



# hepc.bull

## Canada's Hepatitis C News Bulletin

www.hepcbc.ca

### HEPCBC AGM PRESIDENT'S REPORT

Joan King

Welcome to our 3<sup>rd</sup> Annual General Meeting, and happy New Year to all of you. The year 2002 has seen good and bad.

2002 has seen the kidnapping of our website that was [www.hepcbc.com](http://www.hepcbc.com). When our contract came due, no one told us, and another company, seeing the large number of "hits" we got, registered the site in its name. We are now happily situated at [www.hepcbc.ca](http://www.hepcbc.ca).

2002 was a year of loss and change. We are all sad at the death of two very important participants in our organization: Frank Darlington, who was one of our founding members and the shining star of our last AGM, as well as Brian Brownrigg, one of our board members. David Mazoff, as many of you may already be aware has stepped down in his role as executive director, web master and phone responder. We cannot say enough positive about the Herculean effort David put forth for HepCBC. We are still looking for a webmaster. We have also lost our volunteer angel, Karolyn Sweeting, who did just about everything, from printing out labels to shopping. She has gone off to Australia. We have developed a new website, [www.hepcbc.ca](http://www.hepcbc.ca), but we have not been able to replace David or Karolyn. In spite of all these changes HepCBC has managed to forge on.

Our plans for partnering with the Capital Health Region in their projected Hep C Clinic have fallen through. It is with disappointment that I report that our finances have not permitted us to get our own office, and we are still working out of our houses, in the meantime. The Board believes that if we had an office, we could more easily enlist volunteers to help us with our workload, and resolve another vital goal: fundraising. Thanks to the generosity of people in the community, we have been able to continue to send out our educational materials by printing our materials free of charge, or at reduced rates. Since 'education' is one of the prime directives of our organization, funding to support this educational cost is a critical need.

Sharing space is almost as good as having space of our own. We have set up a small library corner in the PWA office, complete with a TV-VCR and computer. Members are welcome to visit this resource space and review videos or surf the internet using the computer.

(Continued on page 7)

### DO NOT PASS GO: DO NOT COLLECT \$200

Ken Thomson

I'm going to ask you to write a short letter or make a phone call.

Whoa!

Hang on a second. Don't jump to the next article yet.

You may be thinking, "Why bother. It's not going to make a difference." Think about this. Budgets are being decided right now. Hepatitis C is on the radar screen, but not strongly enough. Hundreds of thousands of Canadians need services and supports that they are not now getting. Are you getting the help that you need?

Do you wonder how one letter or phone call from you could possibly make a difference? The simple explanation is this: small, personal, efforts have a huge impact because most people never take the time to communicate with their elected representatives. Think about it. Of all the people you know who have a strong opinion on various government policies, how many have actually written a letter to their MLA or MP. Ask your friends, probably fewer than you think ever take the time to communicate with elected officials. Well, this is something that your representatives have thought about, and because they've thought about it, they generally regard one phone call and especially one letter

(Continued on page 7)

### CAN TICKS SPREAD HEPATITIS C VIRUS?

(HealthScoutNews) - Everyone knows that ticks spread Lyme disease. But hepatitis C virus? Scientists at the American Red Cross say they've made a circumstantial case for a tick passing the infection to a Connecticut woman who had no other obvious means of contracting the liver-damaging malady.

The woman, a health-care worker and regular blood donor, was participating in a 1999 Red Cross study of a disease called babesiosis that's transmitted by deer ticks. Blood she gave in July 1999 tested positive for that disease, but not for hepatitis C. Yet when the woman gave blood five months later, hepatitis C appeared, a highly unusual event in regular donors. An August blood sample drawn as part of the study also turned up genetic evidence of the virus upon re-examination.

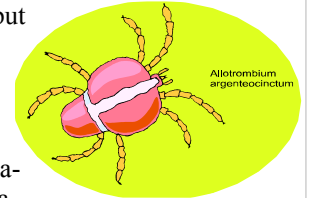
When doctors spoke to the woman, she revealed that she'd been ill in September with symptoms that were consistent with hepatitis C, including fatigue, stomach cramps, loss of appetite and dark urine.

Intriguingly, she seemed to have acquired the infection during roughly the same window of time that she also picked up babesiosis. It is known that ticks transmit at least one virus related to hepatitis C, causing tick-borne encephalitis

SOURCES: Ritchard Cable, M.D., medical director, American Red Cross Blood Services, Farmington, Conn.; Tom Schwan, Ph.D., senior scientist, National Institutes of Health, Rocky Mountain Laboratories, Hamilton, Mont.; Nov. 21, 2002, *The New England Journal of Medicine*

Source: Can Ticks Spread Hepatitis C Virus? Doctors can't find any other reason why woman got the liver disease, by Adam Marcus

<http://www.healthscout.com/printerFriendly.asp?ap=409&id=510380>



### INSIDE THIS ISSUE:

Cupid's Corner	2
Update from the CHCN	3
Treatment	5
Research	5
News	6
Warnings	8
Compensation	9
Coming Up	10

## SUBSCRIPTION/ MEMBERSHIP FORM

Please fill out & include a cheque made out to  
HepCBC - Send to:

HepCBC  
2741 Richmond Road  
Victoria BC  
V8R 4T3

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Prov. \_\_\_\_\_ PC \_\_\_\_\_

Home(\_\_\_\_) \_\_\_\_\_ Work(\_\_\_\_) \_\_\_\_\_

Email: \_\_\_\_\_

Membership + Subscription (1 year): \$20.00

Membership Only \$10.00  
(for those already receiving the bulletin):

Subscription Only \$10.00  
(for those already members of HepCBC):

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

"I enclose a donation of \$ \_\_\_\_\_ so that others may receive the bulletin."

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

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

**ADVERTISING:** The deadline for placing advertisements in the hepc.bull is the 12<sup>th</sup> 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.

## HOW TO REACH US:

EDITORS: Joan King, CD Mazoff, Ian Campsall  
PHONE: TEL: (250) 595-3892  
FAX: (250) 414-5102  
EMAIL: [jking@hepcbc.ca](mailto:jking@hepcbc.ca)  
WEBSITE: [www.hepcbc.ca](http://www.hepcbc.ca)  
HepCAN List <http://groups.yahoo.com/group/hepcan/messages>

HepCBC  
2741 Richmond Road  
Victoria BC V8R 4T3

## REPRINTS

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

## Peppermint Patti's FAQ Version 5.6 Available NOW!!

Peppermint Patti's FAQ Version 5.6 is now available in English and Spanish. The English version includes updated Canadian Links and the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only \$5 each, plus S&H—but if you can afford more, we'll take it. Contact HepCBC: (250) 595-3892, [info@hepcbc.ca](mailto:info@hepcbc.ca)

**HepCBC Resource CD:** The CD contains back issues of the *hepc.bull* from 1997-2002; the FAQ V5.6; the Advocate's Guide; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. The Resource CD costs \$10, including shipping and handling. Please send cheque or money order to the address on the subscription form on this page.

# THANKS!!

HepCBC would like to thank the following institutions and individuals for their generosity: Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Arlene Darlington and friends, Carolyn Sweeting, John Hasell, Gordon Mastine, Chris Foster, Ian Campsall, Darlene Morrow, Will Lawson, Judith Fry, Ron Comber, and Stacey Boal. Heartfelt thanks to Dr. C.D. Mazoff for his continual guidance, troubleshooting and help with technical stuff.

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



Customer support  
- 30 day money back guarantee  
- No busy signals policy  
- Multiple high-speed back bone for added reliability

e-mail: [info@pacificcoast.net](mailto:info@pacificcoast.net)  
web: [www.pacificcoast.net](http://www.pacificcoast.net)

250 380 7322 TOLL FREE 1 888 239-7172



## 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 15<sup>th</sup> of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to HepCBC, and mail to HepCBC, Attn. Joan, 2741 Richmond Road Victoria BC V8R 4T3. Give us your name, tel. no., and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

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

Looking for your dream mate?  
Your Cupid ad could go here!

**AD 24:** SWM Hep C+ Never married. No kids, 40's, living in Pt. Alberni: Seeking pen pal (female). Maybe leading toward friendship and good company. Previously incarcerated and wish to leave that kind of lifestyle behind. Good looking, 6 ft. 2 inches, 220 lbs. I enjoy music, mountain biking, conversation, walks. Private school educated.

