

hepcBC.bull

BC CHAPTERS NEWS BULLETIN

HEPATITIS C SOCIETY OF CANADA DEC 1997

Issue No. 7

ANALYSIS/ Ribozymes Give Hepatitis-C Virus

The Ax

November 3, 1997

*Nikkei English News via Individual Inc. :
(Nikkei Industrial Daily, Oct. 30, 1997)*

TOKYO (Nikkei)--Separate research groups from the Tokyo Medical and Dental University and Osaka University have synthesized ribozymes that prevent proliferation of the hepatitis-C virus by attaching to the genetic material of the virus and cleaving it in half.

The successes suggest a type of gene therapy to treat C-type hepatitis and cirrhosis of the liver.

Ribozymes are the name given to a class of RNA molecules that act as enzymes and have the ability to cleave other strands of RNA and also DNA at specific sites.

The virus responsible for C-type hepatitis is a kind of RNA virus, which means it contains its genetic information in a strand of RNA rather than in a strand of DNA, as is most often the case. The virus infects liver cells and directs those cells to make the proteins coded by the RNA so that more copies of the virus can be assembled.

Both research groups designed their ribozyme molecules to attach to a specific site along the RNA of the hepatitis-C virus and cut the strand in half, destroying the viral blueprint for reproduction.

The Tokyo group, working in cooperation with an American team from the University of Connecticut, synthesized a ribozyme that attaches near the start of the virus RNA. When this ribozyme and simulated virus RNA are inserted into human liver cells in a 10:1 ratio, the cells produce half the amount of viral protein they would if the ribozyme were not present.

The Osaka group targeted another place on the RNA with its ribozyme. In tests this molecule reduced viral protein production in human liver cells by 70%. However, this team has not yet confirmed that the effect was due to the RNA being cut apart.

*Nihon Keizai Shimbun, Inc. -- 10-31-97
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SHARING SUCCESS

by Darlene Morrow

Three years ago I missed my first Khahtsahlano race in 6 years. That was when I first became ill. My husband refused to run the race without me, preferring to wait for me to get better.

But the next year we had to deal with the possibility that the still undiagnosed illness might not go away. And my husband ran the race without me. That was hard. Standing on the sidelines watching everyone else doing what I wanted to do. But I could barely walk for a half hour never mind run! But I felt like my life, as I knew it, was slipping away.

The next year I was diagnosed with HCV and we had to come to grips with the uncertainty of this disease. By December '96 I was forced to quit work because of the fatigue and other HCV related problems.

My life after HCV did not resemble my life before. I had to change so many things—anything to try and feel better. As I started the interferon and later added ribavirin, I decided that this disease had interfered enough in my life. Even if it was the only thing I could do in a day, I was going to start running again. And so began the slow process of building up my endurance.

I would get up to a certain level of training and then go through a bad phase with the HCV and have to stop. Weeks later I would start all over again. It became a lesson in listening to my body. Some days I could run what seemed like forever and on others I could barely squeeze out a half an hour. And on still other days I would walk or rest. But I never gave up.

On November 16 '97 I started that long awaited Khahtsahlano run—a 15km distance. I didn't care if I had to walk because I got too tired. This disease has taken too much away from my life. It was time to take something back.

As I rounded the corner and saw the finish line, I started to cry. I cried because I am not this disease. And I made it!! One small step at a time. I cried in happiness and celebration of this thing we call the human spirit. So strong. So good.

As I passed underneath the Finish sign a woman hollered to me, "Good effort!" I smiled and thanked her, thinking to myself—you don't know the half of it. :-)

Now you'll have to excuse me while I go have a nap.

COMING UP:

Victoria Chapter Meetings: Last Wednesday of each month 1 - 3 PM, and again at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex) NEXT MEETING: **NOTE: Dec. 17th.**

Kelowna Chapter Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: **NOTE: Jan. 31st**

Vancouver Chapter Meetings: Vancouver Chapter Meetings: Second Thursday of every month, 7:30pm, 5745 Wales Street, at the First Lutheran Church, Vancouver. (between Nanaimo & 42nd on Wales Street)

Penticton Chapter Meetings: Third Thursday of every month, 7-9 PM, Penticton Health Unit - Board rooms. NEXT MEETING: Dec. 18th

Kelowna Chapter Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: Dec. 27th

Nanaimo Chapter Meetings: Second Thursday of every month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Dec. 11th

Vancouver Support Group Meeting on Dec 4th, 1997 from 6 to 9 PM Heather Pavillion, C Floor - Board Room. Please enter off Heather Street.

