

# hepc.bull

## Canada's Hepatitis C News Bulletin

www.hepcbc.ca

### LETTER FROM THE CARAVAN OF HOPE

HepCure  
Box 195  
Armstrong B.C. V0E 1B0  
7 July 2004

Honourable Colin Hansen  
Minister of Health Services  
P.O. Box 9050 Stn. Prov. Govt.  
Victoria, British Columbia V8W 9E2

Dear Minister,

Thank you for meeting with the Caravan of Hope on 17 May 2004. The Caravan of Hope represented the estimated 65,000 British Columbians infected with hepatitis C. We commend your government for the care and treatment initiatives already in place. However we have to reiterate a very important point, which is that, at the current treatment rate of 650 people per year, it will take 100 years to treat everybody already infected.

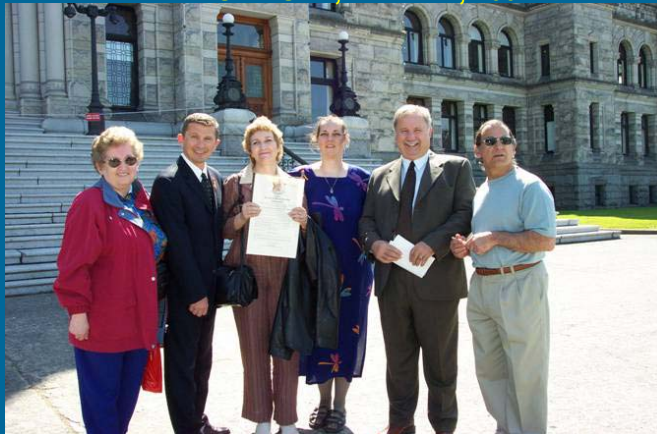
The recent outbreak of hepatitis C in hemodialysis units underscores the need for greater prevention vigilance. Pegasys is recommended for renal patients and should be made available on the formulary for this and other reasons listed below.

At least 55% of hepatitis C infections are not related to intravenous drug use, but rather to medical care facilities, tattooing parlours and the grooming industry. Please follow through on your commitment to inform the associations of these industries to review their disinfection and sterilization procedures, and wherever possible to choose sterilization over disinfection.

You indicated that your ministry relies on professional medical advice when devising treatment and drug approval policy, and that you would place requests for update and elucidation on the issues of imminent concern, these being:

(Continued on page 6)

### CARAVAN OF HOPE, MAY 17<sup>th</sup>, 2004



Left to right:  
Judith Fry, MLA Lorne Mayencourt, Joan King, Marjorie Harris, MLA Randy Hawes, Dr. David Mazoff. (Dr. Arthur Ralfs was an important part of party, but had to leave earlier in the day.)  
Joan King, HepC-BC, is holding the 2004 Provincial Proclamation.

Our meeting with MLAs Lorne Mayencourt and Randy Hawes was excellent. Many concerns were addressed and an invitation to participate in a new chronic disease committee was offered.

The Ron Theil Family, Erik Ages, Carol Romanow, SOLID members, HepCBC members and many others showed up for the Legislative Gallery introductions and members' speech by MLA Lorne Mayencourt and for the 3pm media event on the Victoria Legislative front steps.

Thank you to Bradley Kane and Beverly Atlas for being there as an integral part of the Caravan of Hope. Thank You to All of the supporters who were present and not named..—*Marjorie Harris*

### WILLIAM LYON MacKENZIE LOEPPKY

November 04,  
2002



Bill Loepky, humorist and musician, carpenter and gardener, passed away unnoticed by us until recently, when we received

an e-mail from his wife, Juanita, asking us to remove his name from our database. It's so sad the way people drift in and out of our lives and we lose track. I had several interesting phone conversations with him—enough to notice that he was a very intelligent and gifted individual. He had his own journal, his passion, the *Inditer*, together with an on-line magazine, in which he extolled the virtues of local artists and writers. Bill lived in Victoria, and was retired from a career in broadcasting. Bill's spirit lives on at <http://collection.nlc-bnc.ca/100/202/300/inditer/2000/07-10/deman/indit.htm>

### INSIDE THIS ISSUE:

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**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.