Got Hep C? Single?  
Visit:

<http://nationalhepatitis-c.org/singles/list.htm>  
<http://clubs.yahoo.com/clubs/ontariohepcingles>  
<http://groups.yahoo.com/group/hepcingles-1/>  
<http://forums.delphiforums.com/HepCingles/start>  
<http://clubs.yahoo.com/clubs/hepcingles>  
<http://groups.yahoo.com/group/PS-Hep/>

## LETTERS TO THE EDITOR:

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



Order Your  
"Hepper Bear"  
Now!

\$20 CDN each, including postage. This is a GREAT Fundraiser for Support Groups! Call (250) 595-3892 or email [info@hepcbc.ca](mailto:info@hepcbc.ca) to place your order

## CHCN (The Canadian Hepatitis C Network) in Ottawa Dec 12 & 13 2003

*Health Canada Hepatitis C Prevention, Support and Research Program Community Consultation*

In September 1998, Health Canada launched an initiative on hepatitis C in response to the serious issue created by the growing number of individuals infected with the virus and the human suffering inflicted to these individuals. Included in this initiative was the creation of the Hepatitis C Prevention, Support and Research Program.

This initiative of a 5-year duration is now approaching its fourth year. Planning is currently underway to seek renewal for the Program and future directions. Health Canada decided that it cannot do this planning alone and for that purpose, HepCURE and the newly formed CHCN (Canadian Hepatitis C Network) joined with other Hepatitis C groups to meet with Health Canada on December 12-13 in Ottawa. The objective of this meeting was to collectively reflect on and identify priorities for the Program in a number of areas, including: Prevention, Care and Treatment Support and Partnerships.

The meeting was held at the Government Conference Centre at 2 Rideau Street, Ottawa. Durhane Wong-Rieger, CHCN's Secretariat and Bill Buckels representing HepCURE, a CHCN founding member group, distributed printed copies of CHCN's document entitled "HOW WELL HAS CANADA'S HEPATITIS C PROGRAMME SERVED THE HEPATITIS C COMMUNITY?". This document was prepared by Bradley Kane, Joan King and David Mazoff, with input from CHCN's other members. It is included in this article in its entirety.

Durhane Wong-Rieger, and Bill Buckels joined other CHCN Members including Alexander (Andy) Aitken from Quebec and Bradley Kane from BC, both representing CHCN. Susan Wish from Manitoba's HCRC (Hepatitis C Resource Centre), Scott Hemming from Nova Scotia's Hepatitis Outreach Society, and Eileen Martin from The Hepatitis C Foundation of Quebec, all CHCN Member Groups, also participated wholeheartedly.

Health Canada's Agenda laid out the two days in the form of workshops, with William D. (Bill) Murray, Senior Policy Adviser, Hepatitis C Division, Population and Public Health Branch, Health Canada opening the consultation with "Where we began and what we've accomplished - Presentation on the current status of the program" and "Mid-term evaluation - What have we learned?" Bill also acted as facilitator throughout the 2 days.

After questions and answers our workshops for the first day started with "Hepatitis C care and treatment - What needs to be done and what is the best way to achieve it?" and finished with "Hepatitis C prevention - common issues and suggestions".

Workshop Topics on the second day included "Success stories - identifying common elements", "Information sharing and partnerships", and finished with "Establishing priorities for continued programming - What are the most critical initiatives that need to go ahead?".

CHCN summarized our Key Messages when we prepared for the meeting. At every opportunity we spoke to these messages throughout the consultations. We

know Health Canada was listening, and our messages came through "loud and clear" thanks to the commitment of the CHCN Team as we participated.

### CHCN's KEY MESSAGES for HEALTH CANADA HEP C PROGRAMME CONSULTATION

#### COMMUNITY CAPACITY BUILDING

- ◆ Community-based Hepatitis C organizations have received very little money from Health Canada Hepatitis C Programme to build capacity and ensure success at obtaining program funding.
- ◆ Health Canada needs to actively support the development and effective operation of the Canadian Hepatitis C Network, to promote shared learning, sharing of resources, and support for the community, as well as ability to participate in healthcare policy.

#### HEPATITIS C CARE AND TREATMENT

- ◆ Health Canada must ensure expedited approval status for all new hepatitis drug treatments. Provinces must be put new treatments on provincial formularies, on an unrestricted basis, as soon as licensed.
- ◆ Patients have a right to early diagnosis using appropriate diagnostic tests, access to treatment of choice, and supportive care, and treatment for side effects.
- ◆ There must be active recruitment of hepatologists, training of family physicians and nurses in hepatitis C, and development of hepatitis C comprehensive care clinics.

#### PREVENTION

- ◆ Hepatitis C support groups and the Canadian Hepatitis C Network should be resourced to help develop and provide appropriate prevention education and support.
- ◆ Hepatitis C prevention, including public awareness campaigns, must be funded with the same priority as HIV/AIDS prevention.

#### SUCCESSFUL PROGRAMS

- ◆ The community-based hepatitis C support groups, the BC Collaborative Circle, the Hepatitis C Foundation of Quebec, and the newly formed CHCN are all success stories that require considerably more support from governments.
- ◆ Examples of successful programs (without government funding) include fund raising activities, publications through paper and electronic media, advocacy support, computers to network community members, and individual support. These require government recognition and funding.

#### RESEARCH

- ◆ Governments should support and encourage industry support of the Viral Hepatitis C Network and an independent Hepatitis C clinical trials network.
- ◆ Overall, the government needs to support a Hepatitis C Control Strategy, like the Cancer Control Strategy, which was developed and implemented through collaboration among researchers, clinicians, industry, governments, and support groups.
- ◆ There must be targeted research dollars for hepatitis C prevention and treatment. There must be

adequate, targeted research dollars to improve care and support of those with hepatitis C.

#### INFORMATION SHARING AND PARTNERSHIPS

- ◆ Health Canada should function as a facilitator and supporter of partnerships among the various stakeholders and service providers to the hepatitis C community.
- ◆ Community partners need to be accorded significant roles in decision making and in resource allocation as a partner in the proposed Hepatitis C Strategy.

#### COMPENSATION

- ◆ Health Canada should include all those infected with Hepatitis C through the blood supply system be included in the Hepatitis C compensation program, regardless of when they were infected.
- ◆ Health Canada should ensure that the process for providing compensation is timely and respectful of the individuals seeking assistance.

### HOW WELL HAS CANADA'S HEPATITIS C PROGRAMME SERVED THE HEPATITIS C COMMUNITY?

*Looking Back and Moving Forward  
A Position Statement Prepared for Health Canada's  
Four-Year Evaluation Consultation  
By: Canadian Hepatitis C Network*

#### What Have We Learned?

Over the past four years, the community-based hepatitis C support groups have received very little support from Health Canada's Hepatitis C Programme. The amount of money allocated to hepatitis C grassroots organizations to provide services and support to the community has been miniscule relative to the overall Programme budget and relative to the amounts given to other groups to deliver hepatitis C-related services. While we do not wish to denigrate the intentions or value of other groups, there is an undeniable need and value to supporting those groups which comprise the hepatitis C community and whose primary mandate is hepatitis C. To date, only a very small number of these hepatitis C support groups have received funding. This stands in sharp contrast to the AIDS Strategy, where the majority of community funding and the majority of groups funded are AIDS service organizations. Similarly, within the Breast Cancer Strategy, specific funds have been targeted annually toward building the capacity of the local breast cancer support groups.

While the hepatitis C community recognizes the value of increasing the ability of public health services and family physicians (two sectors that have received significant hepatitis C program funding) to serve the hepatitis C community, it was a responsibility of Health Canada to invest in capacity building of the grassroots hepatitis C community at the same level, at the same time. Clearly, unless there were moneys set aside for these initiatives, many of the newly formed support groups would not be able to compete with the more established public health groups, the AIDS service organizations, and the social service organizations.

We have learned that individuals and community-based support groups can and will do a lot on their

*(CHCN—Continued on page 4)*

(CHCN—Continued from page 3)

own, regardless of government funding, to provide education and support to the hepatitis C community. However, they do this at the expense of their personal lives and their family lives and often at the expense of their physical and financial health. They also are not able, on their own and separate from each other, to make progress on healthcare policy and to improve the healthcare environment for hepatitis C. Consequently, there has been little progress in public and social policy toward improving care, treatment and support, toward addressing employment and financial problems, and toward addressing issues of social stigma and discrimination.

Over the past four years, since the Hepatitis C Programme has been in place, we have learned that hepatitis C support groups need support, training, and development to enable them to take ownership of providing education and support to the hepatitis C community. We have learned that Health Canada has not made the necessary investments in developing the community. It would benefit the hepatitis C community, the hepatitis C support groups, provincial healthcare, and Health Canada if the community were empowered and adequately resourced. It would also assure that services are appropriate, effective, and delivered cost-effectively.