HOW TO REACH US:

CO-EDITORS

Joan Diemecke TEL&FAX:(250) 479-5290

pdiemecke@compuserve.com

Darlene Morrow FAX:(604) 987-7396

hepcbc@sprint.ca

VICTORIA CHAPTER

OFFICE: TEL:388-4311

xx204@freenet.victoria.bc.ca

PENTICTON CHAPTER:

LESLIE GIBBENHUCK TEL:490-9054

bchepc@bc.sympatico.ca

KELOWNA CHAPTER:

ELAINE RISELY TEL:768-3573

eriseley@bcinternet.com

CASTLEGAR/GRAND FORKS/TRAIL:

ROBIN TOMLIN TEL:365-6137

NALA PAQU CHAPTERS:

RIA KLOMP TEL:248-6072

(Parksville)

TEL:752-1718

(Qualicum Beach)

gjones@qb.island.net (Gary Joneson)

HELEN HUBBART TEL:245-8759

(Ladysmith/Nanaimo)

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"I cannot afford to subscribe at this time, but I would like to receive the newsletter. I am applying for a grant." _____

"I would like to make a donation so that others may receive the newsletter without charge" _____

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

DISCLAIMER: HeCSS cannot endorse any physician, product or treatment. Any guests invited to our group 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 organization.

THANK YOU!

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. CFAX 1070 Radio, and Apple Canada.

The deadline for any contributions to the next issue of hepc.bull is Dec. 22nd. Please contact: Joan Diemecke at Tel/FAX (250) 479-5290 or Darlene Morrow at FAX (604) 987-7396, 1203 Plateau Drive, North Vancouver, BC, V7P 2J3 email: pdiemecke@compuserve.com or hepcbc@sprint.ca
 The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING:

The deadline for placing advertisements in the hepcBC.bull is the 15th of each month. Rates are as follows:

Newsletter Ads:

\$10 for 1/6th page, per issue

\$100 for 1/6th page, 12 issues (in advance)

\$20 for 1/3rd page, per issue (vertical or horizontal)

\$200 for 1/6th page, 12 issues (in advance)

whole page:

\$60 per issue

\$600 for 12 issues

1/2 page:

\$30 per issue

\$300 for 12 issues

MEMBERSHIP DESK

Memberships: There is still some confusion between being a Member in Good Standing of the Hepatitis C Society of Canada and Subscribing to the hepcBC.bull, the BC Chapters News Bulletin. The former costs \$20.00 per year and together with a completed New or Renewal Application Form is forwarded to the Toronto Office and you will then receive the National Newsletter plus an Income Tax Receipt. Our negotiating power carries more weight the more paid up memberships we have. To help you remember when it's time for Renewal on becoming a member, the expiry date appears on your Newsletter label in the box marked N/Exp: If it's blank, it means you are not a member in good standing.

If you subscribe to help get the hepcBC.bull Newsletter out each month (not the National Newsletter) and have forwarded a donation of \$10.00 or more if you can afford it, the expiry date appears in the BC/Exp: box of the label. We strive to solicit donations to help carry on our work whether you subscribe to the Newsletter or not. We do urge you to consider being a member in good standing with the Society, and many thanks to you who have become members and also subscribe to the hepcBC.bull Newsletter.

Reminder:—

Any change of address, phone number or Postal Code, please let me, your phone contact (in Victoria) or your Chapter Secretary (B.C.) know at your earliest. It saves our meagre funds. Thanks.

Jim Lodge 386-8227
 e-mail:—ut301@freenet.victoria.bc.ca
 Vice-chairperson & Membership

**FROM THE OKANAGAN**

Greetings from the Okanagan.

I was fortunate this month to do a little more traveling and hear some more of the concerns of persons infected with Hepatitis C. I know we have a gigantic task ahead of us, when I contact the B.C. Center for Disease Control and am told "there is no data to support hydrogen peroxide or bleach killing the Hep C virus." I find it unreasonable that we can access so much info on the Internet yet, our own B.C. Center for Disease Control is not aware of

any data to support (or deny) some of the questions presented.

I was promised copies of what reports they do have last Thursday, but as of the time of writing I had still received nothing.

An interesting and very descriptive book hit the press this month. It is called *Living With Hepatitis C: A Survivor's Guide* by Gregory T. Everson, M.D. and Hedy Weinberg. It supplies an interesting approach to this disease, and, as it is the first of its kind, offers lots of interesting information. Comments expressed about hydrogen peroxide killing or inactivating Hepatitis C, or that liver biopsies do not hurt have been heard, but, all in all, it is worth reading. A must for newly diagnosed! If you have trouble getting it, it can be ordered directly from the publisher at 1-800-367-2550.

I have been hearing horror stories about individuals who are headed for the poor house paying bills for Interferon. Please check out Schering Commitment to Care at 1-800-521-7157. They help anyone who cannot afford to pay for the treatment.

Roche/Roferon produces a newsletter as an educational service for patients with chronic Hepatitis C and their caregivers. It is a free subscription. For your copy call 1-888-300-PATH.

Are you aware that any person who has Hepatitis C should be immunized against Hepatitis A and Hepatitis B? See your local health unit. Hep B shots are covered but you will be responsible for the Hep A. Many have got the Hep A shots covered as well by making lots of noise!!

You should also have an annual flu shot. These are free to any persons suffering from chronic illness, as well as to immediate family members. See your public health for further information.

Do you suffer from brain fog? Lactulose has been proven to help clear your thoughts. It works to clear the ammonia from the colon, so it can not be reabsorbed in the blood.

Do you suffer from itching? I have had many tell me of the success they have found from using "Questran." It is an orange powder that calms the itching and offers relief from the inside out.