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## LETTERS TO THE EDITOR:

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

## NEW!!!

## Peppermint Patti's FAQ

Peppermint Patti's FAQ Version 6 is now available, and Version 5.6 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only \$6 each, plus postage. Contact HepCBC: (250) 595-3892, [info@hepcbc.ca](mailto:info@hepcbc.ca)

HepCBC Resource CD: The CD contains back issues of the hepc.bull from 1997-2003; the FAQ V6; the slide presentations developed by Alan Francis; and all of HepCBC's pamphlets. The Resource CD costs \$10, including shipping and handling. Please send cheque or money order to the address on the subscription form on this page.

## REPRINTS

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

# THANKS!

HepCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, The Ocean 98.5 for their Public Service Announcements, Durhane Wong-Rieger, Bryce Brogan, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Brad Kane, Chris Foster, Darlene Morrow, Will Lawson, Judith Fry, and the newsletter team: Jeanie and Diana. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

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



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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 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, #306-620 View Street, Victoria BC V8W 1J6, (250) 595-3892.

Give us your name, tel. no., and address.

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

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

Want a mate? Your Cupid ad could go here!

## Got Hep C? Single? Visit:

<http://forums.delphiforums.com/HepCingles/>  
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<http://groups.yahoo.com/group/HepCingles2>  
<http://groups.yahoo.com/group/NewHepSingles/>

CHAT: <http://forums.delphiforums.com/hepatitiscen1/chat>

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

## PRE-PLANNING YOUR FINAL ARRANGEMENTS?

Please consider arranging for donations to your local hepatitis C organization.

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## DIAL-A-DIETITIAN

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

## AVAILABILITY OF TREATMENTS BY PROVINCE & TERRITORY FOR HEPATITIS C

Prov- ince	Date of informa- tion	Rebetron (combo) Ifn-alfa2b+ribavirin Schering	Pegatron (combo) Peg-ifn2b+ribavirin Schering	Pegasys (mono) Peg-ifn2a Roche (Interim CDR)	Pegasys/Copegus Peg-ifn2a + ribavirin Roche	Particulars/ Comments
BC	May 04	Special Authorization, Geno. 2/3 -24 wks.	Special Authorization, TN (treatment naïve), Geno. 2/3 -24 wks.	Under Review	Health Canada NOC granted May 04. Now in CDR process.	ALT 1.5x normal, 2x over 6 mos.
AB	May 04	Special Authorization	Special Authorization Unitron also available	Special Authori- zation	Not submitted yet	Anti-HCV, HCV-PCR, ALT/AST or biopsy results. Provincial drug plan has no premiums for over 65
SK	May 04	Exception Drug Status (EDS)	EDS, Unitron also available	Under Review	Not submitted yet	Coverage for 6 mo. w/ potential 2 more 6 mo. periods of coverage
MB	May 04	EDS	Part 3 EDS Doctor must be ID'd by MB gov't as familiar with treating HCV	Special Authori- zation	Not covered	Dr. must provide geno- type, ALT, biopsy, viral load, previous tx
ON	Oct. 03	Written, Physician, Section 8	Written, Physician, Section 8	Section 8 * Individual Clinical Review Mechanism	Not submitted yet	Member TDP, Pay 4% household net income up front
PQ	April 04	Up to 48 wks. Genotype 2/3 -24 wks.	Up to 48 wks. Genotype 2/3 -24 wks.	Medicament Exception		
NB/PE	May 04			Under Review		
NS	May 04		TN, Specialist written request	Exception Status Benefit	Not submitted yet	
NL	May 04	Written/ph./fax request from infectious disease specialist	Written/ph./fax request from infectious disease specialist	Special Authori- zation		
YT	May 04	Special Authorization	Special Authorization, TN	Under Federal Review	Not submitted yet	ALT 1.5x normal, 2x over 6 mos.
NT	May 04			Under Federal Review		
NU	May 04			Under Federal Rreview		Paid for on a pre- approval basis depend- ing on the policies in place in the larger ju- risdictions.
FNIB	May 04			Covered (Individual Ap- proval)		