Integration of hepatitis C care, treatment and support has been a valuable strategy but it has been pursued at the expense of community development. The hepatitis C community does not want to function merely as an occasional consultant, providing input into a Health Canada hepatitis C programme; rather, the hepatitis C community wishes to be treated as a full partner in a Hepatitis C Strategy.

Health Canada needs to actively support the development and effective operation of the Canadian Hepatitis C Network, to promote shared learning, sharing of resources, and support for the community.

## HEPATITIS C CARE AND TREATMENT

### *What needs to be done and what is best way to achieve these objectives?*

There needs to be timely licensure and provincial funding of the most effective therapies. This means that the drug approval process for all new hepatitis C treatments must receive expedited drug approval status. As importantly, the provinces must be mandated (directed) to put new treatments on provincial formularies, on an unrestricted basis, as soon as licensed.

Care and treatment needs to be driven by the ultimate impact on patients and by patient choice. Patients have a right to the most appropriate treatment for their individual situation. They also have a right to have input into the treatment options—what, when, and how treatments are available. Patients have a right to supportive care and to quality of life treatment, especially those which address the mental and physical side effects of treatments.

All patients have the right to expect equal access to treatment and care, regardless of where they live, when they were infected, how they were infected, or their economic situation.

Optimal treatment of hepatitis C is good for the patients and for the healthcare system. Much more money needs to be spent to ensure there is adequate quality treatment.

The system must provide for early diagnosis and early treatment. The criteria for treatment need to be revised to make them more accessible to many more patients.

Currently, criteria prevent patients from entering treatment. They should be revised to facilitate patients getting into treatment. If it is not sure whether a patient will benefit from the treatment, the patient should be given the choice and the benefit of the doubt, rather than being excluded because there is no conclusive evidence that they will definitely benefit. The diagnostic tests must be revised; of particular concern are the requirement for a liver biopsy, which is counter-indicated for many patients, and reliance upon the outdated requirements of the liver enzyme test, which is known to exclude many with active hepatitis C from treatment.

To improve delivery of services, there must be active recruitment and training of hepatologists who will specialize in hepatitis C. There is a need to train more family physicians in the diagnosis and treatment of hepatitis C, and to make the community aware of the specialists and family physicians. The system must invest in the training and support of hepatitis C nurses and in the development of comprehensive care hepatitis C clinics.

## PREVENTION

Hepatitis C support groups should be engaged in and given adequate resources to develop and provide prevention education and support. In particular, the Canadian Hepatitis C Network should be engaged to pilot effective programs and then to implement them nationwide.

The governments must accord hepatitis C prevention the same priority as HIV/AIDS prevention. This means, in addition, funding research to determine which education and prevention methods work best. This means funding public awareness campaigns.

Prevention strategies should focus on real risk factors and not on those which are highly unlikely (for example, NOT sexual transmission). The governments should work with CHCN and the grassroots organizations to conduct research and public education to reduce the stigma of hepatitis C. This is necessary if we are to increase the likelihood of people at risk coming forward for diagnosis, testing and treatment.

## SUCCESSFUL PROGRAMS

The community-based hepatitis C support groups, the BC Hepatitis C Collaborative Circle, the Hepatitis C Foundation of Quebec, and the newly formed CHCN are all success stories that require considerably more support from governments. These are examples of what the community has been able to do on its own. They could contribute significantly more given the appropriate resources.

Programs without government funding have been successful in many ways. Groups have organized, among other things, a "Hepfest," fun runs, and concerts and silent auctions.

Groups maintain publications programs (pamphlets; bulletins, websites, email groups, FAQs). The object is to get information out to communities not being served, and to get them to be able to communicate with other communities through participation in a publication program.

In terms of an advocacy program, groups have worked with their legal services societies to produce documents for advocates and to help advocates advocate for the hepatitis C community. This has

led to forums, the Advocate's Guide, and a legal rights pamphlet.

With regard to computers, one group found, built and distributed computers to communities without these necessary resources so that these poorer communities could participate in a broader network. When possible they would provide a computer to individuals in need, shut-in's, for example, in order to mitigate their circumstances.

There is the "Hepper Buddy" program which provides a number of services, including accompanying a person to his/her biopsy, or being there for them when they first start treatment. In addition, the groups have evolved an effective hospital visiting program that takes place in sites across Canada.

## RESEARCH

Governments should directly support the Viral Hepatitis C Network and encourage industry contribution. Governments and industry should work with the community to develop and support clinical trials in all areas. It is imperative that patients and the hepatitis C community develop a research and clinical trial community, such as the AIDS Clinical Trials Network. However, it should be established and funded independent from the ACTN.

Overall, the government needs to support a Hepatitis C Control Strategy, like the Cancer Control Strategy, which was developed and implemented through collaboration among researchers, clinicians, industry, governments, and support groups.

There must be targeted research dollars for hepatitis C prevention and treatment. Similarly, we need to ensure adequate, targeted research dollars to improve care and support of those with hepatitis C.

It is important that governments (Health Canada and provincial health ministries) create a climate that is favourable to industry investment in research on hepatitis C (like HIV/AIDS, arthritis, and cancer), whereby research investments leading to treatments are supported by expeditious government licensure and formula funding of treatments.

## INFORMATION SHARING AND PARTNERSHIPS

Health Canada's role is not to be the keeper or conduit of information, nor the center or creator of partnerships (that are exclusively with Health Canada); rather, it would more appropriately and effectively function as a facilitator and supporter of partnerships among the various stakeholders and service providers to the hepatitis C community.

The Hepatitis C Programme/Strategy should be based and managed through genuine partnership between governments and the grassroots hepatitis C community. Community partners need to be accorded significant roles in decision making and in resource allocation. In short, the role of the hepatitis C community is not just to provide "input to Health Canada" but to have a joint role in planning and decision making, with appropriate accountabilities.

Bill Buckels, Director,  
HepCURE  
(Hepatitis C United Resource Exchange)  
Box 195, Armstrong, BC V0E 1B0  
<http://hepcure.junction.net>

*Living With Hepatitis C For Over 30 Years  
Rebetron Treatment Treatment Survivor and Responder; PCR Negative*

## RESEARCH

### Is a Biopsy Necessary?

#### 1. Prometheus Laboratories Introduces Non-Invasive Test for the Detection of Liver Fibrosis

SAN DIEGO, Oct. 31 /PRNewswire/ -- Prometheus Laboratories Inc., announced that it is introducing FIBROSpect(SM), a new non-invasive approach to help detect liver fibrosis in patients with chronic hepatitis C

FIBROSpect(SM) measures three biological markers associated with the development of liver fibrosis. The markers are used to help physicians differentiate patients who have no or mild liver fibrosis from patients who have significant liver fibrosis.

Presently, the "gold standard" used to determine the extent of liver fibrosis in patients is a needle biopsy. Liver biopsies are invasive, costly and can be associated with a number of painful or severe complications.

Prometheus Laboratories Inc. is a specialty pharmaceutical company committed to developing new ways to help physicians personalize patient care. The Company's focus is on treating diseases and disorders associated with the gastrointestinal tract, as

well as autoimmune and inflammatory diseases such as rheumatoid arthritis.

Prometheus' corporate offices are located in San Diego, California. Additional information about Prometheus Laboratories can be found at [www.prometheuslabs.com](http://www.prometheuslabs.com).

Source: <http://www.prnewswire.com>

#### 2. More tests! To Replace the Liver Biopsy

These tests are used before transplant to tell the doctors exactly what % (percent) liver tissue is still functioning (in whole liver not just a spot).



Xenobiotic-based quantitative liver function tests:

1. Caffeine clearance-A
2. Indocyanine green clearance - IGC -(detects early cirrhosis)
3. Galactose - estimates functional liver mass
4. Aminopyrine breath test - results correlate severity of cirrhosis
5. Monoethylglycinexylidide Formation (MEGX Test) - differentiate between cirrhosis and non-cirrhosis

Source: HepCure [www.junction.net/hepcure](http://www.junction.net/hepcure)

### Misoprostol for Cirrhotic Patients

Researchers in Italy conducted a study of long-term misoprostol therapy in patients with cirrhosis. Their findings were reported in the July issue of the *Journal of Hepatology*. *J Hepatol* 2002; 37 (1): 15-21

Some 10 patients with advanced cirrhosis were studied in paired experiments, before and 30 to 50 days after oral misoprostol therapy.