Well, it is complete, the first panel of our Hepatitis C mural, "Hands Tell the Story"! It will be displayed for the first time in Toronto at a press conference at 10:00 am Friday, November 21st, 1997. This mural is awesome—6 x 15 feet, 90

(Continued on page 8)

DAVE'S COLUMN

CANADIAN LIVER FOUNDATION

by Michele Scarborough-Cruz



U ASK

by Natalie Rock, RN, BSN
Hepatology Clinical Research Nurse
Dept. of Medicine U.B.C.

Vancouver General Hospital Div. Gastroenterology

Question: What about the flu shot for someone with HCV?

On October 20, 1993, my life took a different path from the one I had previously been taking. Today, October 29th, 1997, I took a moment to reflect upon the path I came to find myself traveling. Actually, all my thought processes were imbued with thinking about it. It's always easier to look back than it is to look forward. Hindsight is 20/20 (far different from my own!) When I came out of intensive care, only to discover that my esophagus had burst, that I was in end stage liver disease, and that it had been caused by hepatitis C, I thought my life was over. In hindsight, I realize it was just beginning, although it took over two years and a liver transplant to get comfortable with the idea.

I realize now, in retrospect, that when one door closes, another one opens, and in my case, the one that opened did so very widely, and into a world that was vastly different from the one that slammed shut on that fateful day.

Oddly enough, one of the first things I thought about was whether or not there was a support group for people with HCV. I was not to find out for another year, and it took yet another year before I became actively involved in the Hep C Society, when Dr. Powell, our founder, asked me to.

This was 3 months after my transplant, and I was still trying to understand the grave new world I was unceremoniously tossed into. As a matter of fact, I'm still trying to figure it all out, because truth only reveals itself in small doses and occasional false starts, and sometimes when you're not expecting it.

Suffering is a by-product of this disease. We all suffer to a greater or lesser degree, depending how symptomatic we are. When I was waiting for my transplant, I didn't say, "Why me?" I said, "Why *not* me?" Why should I be exempt from suffering the slings and arrows that life hurls at anything or anyone living? In retrospect, this helped me a great deal because it reduced the sense of alienation that comes from having a chronic illness. I felt a sense of connectedness to life that I had never experienced before. Words cannot really express the feeling I had, but after my transplant, those feelings were further validated when I saw how other transplant recipients responded to their disease. So does that mean suffering is good? I can't answer that question for anyone else, but in the context of HCV and liver transplantation, for myself, it didn't do any harm. The word "suffering" never entered my vocabulary, as in, "Boy, am I suffering," but suffer, I did, and suffer, we all do. Enough on this for now.

Dave Smith

Editor's note: This article is reprinted, with apologies, from the October issue because of the large number of typographical errors that appeared due to my forgetting to proofread. JKD

The CLF and the Vancouver HCV Support Group will have a joint support group meeting at the Heather Pavilion, VGH on level C in the Board Room on December 4 from 6:30-9:00 pm. This support group will be open to individuals with all types of liver diseases and the information will be available for those newly diagnosed and those with other specific questions. This first meeting will focus on the group consensus as to how they would like things structured. The facilitators will be Yvonne Kwok, a nurse specializing in hepatitis; Audrey Ostaf, and Herb Moeller, both formerly of the HeCSC Vancouver Chapter; and Guilda, the Greater Vancouver Chapter's Chair of Patient Services. Speakers will be invited once a quarter beginning January 1.

March is "Help Fight Liver Disease Month" and we are still looking for volunteers to help in both the public and corporate portions of the campaign. The more individuals we have promoting an awareness of the CLF and liver disease, the more support we will be able to provide in building long lasting educational programs and support in the endeavors of the research which really needs our dollars. Volunteer training for both components of the March campaign will commence as follows:

1. February 21—AM—Public Venue Volunteer Training. PM—Corporate Volunteer Training
2. February 28—AM—Public Venue Volunteer Training. PM—Corporate Volunteer Training

We are also looking for volunteers who would like to become trained speakers, to educate the public about liver disease and the issues facing BC communities. These individuals do not have to have had prior experience as we will be training those volunteers for these types of positions.

The Living with Liver Disease Program: Vancouver General Hospital, 7-9 pm every Monday beginning January 28, 1998—8 sessions

The very successful Living with Liver Disease Program is now going into its second year and has made great progress. Topic additions are still being made at the request of patients who have previously attended and it looks like the '98 program will be bigger and better than ever. In 1998 the program will take a look at the liver, its functions, its diseases and treatments. We will also have a seminar on viral hepatitis and treatments and research will be included here as well. Drug therapy will make up another session in combination with research methods and we will still include topics on nutrition, diet, alternative therapies, psychological aspects of illness and other related topics.

Influenza, more commonly known as the "flu," is caused by a virus that is spread through the air from person to person or by direct contact with fluids from the infected person's nose or mouth. Symptoms include fever, muscle aches, headaches, runny nose, sinus congestion, nausea, vomiting and diarrhea. Complications may arise from contracting the flu because it lowers the body's ability to fight other infections. There are some people who are more at risk of this than others, including children and seniors, or those who have a compromised immune system. As well, people who have diabetes, anemia, cancer, heart disease, lung disease, or kidney disease are at a higher risk of developing complications if they contract the flu. Statistics from the Ministry of Health report that more than 1000 Canadians die every year from influenza or its related complications.