More copies of this chart can be downloaded from: [www.hepcure.ca](http://www.hepcure.ca)

**REBETRON® Combo** (interferon alfa-2b + ribavirin/Schering Corporation)

**UNITRON (R) Monotherapy** (peginterferon alfa-2b/Schering Corporation) **PEG (TM)** or **PEG INTRON** in the USA.

**PEGETRON (TM) Combo** (peginterferon alfa-2b + ribavirin/Schering Corporation) in the USA is **REBETOL (R)**

**PEGASYS Monotherapy** (peginterferon alfa-2a/Hoffmann-La Roche, Inc.) in Canada

**COPEGUS** (Roche ribavirin) is awaiting approval in Canada.

\*Ribavirin may be available under Roche's Ribavirin Access Program (RAP)

## MAKE ME LAUGH

by Ken Thomson

According to a recent letter from Craig Knight, B.C.'s assistant deputy health services minister, "BC spends approximately \$100 million per year on hepatitis C prevention and care ... and wait times are under one month at the five pilot project liver clinics."

After they quit laughing, most of the people with hepatitis C that I know would tend to disagree – quite vigorously. They'd point out that prevention and care services are inaccessible in much of the province, uncoordinated, and grossly underfunded. Thousands of people are still walking around unaware that they are infected with the hepatitis C virus. The criteria for treatment coverage are scientifically inaccurate, outdated, and inhumane.

The situation is unacceptable. It is only going to change if the people living with hepatitis C – and those who care about them – stand up, make some noise, and get involved.

We need to let the public know that this epidemic will soon cost Canadians one billion dollars a year. A huge number of people either now have, or will soon develop, the most serious and deadly complications of hepatitis C: cirrhosis, liver failure, and cancer. Everyone will be affected by the burdens that this will put on our health system.

We need to let people know that it doesn't have to be this way. Hepatitis C is both preventable and treatable. We need a co-ordinated provincial hepatitis C strategy that includes the ongoing, meaningful involvement and input of those who are most affected.

The BC Hepatitis C Collaborative Circle has received some Health Canada funding to facilitate meetings in each of the health regions this September and October. The mandate is to bring together hepatitis C groups and organizations with other community-based organizations, public health, and other health care providers. They will identify existing services and the gaps in needed services, and then develop plans, areas of responsibility, and funding strategies for improving hepatitis C services in each region.

The next three to six months will be critical. Whether you want to get involved in raising public awareness or in improving services at the community and regional levels, contact Ken Thomson directly at [ksthomson@direct.ca](mailto:ksthomson@direct.ca), or by phone at 250-442-1280. You can find more information at the BC Hepatitis C Collaborative Circle web site <http://www.casper.ca/hepcircle>.

Get involved! Make a difference. The life you save just might be your own.

## "ASK THE EXPERT" SERIES ON HEPATITIS C THERAPY

As part of the "Ask the Expert" audio-conference series on Hepatitis C Therapy in Canada, the Canadian Hepatitis C Network is presenting the first session, "Access to the New Pegylated Interferon Combination Therapies", during August and September 2004. This series is designed for patients or caregivers who are considering hepatitis C therapy.

To maximize access and participation, the live two-hour teleconference session will be offered four times. Each session will be limited to 12 pre-registered participants. Each session will feature a Canadian physician expert and a community-based hepatitis C support group host.



We are very fortunate in having four of the top specialists in Hepatitis C in Canada: Dr. Curtis Cooper (Ottawa), Dr. John Farley (Vancouver), Dr. Mark Swain (Calgary), and Dr. David Wong (Toronto).