The authors found that functional hepatic nitrogen clearance slightly increased and that amino acid- and ammonia-N did not accumulate in plasma. Furthermore, no systematic effects on insulin and glucagon were observed.

Giampaolo Bianchi, of the University of Bologna, concluded on behalf of fellow colleagues, "Data are consistent with a nitrogen sparing mechanism of misoprostol, not mediated by hormone levels.

"These effects may be beneficial in clinical hepatology, and need to be tested in controlled trials."

<http://www.gastrohep.com/news/news.asp?id=1373>

## TREATMENT

### Epoetin alfa (Procrit) for combination therapy.

Combination therapy with interferon alfa and ribavirin, or pegylated interferon alfa and ribavirin, is known to have serious adverse side effects necessitating dose reduction, which in turn reduces the effectiveness of the treatment. In particular ribavirin dose must sometimes be reduced due to anemia (reduced hemoglobin levels). The present interim study indicates that weekly treatment with epoetin alfa raises hemoglobin levels so that ribavirin dosage can be maintained. In addition patients report improved quality of life in terms of improved physical and mental vitality.

### Interferon Risk Factors: Neutropenia? Watch Your Black

Neutrophils are white blood cells making up a major part of the human immune system. They are responsible for the initial response to invading pathogens. Neutropenia is the condition of having a lowered number of neutro-

phils and can therefore result in an increased risk of infections. This is of concern in combination therapy for hepatitis C with interferon alfa and ribavirin because interferon is known to cause a decrease in neutrophil counts and low neutrophil counts have been used to deny or discontinue interferon therapy. The present study indicates that, although neutropenia is common during therapy, it does not usually lead to increased infections. The study also looked at people with pre-existing neutropenia, common among black hepatitis C sufferers, and concluded that further reductions in neutrophil counts are minimal. In conclusion neutropenia does not appear to be a valid reason for denying therapy.

*Neutropenia during combination therapy for hepatitis C (Hepatology, 36, 1273-1279, 2002)*

### Comparison of rifaximin and lactitol in the treatment of acute hepatic Encephalopathy

A study published in the January issue of the *Journal of Hepatology* (*J Hepatology*

2003; 38(1); 51-8) assessed the efficacy and safety of rifaximin, compared to lactitol, in the treatment of acute hepatic encephalopathy.

A total of 103 patients with grade I-III acute hepatic encephalopathy were randomized to receive rifaximin or lactitol for 5 to 10 days. Researchers measured changes in the portal-systemic encephalopathy (PSE) index on entry, and at the end of the study, to evaluate the efficacy of the 2 therapies.

While the team found that the global efficacy of both therapies was similar, the percentage of patients showing improvement or episode regression was 82% in the rifaximin group, and 80% in the lactitol group.

Dr Antoni Mas's team concluded, "Rifaximin may be considered a useful and safe alternative therapy to lactitol in the treatment of acute hepatic encephalopathy in cirrhosis."



[www.gastrohep.com/news/news.asp?id=1746](http://www.gastrohep.com/news/news.asp?id=1746)

## Extrahepatic Disorders Tied to Hepatitis C

There is a significant link between hepatitis C virus (HCV) infection and several skin, renal and haematologic disorders, a massive study in the United States has found.

Of specific concern are porphyria cutanea tarda (PCT), lichen planus, vitiligo, cryoglobulinemia, membranoproliferative glomerulonephritis (GN) and non-Hodgkin's lymphoma (NHL).

Patients with any of these conditions should be tested for HCV infection, urge these researchers from The Houston Veterans Affairs Medical Center and Baylor College of Medicine, Houston, Texas.

In this hospital-based study, doctors reviewed the cases of 34,204 HCV-infected patients hospitalised between 1992 and 1999 and 136,816 randomly chosen controls without HCV and matched with cases by year of admission.

Although HCV has been associated before with several extrahepatic conditions, until this one, most studies have involved small numbers of patients and lacked a control group.

These authors used the computerized databases of the US Department of Veterans Affairs.

### Findings:

A significantly greater proportion of patients than controls had PCT, vitiligo, lichen planus and cryoglobulinemia, and there was also a greater prevalence among patients of membranoproliferative GN but not of membranous GN.

Although there was no significant difference between the two groups in prevalence of thyroiditis, Sjogren's syndrome or Hodgkin's or NHL, NHL became significant after the researchers took age into account.

Diabetes was found to be more prevalent in controls than in cases, but there was no significant link after age was considered. Hepatology 2002 Dec;36(6):1439-45. "Extrahepatic manifestations of hepatitis C among United States male veterans."

Source: *Specific Extrahepatic Disorders Tied To Hepatitis C In Large Study A DGReview of: "Extrahepatic manifestations of hepatitis C among United States male veterans."* 12/06/2002 By Anne MacLennan [www.doctorsguide.com](http://www.doctorsguide.com)

## Liver Dialysis Appears Effective for Refractory Hepatic Encephalopathy

Nov. 2, 2002 (Boston) -- Patients with episodic type C hepatic encephalopathy who fail to improve despite 24 hours of standard medical therapy may be able to benefit from charcoal-based hemodialysis using a liver dialysis unit (LDU), report researchers from Loma Linda University Medical Center in California

at the 53rd Annual Meeting of the American Association for the Study of Liver Diseases.

In a prospective study of 18 patients with episodic hepatic encephalopathy (EHE), 16 showed significant improvement in mental status within two days.

"Liver dialysis is a completely artificial device that utilizes charcoal to selectively bind toxins that build up in the setting of liver failure," Dr. Hillebrand told Medscape. "It combines some kidney dialysis-type mechanisms with the liver dialysis?. It uses a membrane to keep the charcoal solution separate from the patient's blood, which improves the compatibility of the machine."

The treatments appeared to be well tolerated, and mental status improved in the majority of patients. There were no significant improvements, however, in measures of liver function or Model for End-Stage Liver Disease (MELD) scores.

Dr. Hillebrand told Medscape that although it's still unclear whether charcoal-based hemodialysis using LDU can reduce viral burden in patients with advanced hepatitis C infections, "the most important thing we've learned is that detoxification works?. If you can detoxify these critically ill cirrhotic patients, you can improve the encephalopathy and you can improve the organ failure. We're taking what we've learned from this experience and are developing a new and what we think will be a better machine."

AASLD 53rd Annual Meeting: Abstract 100249. Presented Nov. 2, 2002. Reviewed by Gary D. Vogin, MD

Neil Osterweil is a freelance writer for Medscape.

Source: [www.medscape.com/viewarticle/443936\\_print](http://www.medscape.com/viewarticle/443936_print) Medscape Medical News 2002. Neil Osterweil

## Spinal Cord Injury

2002 DEC 2 - (NewsRx.com) -- by Sonia Nichols, senior medical writer

The prevalence of hepatitis C virus (HCV) infections among people with spinal cord injuries may be higher than suspected.

Researchers from several institutions in California recently completed a study indicating HCV prevalence among patients with spinal cord injury is higher than in the general population.

Over 50 spinal cord injury patients who received care at an urban rehabilitation center in California participated in the government-funded study.

According to Tse-Ling Fong, Rancho Los Amigos National Rehabilitation Medical Center, Downey, California, doctors per-

formed routine evaluations of each patient that included tests for HCV serum markers and liver enzyme levels.

"Seventeen percent of the cohort was anti-HCV reactive (HCV positive)," said Fong and colleagues.

Among patients who had spinal cord injuries before 1990, HCV prevalence was 21%, whereas among those injured after 1990, HCV prevalence was 7%. Investigators noted that the period in which injury was sustained, in addition to patient age, were the sole risk factors for demonstrating HCV positivity.

Given a high HCV prevalence among the spinal cord injured and the possibility that liver enzyme levels can remain normal in the HCV-infected, practitioners should consider checking for HCV infection in patients with spinal cord injury, Fong and colleagues indicated.

Source: *Hepatitis C Risk Factors High prevalence of hepatitis C virus detected among spinal cord injured* [www.newsrx.com](http://www.newsrx.com)

## Roche Rolls Back Prices

NUTLEY, N.J., Jan. 13 /PRNewswire/ -- Roche announced that Copegus(TM) (ribavirin, USP), the medication used in combination with Pegasys(R) (peginterferon alfa-2a) for the treatment of chronic hepatitis C, is being introduced with a list price or wholesale acquisition cost that is 43 percent less per milligram than the other available brand of ribavirin. Copegus will be available in U.S. pharmacies beginning the week of January 13. The list price or wholesale acquisition cost for Copegus is \$5.06 per 200mg tablet. **For patients prescribed 1200mg of ribavirin per day, there is a list price or wholesale acquisition cost savings with Copegus of approximately \$7,600 for 48 weeks of therapy.**

Pegasys and Copegus combination therapy was approved by the U.S. Food and Drug Administration (F.D.A.) on December 3, 2002, for adults who have compensated liver disease and have not previously been treated with interferon alpha. An estimated 2.7 million Americans are chronically infected with hepatitis C.