Fortunately, there is a flu vaccine that protects against influenza viruses in up to 70% of those vaccinated independent of exposure to various strains. The vaccine should be given in November prior to the start of the "flu season" so that your body has time to develop antibodies. The vaccine requires annual revaccination to maintain protection from one year to the next. Local Health Units will provide the vaccine free of charge to those >65 years young, residents of nursing homes or chronic care facilities, persons with chronic lung, kidney, or heart disease, diabetics, those with cancer, anemia, immune deficiency (including HIV), those under 18 and on chronic aspirin therapy, household members of any of the above high risk groups, and health care workers. For those wishing to purchase the vaccine, it can be obtained from a pharmacist for approximately \$8, no prescription needed. The vaccine contains egg protein; therefore, those who are allergic to eggs or egg products should not be vaccinated.

There is no reason to believe that the flu vaccine will adversely affect patients with hepatitis C, thus there is no restriction for these patients to receive the flu vaccine. Of interest is the fact that hepatitis C may stimulate the immune system and thus actually provide resistance to the flu. As well, many patients with HCV on Interferon (an antiviral drug), have reported that while on treatment they did not get the flu.

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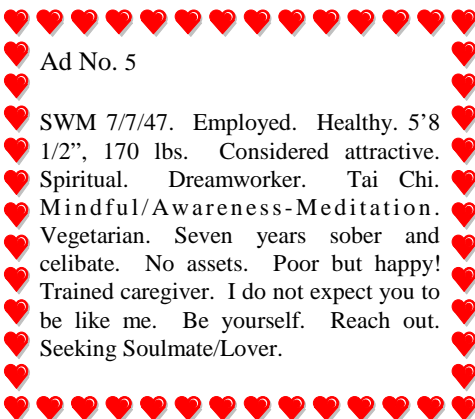
CUPID'S CORNER

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

To place an ad: Write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send checks payable to **HeCSC Victoria Chapter**, and mail to R. Hicks, Box 263-453 Head St., Victoria, BC V9A 5S1. 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: R. Hicks and/or HeCSC cannot be held responsible for any interaction between parties brought about by this column.



Ad No. 5

SWM 7/7/47. Employed. Healthy. 5'8 1/2", 170 lbs. Considered attractive. Spiritual. Dreamworker. Tai Chi. Mindful/Awareness-Meditation. Vegetarian. Seven years sober and celibate. No assets. Poor but happy! Trained caregiver. I do not expect you to be like me. Be yourself. Reach out. Seeking Soulmate/Lover.



WHAT THE HECK?

Correction:

In last month's issue of the hepcBC.bull I stated that there was now an animal model for HCV. While it is true that they have been able to infect a chimpanzee with HCV, the virus must first be bound to E. Coli to be transmitted. This is not a true and exact representation of the HCV in humans.

Darlene Morrow

SICK BENEFITS AND DISABILITY

What options are available to you when you find that you are no longer capable of working? There are two courses of action.

1. Sick Benefits- this can be through your employer and/or through the government's sick benefits from EI (formerly UI - unemployment insurance).

2. Canada Pension Plan Disability

Before you Start:

1. Your doctor must agree that you cannot work full time for you to collect either Sick Benefits or CPP Disability. Only you know how sick you really are. Your doctor will encourage you to continue working for many reasons. One of these is that depression and related problems are often seen in people that have been forced to give up their jobs. Much of our identity is bound up in what we do for a living. When we no longer contribute in that way, many people begin to doubt their self-worth. The ensuing depression can be very difficult to deal with. But, if you are sure that you are no longer able to work, present your case to your physician in a reasonable and honest way. You should be able to work together and do what's best for you.

2. Your Sick Benefits are based on the income you earned prior to applying. Many people have gone on part time instead of full time (myself included), hoping that the reduction in hours will allow them to continue working. This often doesn't work out and the individuals apply for Sick Benefits which are now based on their part-time earnings.

Sick Benefits

Your employer's Sick Benefits will usually run within a given time period. The length of time for which you are covered will depend on your employer's package. When this runs out you can apply for EI Sick Benefits. They run a maximum of 15 weeks.

Canada Pension Plan (CPP) Disability

1. Be prepared to be turned down. This seems to happen often. Only 7% of those



SQUEEKY'S CORNER

Disability: Running the Gauntlet

Fortunately, disability is not something that the majority of people with hepatitis C have to think about. Most cases of Hep C are asymptomatic, and/or many of us have just not progressed—and may never progress—to a state where our liver disease disables us. But the harsh reality is that hepatitis C is and can be a disabling disease.

My own Story

In 1994, I used to teach at a university, read and write really complicated stuff, do recreational triathlons (i.e., run 5 miles uphill in 40 minutes, or bicycle 30km an hour, etc.), body build, zoom about all day if I had to, and then spend the evenings designing some fantastic meal or plunging into some complicated discussion into the wee hours of the morning. Not exactly a party animal—but close. Now?? No More!! Nada!! Nulto!! Non! Zilch!! Gone forever.