Each session will provide an overview of the new pegylated interferon therapies and status of provincial funding for treatment, followed by a question period with the physician and community group host. In addition, participants will have an opportunity to provide input into proposals for co-ordinated hepatitis C programming at local, provincial, and national levels.

### Agenda for Each Session

Objectives and Introductions (10 min.)

Update on pegylated interferon with ribavirin (30 min.)

What are the new treatments and how are they different from standard therapy?

Who should be treated and what are the expected outcomes?

What are risk factors, side effects, and supportive therapy?

What is the status of provincial funding for treatment in Canada?

Question period (40 min.)

Input on local, provincial, and national hepatitis C program activities and Canadian Hepatitis C Strategy (30 min.).

Conclusions and Next Steps (10 min.)

Dates and times are:

Date	Physician	Time (EDT)
Wed., Aug. 18	Dr. Curtis Cooper	4:00 - 6:00 pm EDT
Wed. Aug. 31	Dr. Mark Swain	4:00 - 6:00 pm EDT
Wed. Sep. 8	Dr. David Wong	6:00 - 8:00 pm EDT
Wed. Sep. 8	Dr. John Farley	9:00 - 11:00 pm EDT

Participants must pre-register. Each person will receive background materials and dial-in instructions prior to the teleconference. To register or to receive more information, please visit the Canadian Hepatitis C Network website ([www.canhepc.net](http://www.canhepc.net)) or call 1-866-895-0690 or 416-969-7435.



## TO THE MEMBERS of HepCBC

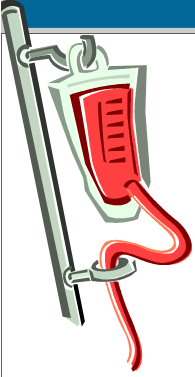
Hepatitis Education and Prevention Society:

**NOTICE IS HEREBY GIVEN** that the Annual General Meeting of the Members of **HepCBC Hepatitis Education and Prevention Society** for 2004 will be held on Tuesday, September 14, 2004, at 306-620 View Street, Victoria, BC at 7:00 P.M.

Please contact the office at (250) 595-3892 and leave your mailing address for a copy of the Agenda for the Annual General Meeting and a list of candidates for the Board, and for an absentee ballot if you need one. You may email us, if you prefer, at [info@hepcbc.ca](mailto:info@hepcbc.ca)

# COMPASSION FOR FORGOTTEN VICTIMS!

by Joan King



I spoke recently to a lady who was transfused on December 31, 1985, and to a gentleman who was transfused shortly after July 1, 1990 with blood that obviously had been donated before that date. Both contracted Hep C during their treatment, yet neither of them is eligible for compensation.

Why not?

Because they were not transfused within the somewhat mysterious "window" between January 1, 1986 and July 1, 1990 – the time within which the federal government admits it was at fault for not screening the blood through available tests, which they decided were too expensive. Only those who received blood tainted with hepatitis C within this window are eligible for compensation.

Paul Martin has said he is willing to revisit the issue of the window, but the Canadian Hemophilia Society has questions as to his exact meaning.



The victims inside the window have supposedly been compensated. The unfortunate victims outside the window may still have a chance to receive help, because activists are on the warpath.

In 1998, Allan Rock set up a second fund, called "Care, not Cash". His plan was to cover the cost of drugs, travel to visit specialists, home nursing care, and other related needs that would improve the quality of life for these victims. Beginning in 2001 and ending in 2014, the federal government was to distribute the funds to the provinces to help those victims falling outside the window.

Health Canada spokesperson Paige Raymond Kovach reported that about half of the fund has been sent to the provinces, while the remainder will be disbursed in the future. The provinces are required to report within five years on how the money was used, but that deadline hasn't been reached yet.

Some of the provinces seem to be using their share of the money for all Hep C patients, transfused or not, which was apparently not the intention of the federal government.

The health ministry in Ontario says it

doesn't know what happened to its part of the money – \$132.6 million. Some say the province has received \$60 million. Another source speculated that the past provincial government may have "scooped the cash" to deal with the budget deficit.