"Roche is very proud of the steps the company has taken to drastically reduce the cost of combination therapy for the millions of Americans chronically infected with hepatitis C," said George B. Abercrombie, Roche President and Chief Executive Officer. "With Pegasys and Copegus, physicians and patients can have confidence knowing that this therapy is backed by an unprecedented development program -- the most extensive ever conducted in hepatitis C."

(AGM—Continued from page 1)

We have survived the past year, and the *hepc.bull* continues to be published monthly and sent to about 700 people. Our website receives an average of 50,000 hits a month. Peppermint Patti's FAQ and one of our pamphlets were translated into Spanish. Our pamphlet series is still growing, albeit slowly. We have taken steps to reach out to the aboriginal community. We have been granted 2 practicum nursing students to help with our efforts toward public education, and hope they can help us with an awareness campaign, for which we have developed a power point program. We took part in the Volunteer Fair at Hillside Mall, and made a display board for that. We have replaced the Ladies' and Men's groups with quarterly general meetings. We took part in the organization of the May 1<sup>st</sup> Hepatitis Awareness Day activities at the Legislature.

2002 has seen the important advent of the BCHepC Circle, and its two conferences, in Nanaimo and in Vancouver, for which HepCBC is at least partially responsible. We are the proud Agency of Record for the Circle, which represents most of the Hep C groups in BC.

We still belong to Volunteer Victoria, who sent us Karolyn Sweeting. Did I say we miss her?

Our Info Line has taken care of numerous requests, through which we meet the needs of the community by mailing out copies of medical articles to Hep C patients so that they may learn more about the disease, or show their doctors, to help educate them. We have partnered with CLF in presenting their Living with Liver Disease program.

We have approximately 97 paid-up, registered members, and 10 associate members, and have had about 45 volunteers, not all of whom are members. About 10 of them are regularly active. We have 158 up-to-date paid subscribers to the *hepc.bull*, and many more who have asked to receive the bulletin free of charge, since they don't have enough money to pay for a subscription. We have 110 email subscribers, as well. Many others read the bulletin on our website, or receive copies of it from their local support group. As I said, there have been an average of 50,000 hits to the website and no doubt many of these visitors are checking the *hepc.bull* or other info at the website.

Thanks to the pegylated interferon treatments, more and more people are responding to treatment, but there are still many non-responders out there, and the vast majority who do not qualify for treatment, or cannot tolerate treatment or choose to not be treated. Schering's product is now approved, but Roche's Pegasys is not yet sold in Canada, although it has been approved in the US. Many people have not responded to Schering's products and may have a better chance with another product. For those not eligible for clinical trials, treatment is extremely expensive, running thousands of dollars a month. We must advocate for the approval of other treatments.

Our Board desperately needs more members, especially some with fundraising experience and community connections. David Mazoff, our executive director, as I said, has stepped down, and is only minimally involved. We have had a couple

of people come by, interested, but perhaps it is the reduced Board, that scares them away. Please consider being a Board member yourself of encouraging a relative or friend to participate.

Next on the NEEDS list immediately following the need for Board members is the need for funds.

We are in desperate need of funding, and help with grant applications. We were honored to receive approximately \$92,000.00 over a period of 3 years, but that money is destined for the Hep C Circle, so none of it can really be used for local expenses, such as rent or the newsletter. We received \$8000.00 from the Legal Aid Services last year, but had to return it because of the changes in legislation. Each bulletin costs approximately \$1.00 to print and mail. We send out 11 issues a year and we would like to be able to send out at least 700 copies to the people on our database. Last month, we could only send out 350. Last year, the bulletin was printed with the help of a \$5000.00 grant from Roche Pharmaceuticals. As you can see the grant has been used up. In order to ensure continued publication, there needs to be a steady infusion of enough money to cover the cost of sending the bulletin out to everyone on our database. At this time, we are scrambling to cobble together enough to mail out the next issue. This last mailing of the January issue had to be a reduced one: paid subscribers only. Does anyone have a real solution to this shortfall? The idea of raising subscription rates is one possible but it does seem unfair when so few are subsidizing the publication. If you think we pay too much to produce each issue I would like to assure you that we get a very reasonable printing price through a supportive Kiwanis member.

In the past we have had a musical event as a fundraiser. To put on such an event takes incredible coordination and effort—another reason why more actively involved Board members are essential. In 2001, HepCBC raised about \$5500 that way.

On a positive note, we now have charity status. We had a somewhat successful Christmas Donation Campaign. Remember those green letters in your newsletters last month? That raised \$345.00 from 9 donors, so far.

We have a couple of new pamphlets and we need help distributing these, as well as the old ones.

We have updated the FAQ to version 5.6, and I invite you to view this edition at the display table. Donations of a minimum of \$5.00 are strongly suggested, but it is felt that they are such a valuable resource that no one should be denied, so don't be afraid to speak up if you've left your wallet at home.

We still have had a subscription donated to us from the medical journal *Gastroenterology*, *Hepatology*, and *The New England Journal of Medicine*. These are available in our library at the Victoria Persons with Aids office.

Our goals for the future include the production of more pamphlets and books, volunteer training and coordination, information seminars, and the development of a fundraising plan. My personal goal continues to be finding a cure for hepatitis C.

This concludes the annual report and update of affairs at this point in time. Thank you for listening. Are there any questions?

(Do Not Pass Go—Continued from page 1)

as representing the wishes of a much larger group of people. It is ironic, but true: while every vote counts, every letter and phone call gets counted more, because recipients assume that for each person who takes the time to write, there is a large community of people who feel the same way, but simply don't take the time to express themselves.' (paraphrased from an article by Kaethe Morris Hoffer)

If our community doesn't care enough to make this small effort, the epidemic really will remain silent. Let them know what is important to you. Is it education, support, community care, access to treatment, disability benefits or ???

If you have web access check out the 'briefing document' at [www.casper.ca/hepcircle](http://www.casper.ca/hepcircle) for background info and ideas. You can find your MP or MLA contact info at [www.nelson.com/nelson/polisci/legislatures.html](http://www.nelson.com/nelson/polisci/legislatures.html) or in the Blue Pages of your phone book.

Take five minutes and do it now. Thanks for caring enough to help yourself and others.

If you need assistance or information, I can be contacted at [ksthomson@direct.ca](mailto:ksthomson@direct.ca) or 250-442-1280.

Ken Thomson

## GILLES GIRARD

Gilles Girard, a member of HepCBC, passed away on Aug 26, 2002.

### Update on Glen Hillson

Glen Hillson, Chair of BCPWA, is in the hospital severally ill and not expected to survive.

Glen was taken to hospital mid-last week because of an infection related to his Hepatitis C. This infection was basically the last straw in terms of his liver being able to work.

Although Glen is in the middle of being assessed for a liver transplant, he is feeling too weak to continue with the assessment. Early this morning he requested to be placed into palliative care, in order that he may die simply, comfortably, and in peace.

The protocol in Canada, and that used by the BC transplant Society, are very prohibited. Glen does not qualify for liver transplant in Canada, at present. He is very weak and his immunity is very fragile.

He will not live long without a new liver, and his chances of surviving a transplant diminish along with his health and stability. Glen is truly a great Canadian, and as you may have heard, is a recipient of the Queens Jubilee Commemorative Medal, a tremendous honour and recognition for his many years of hard work and dedication to the HIV/AIDS Movement.

## ANNUAL ALBERTA HARM REDUCTION CONFERENCE

The conference is being held at the Banff Centre in Banff, Alberta, Canada, March 3 - 4, 2003. Please consider joining us for this important Harm Reduction Conference.

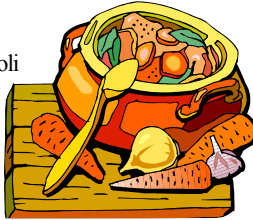
Conference registration and website information will be available soon.

