug store, for instance, for at least a couple of weeks (I'm anticipating a couple of months).

Transplants are done at the Vancouver General Hospital, and you are generally out after a couple of weeks. At that point you have to visit the transplant clinic daily for the first four weeks, then twice a week from the fourth week to the sixth. Beyond that visits are gradually reduced depending on your condition. The visits consist of: blood work, a visit with the clinical nurse, an examination by your transplant physician, a workout with a physiotherapist, and meeting with other members of the team.

Some of the drugs required are Cyclosporine or Tacrolimus, Azathioprine, Mycophenolate Mofetil, Prednisone, as well as others, depending on problems that arise. These drug must be taken every day for the rest of your life.

The new liver becomes infected with Hep C, and, to my knowledge, the jury is out on what to expect, although ten to twenty years seems very reasonable to expect considering the medical breakthroughs possible.

As far as getting to the hospital when your pager goes off, the Transplant Society is very accommodating. They will send an air ambulance if necessary. While waiting on the list you can go anywhere in B.C. that is within pager range, but you can't leave the province. If you visit the Island, you must contact the Transplant Society and let them know which ferries you'll be on, the license number of your car, where you can be contacted, and your general itinerary.

I've been on the list since mid-December of 98. The waiting time is from one day to approximately one year with no way to judge. It depends on getting an appropriate match (blood type and size), and the condition of others on the list in your category. In my case, I'm blood type "O+" which is very common, but it works both ways. There are more type O livers available, but more type O's waiting. The wait can be fairly gruelling. There are sometimes false alarms even to the point of getting to the hospital and being prepped and put to sleep, and the donated organ may be, for a variety of reasons, unfit for human consumption, if you will. In one instance I was called as backup for a fellow who was coming in from out of town, and they like to be sure that, if he doesn't make it in time, or is not a good size match, the organ won't be wasted. Needless to say, that was a tense day for me.

The Transplant Society has an excellent guide that is available with the answers to many questions you may have.

I hope I haven't been too long winded here, and that this has been helpful to you. Good Luck!!

Gordon Kerr
(Coquitlam)

Editor's note: Please refer to the article on transplantation in last month's hepc.bull for more information.

LETTER TO THE EDITOR

Dear Editor,

As a Hepatitis C Virus (HCV) sufferer and a former health care worker I would like to add some information from the perspective of a patient with HCV for over twenty years.

The full effects of this virus are yet to be seen in our society. Methadone clinic patients are testing positive at an alarming rate for this virus. Health care workers are not being properly monitored, and the CDC only wants new cases reported to them, yet 80% - 90% of HCV sufferers are considered chronic.

Why are Police and Fire Departments, to include paramedic rescue teams, not adequately educated about protecting themselves from this virus? What about the issues of liver transplants and organ donations? Where are the discussions concerning blood banks and the ordered 'lookback' by Health and Human Services (HHS)? Who is monitoring the mentally challenged in our State Institutions? What of the American Native population?

Who will coordinate the teaching of HCV in all the Medical Schools across the nation? The issues are broad and far reaching for my community. Many patients, to include Veterans, have been transfused with contaminated blood, or blood products, during surgery in the past. Persons infected with HCV that have never been gainfully employed can not even apply for Social Security. Those that can apply to get Social Security Disability Insurance (SSDI) are being turned down at an alarming rate.

I feel that our physicians and nurses are not yet properly trained or are provided an adequate education concerning HCV, and all the associated "side effects" that disable us on a daily basis. The symptoms and complaints are so vague that it is sometimes very hard for me, myself, to try to explain to my physician what is wrong. Many chronic patients are in pain and are told that because of their liver disease they can not be given a safe pain medication.

I thank you for this opportunity to provide some additional information to your readers.

Sincerely,

Kevin Donnelly
Captain, USAR

(EPIDEMIOLOGY—*Continued from page 3*)
are not representative of the general population.

Canada

- Three-quarters of the HCV population comes from Ontario, British Columbia, Alberta, and Quebec.
- The range is from 2.4% to 8.7%.
- The rate outside the city of Montreal is much higher than in the city core.
- IV drug use is much more prevalent within the city and we have no explanation for this observation.