I began to get so sick and woozy that sometimes I would get lost on streets that I knew like the back of my hand. I would need to ask people to help me get home because I felt like I had to just lie down on the sidewalk and curl up. I was too dizzy and frightened to ride a bicycle—cuz there was no guarantee if I made it somewhere, that I could make it back. My attacks of what I call wooze (which included dry mouth, aching upper back muscles, noticeable pain in the upper abdomen, disorientation, itchiness all over my body, blurry vision, diminished hearing and general disorientation and the feeling that my blood had turned to thick mud), but which doctors label "Fatigue," continued to worsen.

For me, the worst part was the **unpredictable nature** of the attacks. I never knew when they would happen. So, for instance, I might feel good for two weeks, and then when I was ready to go grocery shopping, or do my weekly cooking, I would just collapse. I could not guarantee my employer that I would be able to honour my teaching contracts (I did "faint" at work 3 times, and scared the heck out of my students and colleagues), or that I would be able to grade papers, or that I would be able to drive home.

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I was really lucky. I had really good friends who were there for me and would help me shop, or bring me over stuff to put in the microwave that I bought when I realised that I was losing the ability to cook for myself. The most important thing was that they believed in me—*because* the medical profession didn't. And the more I continued on down the path to dysfunctionality, the medical profession, in general, accused me of making it all up: basically, their position was that, yes, I had Hep C, but the symptoms I had were caused by my weird and overburdened brain. In a nutshell, I was a liar and a fraud.

My friends, many of whom, being professors and artists, and so forth, were very well respected, wrote letters on my behalf to the provincial government, which had (since I could no longer work) put me on a type of temporary medical welfare. The problem with this type of assistance, however, was that I had to do a lot of running around, fill in many many forms, and was always being cut-off without warning, and for no explicable reason. I also had letters from my neighbours and friends at the local Y, who knew me and my love of sports and who had participated with me in various "fun-runs" and other fund-raising events. I had a letter from the chair of the department where I taught at a prestigious university—13 letters in all—but the medical welfare board refused to read them and denied me a more permanent medical disability status, to the amazement of everyone who knew me!

Now don't get me wrong: If I could wake up tomorrow feeling great, or at least 50% better than I do when I get heppy, I'd be working at 2 jobs yesterday. I love to work, and I am often ashamed that I am unable to guarantee my reliability—but more on this later.

So: we went to appeal. Now the funny thing is that my own hepatologist clearly stated on one of the government forms that my illness was permanent, irreversible, and that my fatigue was debilitating. These were her words; she's a big name hepatologist back east, and nobody twisted her arm. But, the disability review board doctors ignored her analysis. I didn't know this at the time, but the people at HQ for the HeCSC told me that roughly 80% of all applications for disability are rejected first time around.

Now my hepatologist is a busy lady. She is running around 14 hours a day doing

liver transplants and lots of other really serious stuff—so filling in the same form 3 times for nothing is not something she likes to do. Besides which, she had already told them.

In the end, after almost 3 years, 2 appeals, 13 letters, and many forms, I was granted a small federal disability that nobody could really live on—but finally, and this is the big point for me, I didn't have to cope with the accusations that it was all in my head. Whoopee-doo! Some victory! I mean it's nothing to be congratulated on—know what I mean? Now I'm disabled—for real!!

But guess what? It didn't end there, no siree! Now because my federal pension was so small, I was granted a top-up by the provincial government, which was not enough to live on, and if not for friends and a very resourceful social worker (Thank you Sylvie ☺) I would not have been able to eat or afford to live anywhere. Sylvie got me into subsidised housing (actually, it was a partial-care residence for seniors; I was placed there because, believe it or not, I actually was too sick at that time to take care of myself).

Suffice it to say, these events only made me more ill. When it was all settled, I moved to BC, had to forfeit my provincial subsidies and was really worried about getting caught on another merry-go-round. Well, sumbuddy upstairs must love me, cuz, the provincial disability people here, and the doctors I saw here, and the people at the Hep C office here all helped me through the process as quickly as possible. I'm still waiting for my own housing; but I can eat and live with a great measure of dignity—which, when you're feeling rilly crappy and facing your own mortality, is a rilly important thing to have.

Talk atcha later

Squeeky

BTW: if any of you have questions about or problems with disability, don't forget to call us. After all, that's what we're here for.

HEPATITIS C AND HOME SUPPORT

Four years ago, I found out that I have hepatitis C. Since then I have not worked and I am on Income Assistance.

At various times in the past 4 years, I have required some home support. Finding out how to go about getting some



DISABILITY - OTHER OPTIONS

We don't look sick. That's rather convenient sometimes, but it can be a drag, as well. When it comes to work, for example, many of us find it hard to be able to do our normal amount of work, due to fatigue or other problems. Since we don't look sick, we have a hard time convincing our employers of the fact.

What if our employer thinks we're not really sick? That's where HeCSC may be able to help.

HeCSC, both local and national, is willing to write letters to your employer, giving him or her information about the disease and its common symptoms. A letter from your doctor is another option.