Have a super day,

Jennifer Vanderschaeghe  
ACCH Administrative Coordinator  
4611 Gaetz Ave., Red Deer, AB T4N 3Z9  
Phone: (403) 314-0892  
E-Mail: [acch@shaw.ca](mailto:acch@shaw.ca)

## VEGAN BROCCOLI CASSEROLE

1 medium potato, peeled and coarsely diced  
1/2 medium carrot, scraped and thickly sliced  
1/2 med onion, peeled and coarsely diced  
1 cup water  
1 tsp salt  
16 oz frozen chopped broccoli  
4 oz firm tofu, crumbled  
1/2 cup nutritional yeast flakes  
1 Tbs lemon juice  
pinch garlic granules  
1 cup uncooked instant brown rice  
10 oz can sliced mushrooms, drained  
3/4 cup water



Preheat oven to 350 degrees F. In a small saucepan, bring potato, carrot, onion, 1 cup water and salt to a boil over medium-high heat. Lower heat to medium, cover and simmer until potato and carrot are tender, about 10 minutes. Meanwhile, thaw frozen broccoli in a colander under hot running water, then set aside and drain well.

When potato mixture has finished simmering, pour into a blender and add tofu, yeast, lemon juice and garlic. Blend until very smooth and creamy. Pour into a shallow, greased 1 1/2 to 2 quart casserole. Add broccoli, rice, mushrooms and 3/4 cup water. Stir well and smooth top of casserole. Bake for 40 minutes, until golden and bubbling. Serves 4.

Substitution: Instead of frozen broccoli, you can use 1 lb fresh broccoli (tops only), chopped and steamed briefly until crisp-tender, then cooled under cold running water and drained thoroughly.

Per serving: 279 cal; 16 g prot; 3 g fat; 46 g carb; 0 chol; 735 mg sod; 7 g fiber.

From: Michelle Dick  
<http://www.fatfree.com/recipes/casseroles/broccoli-casserole>

## DIAL-A-DIETITIAN

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

## RULES OF ENGAGEMENT:

*For dealing with People with Hepatitis C*

1. I am a human being with a point of view. Please respect that.
2. My time is precious to me so please don't waste it.
3. If you have a problem with me, please speak to me. I don't bite. Yet!
4. If you would like me to do something just ask. Don't tell me.
5. If you have an idea please share it. Don't force it on me.
6. You don't have to like me to work with me but you should at least respect my ability to do the job.
7. If something is not working right, let me know (refer to number 2).
8. Please remember that just because I am sick does not mean I have forgot everything I have ever learned. I suffer from hepatitis C not stupidity.
9. It is not necessary to yell because I have a disease. Trust me, my ears work.
10. It is not necessary to talk to me like I am a 2 year old because I have a disease. I have not regressed back to being a toddler so far as I know.
11. I am generally more helpful when I have been included. ESP is not one of my many talents.
12. It will not kill you to be civil to me. There is no need to be rude and unpleasant. (refer to number 1)

*Note: I started these after the Health Ministers meeting in Regina and I have added to them over the years ever since.*

Vikki Boddy ([VBoddy@telusplanet.net](mailto:VBoddy@telusplanet.net))

## TIP OF THE MONTH

**If you still smoke tobacco, really work on stopping. Your liver will thank you for it**



## WARNINGS

### Newer Antidepressants May Increase Bleeding Risk

NEW YORK (Reuters Health) - SSRIs, or selective serotonin reuptake inhibitors. SSRIs include Paxil (paroxetine), Prozac (fluoxetine) and Zoloft (sertraline). may increase the risk of bleeding in the gastrointestinal tract, according to a new study from Denmark.



But one of the study's authors stressed that bleeding was still rare, and that "the risk should be balanced against any therapeutic effect for the depression."

One of the limitations of the study was that researchers were not able to take into account smoking and drinking, both of which can increase the risk of gastrointestinal bleeding.

Among people who were taking an SSRI, but not any other medications that could increase the risk of bleeding, episodes of upper gastrointestinal bleeding were more than three times more common than in similar people who were not taking the drugs. This risk jumped even higher in people who were taking an SSRI in combination with a nonsteroidal anti-inflammatory drug or low-dose aspirin, both of which can increase bleeding risk on their own.

All types of SSRIs seemed to increase the risk of bleeding the same amount, as well as antidepressants that were not SSRIs but that still acted on serotonin.

Archives of Internal Medicine 2003;163:59-64.

<http://www.reutershealth.com/archive/2003/01/13/eline/links/20030113elin001.html> Newer antidepressants may increase bleeding risk by Merritt McKinney



## WANTED:

VOLUNTEER REPORTERS, WRITERS FOR THE *hepc.bull*

Contact: [info@hepcbc.ca](mailto:info@hepcbc.ca)

**LEXMARK**  
Passion for printing ideas.™

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



## 2<sup>ND</sup> NATIONAL ABORIGINAL HEPATITIS C CONFERENCE

"Weaving the Mind, Body and Spirit"

**Chee Mamuk** Aboriginal Program is pleased to announce a call for abstracts for the 2<sup>nd</sup> National Aboriginal Conference. This is your opportunity to share your experiences, wisdom with others who are infected / affected by the Hepatitis C Virus.



The conference is being held in Vancouver, BC, from May 4<sup>th</sup> - 7<sup>th</sup>.

### Conference Topics:

- ◆ Palliative
- ◆ End of life
- ◆ Prevention
- ◆ Harm Reduction
- ◆ Youth
- ◆ Addictions
- ◆ Treatment
- ◆ Co-Infection
- ◆ Research
- ◆ Women
- ◆ Residential School
- ◆ Life Skills
- ◆ Self Care
- ◆ Culture, Traditional Medicine,
- ◆ Ceremonies
- ◆ Prison
- ◆ Living with Hepatitis C (individual, family)

FOR MORE INFORMATION CONTACT:

**Lucy Barney** – Chee Mamuk Aboriginal Program, BC Centre for Disease Control

**Abstract Deadline is February 15, 2003. Please submit abstracts to Abstract Committee**

655 West 12th Ave. Vancouver, BC V5Z 4R4

Ph: 604.660.1673 Fax: 604.775.0808

Toll Free: 1.877.667.6668

Email: [lucy.barney@bccdc.ca](mailto:lucy.barney@bccdc.ca)

Web site: [www.bccdc.org](http://www.bccdc.org)

Scholarships are available.

**Are you in the 86-90 Window?  
Are you having any problems?**

**Contact: Terry Waller  
(250) 642-6766**

*(Terry is not a lawyer but a concerned victim)*



### VOLUNTEER APPLICATION FORM

**NAME:** \_\_\_\_\_

**ADDRESS:** \_\_\_\_\_  
\_\_\_\_\_

**CITY:** \_\_\_\_\_

**PC:** \_\_\_\_\_ **PROV:** \_\_\_\_\_

**TEL:** (    ) \_\_\_\_\_

**FAX:** (    ) \_\_\_\_\_

**EMAIL:** \_\_\_\_\_

### ABILITIES OR AREA OF INTEREST:

Library Printing Copying  
Phoning Fundraising  
Counseling Research  
Refreshments Special Events  
Publications Computer Help  
Errands Grant Applications  
Board Member Other

**Experience:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Time available:** \_\_\_\_\_  
\_\_\_\_\_

**SEX** M F

**Date of Birth:** \_\_\_\_/\_\_\_\_/\_\_\_\_

**Mo Day Year**

**Contact: HepCBC  
2741 Richmond Rd, Victoria,  
BC V8R 4T3**

**Tel. 595-3892 or Email:  
[info@hepcbc.ca](mailto:info@hepcbc.ca)**

## DISABILITIES HELP SHEET

The BC Coalition of People with Disabilities has created a 'help sheet' for filling out the new Disability Benefits forms. Please pass this information on to anyone who is having to reapply for benefits. Hopefully it will reduce some of the confusion and anxiety that this process has created for some people. Here is the link, and another useful page:

[www.bccpd.bc.ca/commlert/helpsheets/DesignationReview.pdf](http://www.bccpd.bc.ca/commlert/helpsheets/DesignationReview.pdf)

<http://www.bccdc.org/content.php?item=29>

## COMPENSATION

### LEGAL ACTION

**Hepatitis C Class Action Suit Line:**  
1-800-229-LEAD (5323)

**1986-1990**

Bruce Lerner/Grant Kovacs Norell

Vancouver, BC

Phone: 1-604-609-6699 Fax: 1-604-609-6688

**Pre-86/Post-90**

Hepatitis C Settlement Fund—KPMG Inc.