While every attempt has been made to ensure accuracy, please keep in mind that these are only my notes.
Darlene

SEMINAR

"Through the Looking Glass: The Health and Socioeconomic Status of Hepatitis C Positive Transfusion Recipients, 1986-1990"

Presenters: Robert Hogg and Kevin Craib, BC Centre for Excellence in HIV/AIDS and the Centre for Health Evaluation and Outcome Sciences (CHEOS)

*12 noon -1 pm, April 15, 1999
Hurlburt Auditorium, 2nd Floor, Providence Wing, St. Paul's Hospital*

We would like to invite you to join us for another in our seminar series on health outcomes research. On Thursday April 15, 1999 at 12 noon, Dr. Bob Hogg and Mr. Kevin Craib will present new data from their study on the health status of British Columbians infected with Hepatitis C. The federal Attorney General's department commissioned this study in an effort to reflect "quality of life" data for use in court during class action compensation disputes. Lawyers on both sides of the compensation issue agreed that a survey of this nature would help establish the true health outcomes of these claimants.

Under the direction of Dr. Hogg, a telephone interview was designed to compare the quality of life of people who contracted Hep C via blood transfusions in the late 1980's as compared to people who had the same surgeries and blood transfusions but did not contract the virus. This will be our first opportunity to present this data to other researchers, policy makers and the media.

A light lunch will be served to save time for all attendees. Due to limited space, attendance is by invitation only.

If you have any questions about this event, please contact Robyn Sussel at (604) 631-5380 robyn@hivnet.ubc.ca or Sophie Geeraerts at (604) 631-5758 sophie@hivnet.ubc.ca

(VX-497—*Continued from page 1*)

suggest that this compound has the potential to contribute to the treatment of HCV infection, a disease of both viral proliferation and liver inflammation."

The Phase II clinical trial announced today is a dose range finding study designed to measure the safety and pharmacokinetics of VX-497 as a single agent in HCV-infected patients unresponsive to prior treatment with interferon alpha, a standard HCV therapy. The study will also make a preliminary assessment of VX-497's efficacy in reducing levels of serum alanine aminotransferase (ALT) and HCV viral RNA in plasma. Decreases in serum ALT would indicate an improvement in overall liver function and reduction in liver inflammation, and decreases in viral RNA would provide direct evidence of an antiviral effect of VX-497. Both measures are considered key endpoints in measuring anti-HCV activity. The trial involves 30 preselected patients, who will be treated initially for a period of four weeks. If the compound is well-tolerated, patients may be treated with VX-497 for an additional three months. Future studies with VX-497 may evaluate the compound as monotherapy or in combination with other agents for the treatment of HCV.

In addition to the current trial involving VX-497, Vertex is actively working to discover inhibitors of the HCV protease and helicase enzymes, which are critical for viral replication.

*Additional Vertex Contacts: Michael Partridge, Manager, Corporate Communications (617) 577-6108 or Justine Schultz, Corporate Communications Specialist (617) 577-6619
Vertex's press releases are also available by fax-on-demand at (800) 758-5804 - Code: 938395*

SAD STATS

At last count, as of the March issue:

- Total cost of producing and mailing the bulletin since February 1996: \$17,101.09
- Total received from subscriptions, donations to the bulletin, and ads: \$3085.70.
- Number of subscribers who are up-to-date: 103
- Number of newsletters being sent out: 960

Luckily, we receive other donations which help pay for our newsletter. I think it is important to get the information provided in the newsletter to all those who need it, perhaps especially those who cannot afford to "subscribe." If we run out of money, and we have come pretty close on a few occasions, we would be in danger of not being able to mail out that issue, other than to those who have paid. Please! If you are able to subscribe, do so. Our resources are low right now, due to printing out our transmission pamphlets and FAQs, and because of the upcoming Fun Run and HepFest Northwest.

How do you know if your subscription has run out? There should be an expiry date on your address label. If there's not, either your subscription has run out, you have never subscribed, or we've messed up. In that case, please let us know. We send you the bulletin anyway, because we want you to be informed, even if you can't contribute. If you are getting the bulletin by mistake, or if you really don't want it, please give us a call. Thanks!

Judith Fry Says:

Ribbon Day, Canada!!!