Once we recognise the problem, fatigue and other symptoms, and identify it as something that needs a solution, we may often be able to continue working, if our employer is willing to make reasonable accommodations. One possibility you might wish to discuss with your boss is getting time off for things such as interferon treatment or for days you are extra-tired. If you have a job that requires a great deal of physical activity, at some point you may wish to find out about being transferred to a more sedentary job. Another option to consider is working from home. You may be able to work out something like job sharing.

The best thing for each of us is to continue working for as long as possible. Not only does working benefit us economically, but it also promotes emotional and physical well being by confirming our place as contributing members of society. (There are rumors in other parts of the Hep C world that a person is a more favored organ recipient candidate, the longer he/she remains a member of the work force.) However, when it is no longer possible for us to work, we must believe that we have the right and obligation to rest and take care of ourselves.

Joan Diemecke

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assistance with my household duties has been trying at times, but I'm hoping that by sharing my experience in this matter and passing along the information, that other Hep C'ers will benefit and find it easier than I did.

If you are currently on Income Assistance and you need a temporary home support worker, call your Financial Aid Worker (FAW) and discuss your needs. I was required to get a letter from my doctor (I chose my specialist.) The letter had to state my specific medical condition, what specific help I required, the number of hours per week, and the duration of help needed (i.e., 6 weeks, or 2 months.)

Currently the Homemakers' Policy (in the FAW's Policy Manual) is in revision. I was told recently that the FAWs will currently follow the policies in the manual, but that in the future there will be changes.

I recently researched how to go about getting long-term care, which is handled through the Public Health Unit (on Cook St. in Victoria) Tel. 388-2230. When I spoke to Gloria at Central Intake, she gave me the following information:

A letter from your doctor(s) is required, stating what chronic health problem(s) you have. The letter(s) are looked at by someone in Central Intake, and a decision is made as to whether or not to go ahead with a referral. Once a referral is made, it is passed along to a case manager who follows with a home visit to assess each individual situation.

Long-term care deals only with personal care (i.e., bathing, dressing.) They do not deal with household duties (i.e., cleaning.) It was mentioned that if meal preparation should be required, there are 3 companies (Victoria/Vancouver) that could help with that need:

1. **Meals on Wheels** - Victoria - 385-5919
Provides - Hot lunches delivered (11-1) Monday-Friday \$4.80
Frozen meals are delivered on Fridays, as there is no weekend service.
24 hrs. notice is required.
Delivery included.
2. **Better Meals** - Vancouver (Providing meals in Victoria, too) (604) 299-1877
Provides - Frozen dinner meals \$5.25
Breakfast, sandwiches, salads, pies
Individual dinners and snacks \$2.00 to \$4.00
3. **Chef on the Run** - Victoria - 595-3151
(Providing delivery also to Brentwood Bay and as far as Parksville once a

week. There is also a store in Sidney.)

Provides - Hot meals \$6.00
Delivery is extra
Low fat; Low salt
Meals suitable for diabetics and people with heart conditions
Menus provided in Wed. edition of Victoria, Saanich & Esquimalt newspapers.

I hope that this information will be helpful to others.

Renee Whitley



TO WHOM SHOULD COMPENSATION BE GRANTED?

To debate whether some people should qualify for compensation because they have developed severe medical problems while others not qualify—even though they test positive for hepatitis C, because they do not manifest major health symptoms right now—is to deny the fact of wrongdoing on the part of those responsible for the blood supply. *Each* person transfused with tainted blood was wronged, regardless of present state of health. The real issue is, did they, or did they not, all of them, regardless of present health condition, receive blood that had not been tested, despite the fact that testing procedures were in existence at the time?

To say that some people who test positive for hepatitis C should qualify for compensation because they suffer health problems as a result, and others not receive compensation because their health is presently stable, assumes that such people *do* exist. Is hepatitis C a deadly virus, or is it not? Has it been proven that anyone can have a deadly virus like Hep C coursing through their veins with absolutely no health damage? If the immune system is continuously working to attempt to overcome the virus, is it not being compromised when run-of-the-mill infections, flus, and colds are experienced? It is quite conceivable that ordinary "bugs" are harder to eliminate from one's system if the immune system is already concentrating on a chronic virus over year after year.

Suppose that a Hep C positive person exists who suffers no ill effects and will never

exhibit any health-related problems (I'd really like to meet such a person): what about their peace of mind? They know that they carry the potential for health problems. That has to be a burden. One Hep C victim admitted that one's outlook on life changes the moment they know they are infected. They know they were a part of a cold-hearted, calculated business decision that put financial considerations ahead of the value of life. They carry proof that the blood system was not safe—which is, or should be, distressing and disconcerting to us all.

And what about some other peace-of-mind issues: contaminating family members, friends, healthcare workers, or emergency teams such as fire, rescue, police, EMT, etc., should they ever be involved in an accident? When one becomes a known Hep C carrier, public health officials ask questions with respect to sexual partners, family members, and other long-term inhabitants of the household. Obviously *they* have concerns about sexual and household transmission to ask and record such information. Shouldn't the infected person also be concerned about such possibilities? No one ever mentions the loss of freedom to married couples who must practice some methods of protecting the uninfected partner for as long as they live together.