Claims Administrator

2000 McGill College Avenue, Suite 1900

Montreal (Quebec) H3A 3H8

1-888-840-5764 (1-888-840-kpmg)

[HepatitisC@kpmg.ca](mailto:HepatitisC@kpmg.ca)

[www.kpmg.ca/microsite/hepatitisc/english/forms.html](http://www.kpmg.ca/microsite/hepatitisc/english/forms.html)

Klein Lyons

Vancouver, BC 1-604-874-7171,

1-800-468-4466, Fax 1-604-874-7180

[www.kleinlyons.com/pages/class\\_actions/Hepatitis\\_C.htm](http://www.kleinlyons.com/pages/class_actions/Hepatitis_C.htm)

Mr. David Harvey/ Goodman & Carr

Toronto, Ontario

Phone: 1-416-595-2300, Fax: 1-416-595-0527

Ernst & Young Law Office (Ontario)

1-800-563-2387

Lauzon Belanger S.E.N.C. (Quebec)

[www.lauzonbelanger.qc.ca](http://www.lauzonbelanger.qc.ca)

Goodman and Carr LLP

[pre86hepc@goodmancarr.com](mailto:pre86hepc@goodmancarr.com)

[www.goodmancarr.com](http://www.goodmancarr.com)

**Other:**

William Dermody/Dempster, Dermody, Riley and Buntain

Hamilton, Ontario L8N 3Z1

1-905-572-6688

### LOOKBACK/TRACEBACK

**The Canadian Blood Services, Vancouver, BC**

1-888-332-5663 (local 207)

**Lookback Programs, Canada:** 1-800-668-2866

**Lookback Programs, BC:** 1-888-770-4800

**Canadian Blood Services Lookback/Traceback & Info Line:** 1-888-462-4056

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

1-888-666-4362

**Manitoba Traceback:** 1-866-357-0196

**RCMP Blood Probe Task Force TIPS Hotline**

1-888-530-1111 or 1-905-953-7388

Mon-Fri 7 AM-10 PM EST

345 Harry Walker Parkway, South Newmarket, Ontario L3Y 8P6 Fax: 1-905-953-7747

### CLASS ACTION/COMPENSATION

**National Compensation Hotline:** 1-888-726-2656

**Health Canada Compensation Line:** 1-888-780-1111

**Red Cross Compensation pre-86/ post-90 Registration:** 1-888-840-5764

**Ontario Compensation:** 1-877-222-4977

**Toronto Compensation:** 1-416-327-0539, 1-877-434-0944

**Quebec Red Cross Compensation:** 1-888-840-5764

**1986-1990 Hepatitis C Class Actions Settlement**

6/15/99 [www.hepc8690.ca/](http://www.hepc8690.ca/)

### ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-888-726-2656 or 1-877-434-0944.

[www.hepc8690.com](http://www.hepc8690.com) [info@hepc8690.com](mailto:info@hepc8690.com)

### MISCELLANEOUS

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

## COMING UP IN BC/YUKON:

**Armstrong HepCure** Office and library, by appointment. Contact: Marjorie, 546-2953, [ambrose@sunwave.net](mailto:ambrose@sunwave.net), [www.junction.net/hepcure](http://www.junction.net/hepcure)

**Campbell River Hep C Support Group** Support and information, call 830-0787 or 1-877-650-8787 or email [niac\\_hepc@hotmail.com](mailto:niac_hepc@hotmail.com)

**Castlegar** Contact: Robin, 365-6137

**Comox Valley:** Contact North Island Hep C Community Support Project 1-877-650-8787,

**Cowichan Valley Hepatitis C Support** Contact: Leah, 748-3432.

**Cranbrook HeCSC-EK:** 1<sup>st</sup> & 3<sup>rd</sup> Tues. monthly, 1-3 PM, #39 13<sup>th</sup> Ave South, Lower Level. Next meetings Feb. 4<sup>th</sup> & 18<sup>th</sup>. Contact: 426-5277 or 1-866-619-6111 [hepc@cmha-ek.org](mailto:hepc@cmha-ek.org), [www.hepceastkootenay.com](http://www.hepceastkootenay.com)

**Creston/Golden/Invermere** Educational presentation and appointments: Contact Katerina 426-5277

**Grand Forks Hep C Support Centre** Each Mon, 3:30-5:30 PM, & 1<sup>st</sup> Mon. monthly, 6:30 PM, 7215 2<sup>nd</sup> St. (Boundary Women's Resource Centre) Contact Ken, 1-800-421-2437

**Kamloops** (People in Motion) 1<sup>st</sup> and 3<sup>rd</sup> Tues monthly 12:30 PM, 6E-750 Cottonwood Ave, North Kamloops. Next meetings Feb. 4<sup>th</sup> & 18<sup>th</sup> Contact Pam: 851-7300, [pamela.zulymiak@interiorhealth.ca](mailto:pamela.zulymiak@interiorhealth.ca).

**Kelowna Hepkop:** Last Sat. monthly, 1-3 PM, Rose Ave. Education Room, Kelowna General Hospital. Next Meeting: Next meeting Feb. 22<sup>nd</sup>. Contact Elaine Risely (250) 768-3573, [erisely@shaw.ca](mailto:erisely@shaw.ca) or Lisa Mortell 766-5132 [lmortell@silkn.net](mailto:lmortell@silkn.net)

**Kimberley Support Group** 2<sup>nd</sup> Tue. monthly, 7-9 PM. Next meeting Feb. 11<sup>th</sup> Contact Katerina 426-5277

**Kootenay Boundary** 2<sup>nd</sup> Tues. monthly, 7 PM, Room 108, Selkirk College, Trail. Next meeting: Feb. 11<sup>th</sup>. For individual support, info & materials, contact: Brian Reinhard, (250) 364-1112, [reiny57@yahoo.ca](mailto:reiny57@yahoo.ca)

**Mid Island Hepatitis C Society** Contact Sue for info 245-7635. [mihepc@shaw.ca](mailto:mihepc@shaw.ca)

- **Ladysmith** Friendship & Support Group meets monthly, Ladysmith Health, Centre, 224 High St
- **Nanaimo** Friendship and Support Group 2<sup>nd</sup> Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo.

**Mission Hepatitis C and Liver Disease Support Group** 3<sup>rd</sup> Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting Feb. 19<sup>th</sup>. Contact Gina, 826-6582 or Patrick, 820-5576. [mission-support@eudoramail.com](mailto:mission-support@eudoramail.com)

**Nakusp Support Group Meetings:** 3<sup>rd</sup> Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Next meeting: Feb. 18<sup>th</sup>. Contact: Vivian, 265-0073 or Ken, 1-800-421-2437

**Nelson Hepatitis C Support Group** 1<sup>st</sup> Thurs. monthly. ANKORS Offices, 101 Baker St., Next meeting: Feb. 6<sup>th</sup>. Contact: Ken Thomson, 1-800-421-2437, 505-5506, [info@ankors.bc.ca](mailto:info@ankors.bc.ca)

**New Westminster Support Group** 2<sup>nd</sup> Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, 623 Agnes Street, New Westminster. Next meeting: Feb. 10<sup>th</sup>. Speaker: Dr. John D. Farley on Hepatitis. Contact: Dianne Morrisette, (604) 517-6120, [dmorrisette@excite.com](mailto:dmorrisette@excite.com)

**Parksville Support Group** Contact Ria, 248-6072

**Parksville/Qualicum** 102a-156 Morison Avenue, PO Box 157, Parksville, BC V9P 2G4. Open daily 9 to 4, M-F. Contact: 248-5551, [sasg@island.net](mailto:sasg@island.net)

**Penticton Hep C Family Support Group** Contact: Leslie, 490-9054, [bchepc@telus.net](mailto:bchepc@telus.net)

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

**Prince George Hep C Support Group** 2<sup>nd</sup> Tues. monthly, 7-9 PM, Health Unit Auditorium. Next meeting Feb. 11<sup>th</sup>. Contact: Gina, 963-9756, [gina1444@yahoo.ca](mailto:gina1444@yahoo.ca) or Ilse, [ikuelper@northernhealth.ca](mailto:ikuelper@northernhealth.ca)

**Princeton** 2<sup>nd</sup> Sat. monthly, 2 PM, Health Unit, 47 Harold St. Next meeting Feb. 15<sup>th</sup>. Contact: Brad, 295-6510. [kane@nethop.net](mailto:kane@nethop.net)

**Queen Charlotte Islands/Haida Gwaii:** Phone support. Contact Wendy: 557-9362, e-mail: [wmm@island.net](mailto:wmm@island.net), [www.island.net/~wmm/](http://www.island.net/~wmm/)

**Quesnel HeCSC** Last Mon. evening every other month. Contact Elaine Barry, 992-3640, [ebarry@goldcity.net](mailto:ebarry@goldcity.net)

**Richmond: Lulu Island AIDS/Hepatitis Network:** Meetings/drop-in dinner each Mon. 7-9 PM. Contact Phil or Joe, 276-9273.