**Let's make May 23rd
National hepatitis C
Day!**



HeCSC LETTER SENT TO LAWYERS

In a lengthy, detailed letter dated March 3, 1999, and sent to the Class Action lawyers Harvey Strosberg, J.J. Camp, and Pierre Lavigne, Jeremy Beaty, Chair of the Hepatitis C Society of Canada took a strong stance, representing the views of the victims transfused between 1986 and 1990. Mr. Beaty said that HeCSC has begun a process of assessing the proposed settlement, which cannot be finalised until receiving the final proposal and more comments from the victims. In his letter, he included a list of issues and concerns from "these victims, our Board of Directors, Chapter Heads, members and other individuals," adding that they are also seeking a legal evaluation to be received before the end of March.

"It is very clear that the compensation plan was designed without due consideration for the victims who have to deal with the disease on a daily basis." ..Jeremy Beaty

Mr. Beaty included a long list of complaints and concerns in his letter, including: having to pay legal fees in making claims for benefits; PCR tests and biopsies will overload the medical system and postpone compensation; having to sign a waiver to receive the initial \$10,000 (which he states is inadequate); other actions such as the mass tort action for children and compensation for the HIV secondarily infected, will be paid out of the Fund, as well as legal fees and administrative costs; the economic impact on HCV + children has been ignored; the victims have to carry all the risk as to whether or not the fund will be sufficient; the holdbacks are unacceptable; the lack of insurance provisions; the victims don't trust the doctors to move them from one level to the next; home care will be paid out of the Fund even though it is covered under provincial health plans; and the fact that if the victim dies from non-Hep C causes, he/she doesn't qualify for death benefits.

Mr. Beaty went on to list the options that HeCSC believes should be considered in the negotiations:

- Qualify blood infected hepatitis C victims for the disabled deduction.
- Access to RRSP assets from victim or spouse, without income attribution, to pay down the mortgage.
- Access to mortgage insurance through CMHC.
- Increased child tax credit where the child is the victim or where the parent is unable to provide care due to illness.
- A defined "death benefit" regardless of cause.
- For those victims who are able to continue to

work, make income, mortgage, travel, life and health insurance programs available at regular rates. The governments would guarantee the excess mortality with a private insurer.

Copies of the letter were being made available to all members of Parliament for their consideration, the media and the HeCSC membership at large. A copy of the letter was sent out to each of the Chapters, as well.

It is felt that this letter would never have been written but for the pressure of local chapters. Keep up the good work—ed.

LABORATORY TESTING FOR DIAGNOSIS AND FOLLOW UP

By Mel Krajden, M.D.

MRC Notes from the HCV Conference in Ottawa on January 15 & 16, 1999

While every attempt has been made to ensure accuracy, please keep in mind that these are only my notes. Darlene

BC LCDC
655 West 12th Street
Vancouver, BC, V5Z 4R4
Tel: (604) 660-6044 Fax: (604) 660-0403

How good are serological tests for HCV? The antibody binds to the protein + the structural protein NS4 + the envelope.

EIA-3 is 97 percent accurate Strong EIA IB+ (IB=immunoblot) is 73 x cutoff >3x cutoff can be positive or negative.

Between April '97 and March '97, the BC CDC - 110,000. The response to the lookback was 5%. Approximately 8883 or 8.1 percent were positive. Using RIBA- 23 % were positive and of those between 85 and 95% were PCR positive. Of the 47% that were indeterminants, between 5 to 16% were PCR positive. Serology cannot distinguish between active and resolved HCV.

Samples: Serum must be separated between 4 and 6 hours or there is a nucleotide degradation. Once in individual tubes and separated, the nucleotides are stable at 4°C. for up to 4 days.

The commercial PCR test costs around \$250 Canadian. Amplicor measures between 10³ to 10⁶. Chiron - 0.2- 120 Meq/mL. bDNA 4-10 fold higher than Amplicor.

Is the HCV load stable over time?

Chiron 10-20%; Amplicor 20-40%. Reproducibility is 1-4 fold.

Clearly there is need for improved standardisation.

We must be better able to measure the anti-viral efficacy, replication, and the sustained response to therapy.

70% of what we see in BC is genotype 1.

We must have better data management. We must utilize information from public health, study populations, intervention and prevention programs, optimizing outcome programs, risk factors, and the disease itself.