Or how about the inability to purchase life insurance or take out mortgages, or business loans? I'd like to see lenders who would negotiate loans with those testing Hep C positive even though they presently manifest no symptoms. Lots of Hep C infected people might like to know that information in order to rush out and buy life or travel insurance, or increased health insurance or to take out a mortgage or a business loan.

To await a decision that, at some point in one's slow but certain demise, there will be some benchmark criteria to qualify for compensation, is to ride a pretty slippery slope. Reluctant compensators might be expected to increase the necessary qualifications at some future time. And, how can a well, uninfected person make a decision as to how many qualifying symptoms make one "sick enough" to qualify anyways?

Perceptions of what others think and how they react to news that one has become infected with Hep C can never be predicted in advance. One infected lady told the writer that most of her friends "hit for the hills" when they found out. The shunning which is part of human nature, even to someone who assures their acquaintances that they "feel all right," certainly exists.

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The isolation, rejection, and powerlessness associated with disease are very real.

To decide that one's illness has not yet progressed enough to qualify for compensation is to deny what, at least in North American society, is somewhat of a normal "right": to enjoy retirement. Ask anyone, as of Feb. 27, if they are not exhausted by all the RSP and retirement fund ads in the media. We have all come to "expect" (barring an "act of God," dread disease or accident), a retirement. If not at 55, because we invested early and wisely in some mutual fund, then at least by 65. No one would think that we should deny some people a retirement at, say 65, because "you'll still feel well and don't qualify for a pension until you feel sick; then we'll give you your pension." Most Hep C infected people won't make retirement age—the time our society "rewards" loyal and faithful contribution, and the time we all look forward to—or must, for investment and retirement plans to be advertised so heavily toward the end of February of each year as the deadline for contributions approaches. Someone who does not know how long (tomorrow? next year? five years?), might want to slow down and protect that precious health state and enjoy whatever time they have left.

Some to whom compensation is awarded might choose to change occupations to reduce stress (extremely hard on patients with compromised immune systems), to move to less physical labour as energy levels decrease, or to move from occupations dangerous to the liver, such as those jobs where the employee is exposed to chemicals or hazardous substances which put an extra burden on an already failing liver. Or, for those who have become unemployed because of fears by the employer that contamination of others might occur (the healthcare system or the food industry, or anywhere that infected employees are in close proximity to other employees, where the danger of casual transmission exists), those with stable health conditions might seek retraining with an education allowance.

Those whose occupation requires long-term planning, such as those who are self-employed, are put in extremely difficult positions by the news that they are infected. How does one plan for the future when one doesn't know how long that will be? The unexpected can happen to anyone, but one can *expect* the deterioration of health from the moment of transfusion with blood

tainted with Hep C.

What about the effect on family members? Of course there is stress, pain, suffering, and grief related to watching a loved one suffer and their health deteriorate. In each story of tainted blood there is the *infected*, but also the *affected*, the family. Knowing that one lives day-by-day with a deadly virus in the household is stressful. Watching the health and strength of a loved family member deteriorate is stressful. Wondering about the future is stressful. So is wondering when, and if, justice will *finally* be served. Affected families are, in some ways, dysfunctional families. Coping mechanisms must be adopted to deal with Hep C in the family. Family members take on added responsibilities, decisions, physical tasks, financial burdens, and time commitments to learn about the disease and attend medical appointments. There are changes in lifestyle, goals and priorities. That's in the "ordinary" family. In the self-employed family, especially where the major breadwinner and decision-maker is infected, healthy family members find themselves taking on ever-increasing responsibilities and duties, all the time wondering how long this can go on.

To whom should compensation be granted? Anyone who was transfused with Hep C tainted blood, regardless of present state of health. That some suffer greatly while others experience only mild health problems does not negate the fact that *all* were given "bad blood." If we say that some shouldn't qualify for compensation because their problems aren't major, we minimise the fact that someone or some agency or agencies made a conscious decision to endanger lives for the sake of bucks. To make compensation conditional is to say it was "okay" to use tainted blood.

Are Hep C sufferers seeking compensation trying to get something they don't deserve (i.e., some monetary recognition of their plight)? No. They already got what they don't deserve—a deadly virus from a blood system that failed them. Big time!

Those who think it's such a good deal—easy money, a free ride—should have gone and begged a unit of untreated, Hep C contaminated blood. Alas, it's all gone—they used it all up on unsuspecting victims who must now negotiate for compensation when they don't feel well, are dying, or just want to enjoy what time they do have left. Their health, their peace of mind,

their dignity, their sense of security, often even their friends, have been taken away. So has much of their liberty. And, eventually, so will life. Perhaps the greatest injustice of all, is the loss of the right to life, liberty, and security of the person, which are supposedly guaranteed in the Canadian Charter of Rights and Freedoms. And we want to deny some compensation for *this* loss?

Leslie Gibbenhuck



The British Columbia Transplant Society

The BCTS has a webpage on the internet at <<http://www.transplant.bc.ca>>. The website has Newsletters, FAQs, a Research Foundation, Living Donors and links to other transplant sites and medical sites of interest here in BC as well as the rest of Canada.

Although you can not sign up for the registry on the internet you can do so through the Motor Vehicle Branch or London Drugs.