**Slocan Valley Support Group** Contact: Ken, 355-2732, [keen@netidea.com](mailto:keen@netidea.com)

**Smithers: Positive Living North West** 2<sup>nd</sup> Wed. monthly, 7-9 PM, 3731 1<sup>st</sup> Avenue, Upstairs. Next meeting: Feb. 12<sup>th</sup>. Contact: Deb. 877-0042, 1-866-877-0042, or Doreen, 847-2132, [plnw\\_hepc@bulkeley.net](mailto:plnw_hepc@bulkeley.net) for times.

**Sunshine Coast—Sechelt:** Contact: Kathy, 886-3211, [kathy\\_rietze@uniserve.com](mailto:kathy_rietze@uniserve.com)—**Gibsons:** Contact Bill, pager 740-9042

**Vancouver:** For information please call HepHIVE at 604-254-9949 ext 232.

**VANDU Vancouver Area Network of Drug Users** Each Mon., 2 PM, 327 Carrall St. (off Pigeon Park) Bus fare & snack. Contact: Crisly or Ann, 683-8595, space limited, so come early. [vandu@vcn.bc.ca](mailto:vandu@vcn.bc.ca), [www.vandu.org](http://www.vandu.org)

**Vernon HeCSC HEPLIFE** 2<sup>nd</sup> & 4<sup>th</sup> Wed. monthly, 10 AM-1 PM, The People Place, 3402-2<sup>nd</sup> Ave. Next meetings Feb. 12<sup>th</sup> & 26<sup>th</sup>. Contact: Sharon, 542-3092, [sgrant@telus.net](mailto:sgrant@telus.net)

**Victoria HeCSC** Last Wed. monthly. Contact: 388-4311, [hepcvic@coastnet.com](mailto:hepcvic@coastnet.com)

**Victoria Support and Information** 1<sup>st</sup> Wed. monthly, 7 PM. Hep C Outreach Workers avail. each Wed. 7-11 PM, or weekdays 9-4, Street Outreach Services (needle exchange). Contact 384-2366, [hermione.jeffris@avi.org](mailto:hermione.jeffris@avi.org)

**Victoria HepCBC & INFO line** General Meetings quarterly, 1<sup>st</sup> Tues., 7-9 PM, 541 Herald St. Next meeting: ??????. Contact: (250) 595-3892, [info@hepcbc.ca](mailto:info@hepcbc.ca), [www.hepcbc.ca](http://www.hepcbc.ca)

**YouthCO AIDS Society HepCATS** Hep C advocacy, training and support for youth 15-29 living with Hep C or co-infected with HIV. #203-319 W Pender St., Vancouver. Contact Leahann Garbutt, (604) 688-1441, (604) 808-7209, [information@youthco.org](mailto:information@youthco.org), or [www.youthco.org](http://www.youthco.org)

**Yukon Positive Lives** 3<sup>rd</sup> Wed. monthly, Whitehorse. Next meeting Feb. 19<sup>th</sup>. Contact Heather 660-4808, [fromme@marshlake.polarcom.com](mailto:fromme@marshlake.polarcom.com), [www.positivelives.yk.ca](http://www.positivelives.yk.ca)

## OTHER PROVINCES

### ATLANTIC PROVINCES:

**Cape Breton HeCSC** 2<sup>nd</sup> Tues. monthly. Contact 564-4258

**Cape Breton-HepC-CB** 2<sup>nd</sup> Wed. monthly, 7 PM YMCA Board Room, Charlotte St., Sydney. Contact: Maria MacIntosh at 567-1312 <http://www.accb.ns.ca/>

### HeCSC NB Meetings:

• **Fredericton, NB** Contact: Sandi, 452-1982 [sandik@learnstream.com](mailto:sandik@learnstream.com) or Bob, 453-1340, [bobc215@hotmail.com](mailto:bobc215@hotmail.com)

• **Saint John & Area:** Telephone support line: Contact Allan Kerr 672-4372, [kerrs@nbnet.nb.ca](mailto:kerrs@nbnet.nb.ca)

**Hepatitis C Moncton Inc. of N.B.** 2<sup>nd</sup> Tues. monthly, 7 PM, 77 Vaughan Harvey Blvd. Contact Debi, 858-8519, [hepcmonec@rogers.com](mailto:hepcmonec@rogers.com)

**Hepatitis Outreach Society**, Simpson Hall, Suite 452, 300 Pleasant Street, Dartmouth, P.O. Box 1004, NS, B2Y 3Z9. 1-800-521-0572, or 902-420-1767, [rahecc@ns.sympatico.ca](mailto:rahecc@ns.sympatico.ca), [www.ahcc.ca](http://www.ahcc.ca) Meetings:

• **Bridgewater:** Last Wed. monthly, 7 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room

• **Halifax:** 3<sup>rd</sup> Tues. monthly, 7 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110

• **Kentville:** 2<sup>nd</sup> Tues. monthly, 6:30 PM, Kings Tech Campus, 236 Belcher St, Conference Room A-226

• **New Glasgow:** 3<sup>rd</sup> Mon. monthly, Aberdeen Hospital, Conference room #1 South.

• **Truro:** Last Tues. monthly, 7 PM, Colchester Regional Hospital, 25 Willow St, Conference Room

• **Yarmouth:** 1<sup>st</sup> Tues. monthly, 7 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1—Main level

### ONTARIO:

**Barrie HepSEE Chapter** 3<sup>rd</sup> Tues. monthly, 7-9 PM, AIDS Committee of Simcoe County, 80 Bradford St, Suite 336 Contact: Jeanie, 735-8153 [hepcbarrie@rogers.com](mailto:hepcbarrie@rogers.com)

**Durham Region, GTA and Peterborough, ON support.** Contact: Smilin' Sandi [smking@rogers.com](mailto:smking@rogers.com) "Sandi's Crusade Against Hepatitis C" <http://members.rogers.com/smking/>

**Kitchener Area Chapter** 3<sup>rd</sup> Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact:

Carolyn, (519) 880-8596 [lollipop@golden.net](mailto:lollipop@golden.net)

**Niagara Falls Hep C Support Group** Last Thurs. monthly, 7 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact: Rhonda, (905) 295-4260, Joe (905) 682-6194 [jcolan-gelo3@cogeco.ca](mailto:jcolan-gelo3@cogeco.ca) or [hepcnf@becon.org](mailto:hepcnf@becon.org)

**Trenton ON** support. Contact: Eileen Carlton 394-2924 [carfam@quintenet.com](mailto:carfam@quintenet.com)

**Windsor Support Group** Each Thurs., 7 PM, 1100 University Ave. W. Contact 739-0301 or Ruth or Janice (Hep-C), 258-8954, [truds@MNSi.Net](mailto:truds@MNSi.Net)

### PRAIRIE PROVINCES:

**HeCSC Edmonton:** Contact Jackie Neufeld: 939-3379.

**HepC Edmonton Support Group:** Contact Fox, 473-7600, or cell 690-4076, [fox@kihewcarvings.com](mailto:fox@kihewcarvings.com)

**HepSEE WPG:** Contact David: [hepsee@shaw.ca](mailto:hepsee@shaw.ca) or 1(204)897-9105 for updates on meeting schedules.

**Winnipeg Hepatitis C Resource Centre** 1<sup>st</sup> Tues. monthly 7-9 PM. # 204-825 Sherbrook St. (south entrance—parking at rear) Contact: 975-3279, [hcre@smd.mb.ca](mailto:hcre@smd.mb.ca)

### QUEBEC:

**Hepatitis C Foundation of Quebec**, Contact Eileen, 769-9040 or [fhcq@qc.aibn.com](mailto:fhcq@qc.aibn.com). Meetings:

• **Hull:** Each Tue. 7-8 PM, 57 Rue Charlevoix.

• **Sherbrooke** 2<sup>nd</sup> Monday monthly, 7-9 PM, Les Grandes Coeurs D'Artichauts Au Centre Jean-Patrice Chiasson (2<sup>e</sup> etage) 1270 Galt Street West. Contact: 820-7432

• **Verdun:** 3<sup>rd</sup> Wed. monthly, 7-9 PM (English), 1<sup>st</sup> Wednesday monthly, 7-9 PM, (French) 4341 Verdun Ave.

### HeCSC

• **Quebec City Region**, 1<sup>st</sup> Wed monthly, 7 PM, 876 rue D'Alençon, St. Nicolas, QC. Contact: Renée Daurio, 836-2467, [reneeaurio@hotmail.com](mailto:reneeaurio@hotmail.com)