Clearly, information is the key.

CLASS ACTION SUITS:

BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, BC V6B 1Z5
1-(888)-236-7797



Grant Kovacs Norell
Bruce Lemer
Grosvenor Building
930-1040 West Georgia Street
Vancouver, BC, V6E 4H1
Phone: (604) 609-6699 Fax: (604) 609-6688

Before August 1, 1986
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, BC V5Z 1K1
(604) 874-7171 or 1-(800) 468-4466
(604) 874-7180 (FAX)

also:

Dempster, Dermody, Riley and Buntain
William Dermody
4 Hughson Street South, 2nd Floor
Hamilton, Ontario L8N 3Z1
(905) 572- 6688

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

ONTARIO AND OTHER PROVINCES

Pre 1986/post 1990
Mr. David Harvey
Goodman & Carr
200 King Street West
Suite 2300
Toronto, Ontario, M5H 3W5
Phone: (416) 595-2300
Fax: (416) 595-0527

CLASS ACTION FOR CHILDREN

Poyner Baxter Blaxland
Jim Poyner or Ken Baxter
Tel. (604) 988-6321
Fax (604) 988-3632
poyner.baxter@bc.sympatico.ca

or

Siskind, Cromarty, Ivey and Dowler
Michael Eiazenga
Tel. (519)672- 2121 Local 332
Tel. 1-(800) 461-6166

TRACEBACK PROCEDURES:

INQUIRIES-CONTACT:

The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-(888) 332-5663 (local 207)

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

CLASS ACTION/COMPENSATION

If you would like more information about class action/compensation, you can contact:
Trisha Plunkett Tel. (250) 479-5369
E-mail: plunket@islandnet.com

National Compensation Hotline
Tel. 1-(888) 780-1111

Hepatitis C Society of Canada - 1999 Budget Summary

Our Response & Opinion

Victoria Chapter

One of our steering committee members has said many a time that very often a society becomes the focus of attention rather than the cause for which it was formed to fight in the first place. Reading through the budget summary we are of the opinion that this is what has happened to the Hepatitis C Society of Canada.

\$142,385 for Core expenses?--(i.e., salaries and administration). And what has this \$142K produced? A closed compensation deal? Research monies? A Cure? Treatment assistance for those driven bankrupt by HCV? Home care assistance for those not only poisoned by the government, but also abandoned? Effective national awareness and education campaigns? Obviously this amount was enough to cover the \$8,702 and \$19,081 additionally spent for Advocacy(?) and the Compensation Working Group, especially since *the majority of transfused persons have been left out of the Compensation Deal!*

\$25,861 for AGM/Conferences Where did they meet and stay, the Chateau Laurier? Then another **\$18,309** for Board Meetings! Think of all the work other chapters have done without a priddy penny from Toronto! This bulletin, FAQ documents, computer equipment, pamphlets (that actually tell you something)—none of us could even imagine what we could do with all this money, when we do all we do on a shoestring.

And perhaps, in our opinion, the most outlandish expense of all is the **\$60,036** for Chapter Development. Why was it necessary to spend this kind of money? Local chapters were and are quite capable of assisting nearby areas to set up chapters at virtually no cost. There was no need for anyone to come out from Toronto and treat us in a condescending way as if we were a bunch of kindergarten kids with no experience.

Meanwhile local chapters struggle for every penny they can raise, their members volunteer their time, we stay with other members and car pool to cut down on expenses. No grandiose hotels for our meetings, we find the cheapest place that fits our needs.

It seems to us that the society has its priorities mixed here, and the spending of thousands of dollars which could be more usefully used in other areas says more about the situation than a thousand words from us.

We are of the opinion that there should be more input from the members, on all counts, especially at the national committee level, where decisions are made behind closed doors about courses to pursue with respect to education, chapter funding, salaries and political action, without input from, or majority control by the average member. For instance: the Board is not pursuing a position wherein they are trying to identify other time periods when the Government of Canada, provincial governments or indeed any other actors in the blood system were negligent. What right had the board to accept these conditions, without consulting with those directly affected, namely those outside the so-called 1986-90 "window of opportunity?"

This is your society, so we thought you should know what is going on.