"We will make sure that every penny of the funding from the federal government is spent on the treatment and care of hepatitis C victims," Ontario Health and Long-Term Care Minister George Smitherman said. "[W]e are taking decisive action to put a program in place so that victims of hepatitis C get the care they need."

Smitherman has requested a full report of Ontario's portion of the fund. He admitted that, although the fund was established in 1998, Hep C victims still have no program to assist them.

Alberta Health Minister Gary Mar said that Alberta's money was being used for all hepatitis C victims in the province, not just those who received tainted blood. "Health Canada has the ability to reduce, adjust, or terminate the funding if it is not satisfied," he added.

In a letter to Toronto lawyer David Harvey, Mar wrote that, "Alberta signed the agreement on the condition that funding would be used for health services of benefit to medically eligible persons ... regardless of the source of their infection." A Health Canada representative purported to have no knowledge of such a condition.

Harvey has asked for an audit, and has told the Auditor General that, even though many have contacted him who cannot pay for their treatment, he knows of no special access to treatment or services which has been provided as a result of the funds.

Activists say that those who have applied for drug costs have not been paid. Many are asking their provincial government for reports as to how the money was distributed. So far, their attempts to get information have been fruitless.

Vikki Boddy from Lethbridge, well known to our readers, sent a bill to Gary Mar for her costs and her claim was refused. She was told that the fund was not intended for that purpose.

Some activists are asking that the money left over from the fund to compensate those within the window be distributed to those less fortunate outside the window. They say that there have been fewer than 9,000 claims, totaling only \$371 million of the \$1.2 billion set aside for that purpose.

Mike McCarthy, a well-known activist,

said the "Care, not Cash" deal is a fiasco, and is calling for cash compensation for all victims of tainted blood, regardless of the transfusion date. John Plater, vice-president of the Canadian Hemophilia Society, said that they have no record of any patient in the country receiving money from the fund for out-of-pocket expenses.

It is not known why there have been so few claims. It may be that there were fewer victims than expected, or it may be that the red tape is just too much for them to handle. We need to know.

By now, of course, there are victims who will never receive money. Daryl Thomson was transfused as a teenager, and died a year ago from Hep C at age 34.

Alison Wright, of Delta, BC, sums it up in a letter to Paul Martin and others: "I just went to have a baby. My life was ruined. The Canadian Government has compensated people for cows and chickens and ice and fire but won't compensate all of the victims of this tragic medical disaster."

Sources:

CCNMatthews – Jun 25, 2004.

Rob Ferguson, *Queen's Park Bureau*, Jul. 9, 2004, *Money for those outside the window*,

[http://www.thestar.com/NASApp/cs/ContentServ?pagename=thestar/Layout/Article\\_Type1&c=Article&cid=1089324611931&call\\_pageid=968332188492&col=968793972154](http://www.thestar.com/NASApp/cs/ContentServ?pagename=thestar/Layout/Article_Type1&c=Article&cid=1089324611931&call_pageid=968332188492&col=968793972154).

Dennis Bueckert, *Hepatitis C victims want to know what happened to \$300-million fund for care*,

<http://cnews.canoe.ca/CNEWS/Canada/2004/07/07/530897-cp.html>.

McGuinty government commits to hepatitis C federal funding,

<http://www.newswire.ca/en/releases/archive/July2004/09/c2012.html> July 9, 2004;

<http://www.health.gov.on.ca>.

*What does it take to get help for victims of hepatitis C?*

[http://www.thestar.com/NASApp/cs/ContentServ?pagename=thestar/Layout/Article\\_Type1&c=Article&cid=1089411014401&call\\_pageid=970599119419](http://www.thestar.com/NASApp/cs/ContentServ?pagename=thestar/Layout/Article_Type1&c=Article&cid=1089411014401&call_pageid=970599119419).

For further information: Members of the media: Eva Lannon, Minister's Office, (416) 327-4320; Dan Strasbourg, Ministry of Health and Long-Term Care, (416) 314-6197. Members of the general public: (416) 327-4327 or (800) 268-1154.