The BCTS pioneered the development of regional clinics throughout the province for post-transplant ambulatory care outside the lower mainland, incorporating local resources in Victoria, Kamloops, Kelowna, Prince George, Penticton, and Trail. This minimizes the cost and inconvenience for patients and their families who are not Lower Mainland residents, but who previously had to spend lengthy periods of time in Vancouver for post-transplant treatment and care. Additional clinics are planned for North Vancouver Island and the Fraser valley.

The BC Transplant Society
 East Tower, 4th Floor, 555 West 12th
 Avenue, Vancouver, B.C. V5Z 3X7
 Telephone: (604) 877-2100
 Fax: (604) 877-2111
 Toll Free: 1-800-663-6189
 email: webmaster@BCTS.HNET.BC.CA
 Email: hepcbc@sprint.ca
 Internet: <http://www.geocities.com/HotSprings/5670>

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people turned down actually appeal. Defend your rights!! Include the decision to appeal in your personal plan.

2. You must have your doctor's backing! Be sure. You can get a copy of your file through the Privacy Act much quicker than on your own. If you go through the Privacy Act they must respond within 30 days or be in violation of the Act.

3. You must be able to prove that you can not work even 50% of the time at any kind of job whatsoever. That includes career changes to sedentary work. You must be able to say that you can do NO type of work and will never be able to. Otherwise this becomes a matter of vocational rehabilitation as opposed to a disability pension concern.

4. Be prepared for what may seem like an invasion of privacy. The Disability Form includes a page that contains your explanation of the difficulties/ functional limitations in bowel and bladder habits, personal needs, remembering, concentrating, sleeping, and household maintenance, to name a few.

Phone: 1-800-277-9914

Human Resources Development Canada,
CPP and OAS Programs, P.O. Box 1177,
Victoria, BC, V8W 2V2

Disability Benefits

FROM THE CPP INTERNET SITE
<<http://www.cpp-rpc.gc.ca/>>

A disability pension is provided to CPP participants who are unable to work due to a severe and prolonged physical or mental condition. Disability pensions are payable until age 65 (when they are converted to retirement pensions) or until recovery from the disability.

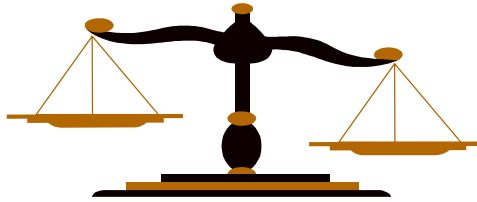
To be eligible, the person must have made CPP contributions for at least five of the last ten calendar years, or two of the last three calendar years. The chief actuary projects that payments under the disability benefits in 1996 will be some \$3.3 billion, or 17 per cent of total CPP expenditures.

The amount of disability benefit paid is based on two portions: a flat-rate portion, and an earnings-related portion, equal to 75 per cent of the retirement pension that the contributor would have received at age 65. The maximum monthly CPP disability benefit in 1996 is \$870.92.

Disabled contributor's child's benefit:
Each child of a CPP contributor who

receives a disability pension is also entitled to a benefit, as long as the child is under 18, or between 18 and 25 and is attending school full time. The monthly benefit payment in 1996 is \$164.17 (the same as the orphan's benefit). Payments in 1996 will total some \$329 million, or almost 10 per cent of CPP disability expenditures.

by Darlene Morrow



(Continued from page 2)

squares containing red and yellow hands, joined together to symbolically stop the spread of Hepatitis C. This is the same day the Krever Report will be handed to the Government. We have waited 3 long years to see the outcome of this report and hope it will contain all the answers we have been waiting for.

I will start the second mural and encourage all infected persons to become a part of this message. My dream would be to collect 300,000 hands from every infected Canadian and proudly display the magnitude of the disease. Should you want a square, an address, or further information, call Leslie Gibbenhuck, P.O. Box 21058, Penticton, B.C. V2A 8K8, Phone (250) 490-9054, Fax (250) 490-0620.

If COMPENSATION (not to be confused with litigation or class action) is to be discussed, who would you like to represent you? This question has come to mind on many occasions, and is something all transfused persons need to consider. Who would best meet the needs of all—lawyers or an organization or a combination of both?

Do you want the Hepatitis C Society of Canada to actively negotiate on your behalf, or do you think a new organization should be formed to represent B.C.? Do you want representation by persons who will be affected by these compensation decisions? Or do you have something else in mind? These are questions which need your careful consideration and we need your input. If you can let me know by mail or phone I will report back to you in the next newsletter. I believe everyone should have a say, so contact me as soon as possible. Something to think about, until next month...

Stay positive, stay well.

Leslie



ADVOCACY ANNOUNCEMENT

CLASS ACTION SUITS:

BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, B.C. V6B 1Z5
1-800-689-2322

Lemer Kambas
Bruce Lemer
Suite 1550, 625 Howe Street
Vancouver, B.C. V6C 2T6
(604) 669-4004

Before 1986 and after 1990
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, B.C. V5Z 1K1
(604) 874-7171
(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).

TRACEBACK PROCEDURES:

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.

TRACEBACK INQUIRIES

Contact:
Dr. Lisa Jeppesen, Dr. P Doyle, or Glenda
The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-888-332-5663 (local 207)