The Steering Committee
HeCSC Victoria

[Click Here
for
HeCSC Budget](#)

Date:

Dear Ms. Priddy:

As you are no doubt aware, the BC Strategy on Hepatitis Group is meeting on Monday, March 29, 1999. The Hepatitis C Community has been very patient in waiting for the government to do something constructive about this disease. We applauded the original idea of the Hepatitis Center of Excellence in 1997. Two years later we are still waiting.

The collapse of this project has largely, if not totally, been due to two problems: first, the egos of the people involved and their inability to overcome personality conflicts for the greater good of the health of their patients—the people that suffer from HCV; second, the inability of the separate organizations to work together as a cohesive unit.

This is a SHAMEFUL situation and the government must be severely chastised for allowing it to happen. It is time for you to get off of your collective butts and get this project going. We will no longer sit by and wait politely while the children bicker. Surely to goodness, it is not impossible to overcome petty differences when we are talking about the LIVES of people. These are not inanimate objects!!! They are living, breathing people. People whose qualities of lives are greatly reduced due to this disease.

This disease will cost the government and the people of this province GREATLY. Indecision and the lack of activity on your part will only increase that cost. We NEED a clinical trials network. The HIV CTN (Clinical Trials Network) at St. Paul's has offered to use its existing infrastructure to add HCV to its mandate. WE do not want to see a duplication of facilities. The money that is saved can go to further the research into HCV. In France the HIV mandate has been expanded to include HCV. The same thing should happen here. BC must take the initiative.

Two years ago, the HIV CTN put an offer on the table to begin an HCV registry. They offered to find the funding. That registry is still not operational!!!! WHY???? This registry would give us valuable information about the disease through the tracking of an infected person's disease states, treatment responses, viral loads, and so forth. This should be started tomorrow!! As well, genotyping is a critical component of effective treatment for HCV. The HIV CTN can do this genotyping. You are providing persons infected with HCV with substandard care as long as this is not done.

We want to see some action. We do not want to be placated or promised the moon. What we need and want is the best science that money can buy to help fight this disease. And we want more community representation with the BC Hepatitis Strategy Group. They have allowed us 3 members to participate after the strategy planning has been organized. We do not want a limit. We have only been allowed to have one community representative at the strategy meeting on Monday. We need more people involved at this stage. The time for you to act is now. Please intervene on our behalf and encourage the Vancouver/Richmond Health Board to open its doors to the HCV community.

Sincerely

Name:

Address:

Email:

Phone:

Friday, March 26, 1999

Dear Member:

We are at a very important crossroad and we need your help. The Center of Excellence in Hepatitis was originally proposed 2 years ago. As you know, nothing came of that. This was largely due to personality conflicts, and political BS.

Now, there is a hope for a revival of that proposal. It is now called the Hepatitis Strategy of BC and is headed by a newcomer who is thought to be politically neutral. That newcomer is Dr. Mel Kraiden from the BC LCDC. We have met with him and feel that he is working to better conditions for people with HCV.

We have asked that the Hepatitis C community be included in all phases but we are not entirely happy with the response that we have been given. We have been allowed three members to represent the community. It is not enough. We need to unite as a large group and pressure the government to act on this agenda & to get more of our community at the table.

It is very possible for several things to happen immediately. We have been working very closely with the HIV CTN (clinical trials network) at St Paul's. They offered to begin a registry on HCV 2 years ago. They even offered to find the funding. This registry would give us valuable information about the disease through the tracking of an infected person's disease states, treatment responses, viral loads, and so forth. The registry is still NOT operational. This is inexcusable.

We also need a clinical trials network—so that everyone of us can get into some kind of treatment program. The HIV CTN at St. Paul's has offered to use its existing infrastructure to add HCV to its mandate. We do not want to see a duplication of facilities. The money that is saved can go to further the research into HCV. In France the HIV mandate has been expanded to include HCV. The same thing should happen here.

Genotyping is a critical component of effective treatment for HCV. The HIV CTN can do this genotyping. As long as this is not being done, we are getting substandard care.

We would like you to send a letter to the Health Minister. We must put political pressure on the government to get moving on this agenda. We have the numbers if we can get everyone involved. So PLEASE—do your part. Let's flood the Health Minister's office with letters.

Sincerely
Darlene Morrow