(CARAVAN OF HOPE—Continued from p. 1)

1. Add Pegasys mono therapy to the provincial formulary immediately. We have been waiting since September 2003 when it went into the BC Interim Common Drug Review.

i. Pegasys reduces the significant 24% drop-out rate from current Peg-Intron and is more easily tolerated.\* In summary, the results of the present study demonstrate that treatment with pegIFN-alpha 2a relative to IFN-alpha 2b/RBV minimizes the adverse impact of therapy on health-related quality of life (QOL). PegIFN-alpha 2a treatment resulted in improved work productivity, less activity impairment, decreased need for prescription drugs to treat adverse effects, and better adherence to therapy, indicated by a reduced drop out rate.

\* Perrillo, R., Rothstein, K.D., Rubin, R., Alam, I. et. al. "Comparison of Quality of Life, Work Productivity and Medical Resource Utilization of Peginterferon Alpha 2a vs. the Combination of Interferon Alpha 2b Plus Ribavirin as Initial Treatment in Patients with Chronic Hepatitis C." *J Viral Hepat* 11(2):157-165, 2004. Blackwell Publishing.

The "Management of Viral Hepatitis: A Canadian Consensus Conference 2004" (Sherman, Morris et. al. Canadian Viral Hepatitis Network <http://www.cvhn.ca/hepc2004>) states the following:

ii. Pegasys is indicated for use in patients with renal (kidney) impairment and transplantation (pg 23).

iii. Genotype 2 & 3 (hepatitis C) infection is optimally treated with a 24-week regime using (Pegasys) peginterferon alpha 2a (pg 20).

iv. Pegasys plus ribavirin is a choice for re-treatment of relapsers and non-responders (pg 22).

2. Make all treatment options available to previously treated relapsers and non-responders.

Preliminary data suggest that about 10% of non-responders and about 20% of relapsers achieve a sustained virological response (SVR) (pg 22).

3. Remove the ALT criterion for treatment qualification.

The "Management of Viral Hepatitis: A Canadian Consensus Conference 2004" states the following: "Approximately 30% of HCV patients have persistently normal ALT. Treatment with pegylated interferon and ribavirin results in equivalent SVR rates (in these patients) compared to patients with abnormal ALT. Therefore, patients with persistently normal ALT should be considered for therapy."

4. Treatment is rigorous and poorly tolerated therefore it is wise to protect treatment investment by reducing the 24% drop-out rate by:

i. Opening more "Hepatitis C Integrated Prevention and Care Treatment Clinics," to provide multidisciplinary care and expedited referrals.}

ii. Putting Pegasys mono therapy on the provincial formulary because it is easier tolerate for renal patients and it is optimal treatment for genotype

iii. Treating Cytopenias: Place Eprex (erythropoietin) and GM-CSF and G-CSF on the provincial formulary to prevent treatment drop-out because "Interferon and ribavirin therapy induces declines in red blood cells, white cells and platelet counts." As well, often cirrhotic patients will present with these.

"Studies show that the use of erythropoietin allows the ribavirin dose to be maintained. GM-CSF and G-CSF have been used to treat interferon-induced neutropenia.

—"Management of Viral Hepatitis: A Canadian Consensus Conference 2004."

As I am sure you are aware, for the first time in decades new classes of hepatitis C medications have become available over the last few years. And there are more to come! Access to new medications is one of the most important priorities for British Columbians with hepatitis C, along with access to specialists. We receive phone calls and correspondence about this issue on a daily basis and need to provide our members with the most up-to-date and accurate information.

Thank you for your time on these matters and I look forward to your responses.

Hepatitis C is both preventable and treatable.

Marjorie Harris, President, HepCURE  
Box 195, Armstrong, BC V0E 1B0

Arthur Ralfs, Treasurer, HepCBC  
306-620 View Street, Victoria, BC V8W 1J6

Phone: (250) 546-2953

Website: [www.hepcure.ca](http://www.hepcure.ca)

Email: [hepcure@sunwave.net](mailto:hepcure@sunwave.net)

CC: MLA Randy Hawes, MLA Lorne Mayencourt



## CHIRON COOPERATES

Chiron Corp. is agreeing to let researchers waive up-front patent fees and pay yearly to use the hepatitis C virus. In exchange, Chiron will take a higher portion of the royalties on any resultant product the researchers sell. The first contract of this sort is with Prosetta Corp.

Chiron was the first company to identify the hepatitis C virus (in 1987). It patented the virus so that anyone who has wanted to research it has to pay Chiron. The patents will not expire until 2015. Until then, the seven-figure cost has been high enough to scare many potential researchers away. Meanwhile, Hep C patients have been suffering the consequences.

Chiron is one of the drug companies trying to block the importation of cheaper drugs from Canada into the U.S.



Source: Denise Gellene, Times Staff Writer, Chiron Relaxes Patent Licenses

## LETTER TO THE EDITOR

To HepCBC,

We are writing this note to pass on hope to those undergoing, or considering taking, the combo treatment for Hep C.

My husband contracted Hep C in January 1991 through blood transfusions after an accident. The Red Cross notified our doctor 8 years later to have Wayne tested for Hep C. Sure enough, he had it. We decided to try natural ways to treat it, using milk thistle, special diet, and lots of rest, but his numbers kept climbing, and in early 2002, at age 53, the specialist strongly recommended he go on the combo treatment for 6 months.

It was not an easy time, especially the last 2 months. With the help of our family, we were able to keep his spirits up and give him hope. Six months later, he tested negative, and 6 months later, he is still in remission. So far, so good, and he is very glad he took the treatment. We want to let those who are considering the treatment know that it is not easy to get through, but it worked for Wayne.

Thank you.

Wayne & Carol Plautz

### David Harvey's Traceback Tips:

For Canadian Blood Services (CBS) to do a traceback (i.e., trace the donor of the blood you received to see whether the donor has Hep C), they need the unit number of the blood you received. Without a unit number, CBS cannot do anything. So, what you need is a unit number from your hospital.

Hospitals are only required to keep records for a particular period of time, after which they may destroy them. Storage costs for hospital records are significant, so many hospitals routinely destroy records after the allotted time. Others put things on microfiche. Others keep everything. Even those that have record retention policies that provide for destruction of records will routinely not destroy them. It's a real mix, depending on the hospital, the time frame, etc. You should continue to press the hospital to be sure whether your chart does actually exist.

Even if your hospital chart has been destroyed, there are several other places you can look. Many hospitals have separate records in the blood bank which may show which units were cross-matched for which patients. You should specifically ask the hospital about blood-bank records. Also, your family doctor or specialist may have received copies of reports from when you were in the hospital. You should check those records. If your family doctor or specialist from that time is no longer practicing, contact the college of physicians in your province to determine whether they know what happened to that doctor's records when he or she stopped practicing.

*David Harvey*

### Jeannie's experience:

My traceback records of transfusions through CBS were not found. What were found were hospital records of three of my stays from 1973–1980, all from hospitals in Toronto. My family doctor had me sign requests that he sent out to each of these two hospitals. The hospitals called him and indicated that all my information was on microfiche. The doctor replied, "Transcribe and send out hard copy immediately."

Not surprisingly, this information indicated that I was transfused with 2 units of packed red cells on January 6th, 1973 at North York General Hospital. This is what helped me. Stamped on the documents my

doctor received is "CONFIDENTIAL: This document or any copy thereof may not be released, copied or published in whole or in part without the written consent of North York General Hospital, Willowdale." My doctor gave me my own copy.

*Jeanie  
Barrie, Ontario*

## HEPATITIS C COMPENSATION COALITION

I am forming a "Hepatitis C Compensation Coalition". The coalition will lobby government to extend compensation to pre-'86–post-'90 victims, and improve the current compensation program for '86–'90 victims. One of the main reasons I want to do this is to show the government that I am writing letters and making Freedom of Information Requests on behalf of many people across the country. Would anyone like to lend their name to the coalition? I'd really like to be able to say that the coalition represents people with Hep C from across the country.

I've also created an on-line petition regarding Hep C compensation.

With a minority government in Ottawa, and the support of all opposition parties, we have a new opportunity to press for equal compensation for everyone who contracted hepatitis C from the blood system, regardless of the date of their infection.

Please take a moment to look at it, and if you agree, sign it. It can be found at <http://www.petitiononline.com/hcvcomp/petition.html>, and by sending an e-mail to David Harvey at [dh@reko.ca](mailto:dh@reko.ca), stating that you want to be a part of the Hepatitis C Compensation Coalition.

Please let me have your ideas.

*David Harvey*  
[dh@reko.ca](mailto:dh@reko.ca)  
416-362-1989



### LEGAL ACTION

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

#### 1986-1990

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

#### Pre-86/Post-90

Hepatitis C Settlement Fund—KPMG Inc.  
Claims Administrator  
2000 McGill College Avenue, Suite 1900  
Montreal (Quebec) H3A 3H8  
1-888-840-5764 (1-888-840-kpmg)

[HepatitisC@kpmg.ca](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/hepc/intro.html](http://www.kleinlyons.com/hepc/intro.html)

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

**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 1-877-434-0944.

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

### MISCELLANEOUS

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



## COMING UP IN BC/YUKON:

**Armstrong HepCure** Office and library, by appointment. Contact: Marjorie 546-2953, amberose@sunwave.net, www.hepcure.ca

**Campbell River/ Comox Valley** Hep C Support and information, call 830-0787 or 1-877-650-8787 P.O. Box 52, Port Hardy, Dan Webb (250) 902-2238 or 1-866-902-2238 [niacph@hotmail.com](mailto:niacph@hotmail.com)

**Castlegar** Contact: Robin 365-6137

**Comox Valley** Contact: AIDS Vancouver Island Hep C Community Support (250) 338-7400 355 6<sup>th</sup> St. Courtenay, B.C. Mon.-Thurs. drop-in support 9-4 p.m. Del : [dgggrimstad@shaw.ca](mailto:dgggrimstad@shaw.ca)

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

**Cranbrook HeCSC-EK Support Group** Monthly meetings- Call for details. Katerina (250) 417-2010, hecsc-ek@shaw.ca or Leslie (250) 426-6078, [ldlong@shaw.ca](mailto:ldlong@shaw.ca)

**Kamloops Hepatitis C Self-Help Support Group:** 1<sup>st</sup> & 3<sup>rd</sup> Thurs. monthly. 1 p.m. AIDS Society, 437 Lansdowne St. Call (250) 372-7585 or Susan (250) 554-7055, ask@telus.net

**Kelowna Hepkop:** Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine Riseley (250) 768-3573, [eriseley@shaw.ca](mailto:eriseley@shaw.ca) or Lisa Mortell 766-5132 [lmortell@silks.net](mailto:lmortell@silks.net) or toll-free 1-866-766-5132.

**Kootenay Boundary:** For individual support & info contact Brian Reinhard (250) 364-1112 [reiny57@yahoo.ca](mailto:reiny57@yahoo.ca)

**Mid Island Hepatitis C Society** Friendship and support group, 2<sup>nd</sup> Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Sue for info 245-7635, [mihepc@shaw.ca](mailto:mihepc@shaw.ca)

**Nakusp Support Group Meetings:** 3<sup>rd</sup> Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Contact Vivian 265-0073

**Nelson Hepatitis C Support Group** 1<sup>st</sup> Thurs. monthly. ANKORS Offices, 101 Baker St. Contact Alex Sherstobitoff, 1-800-421-2437, 505-5506, [info@ankors.bc.ca](mailto:info@ankors.bc.ca) <http://www.ankors.bc.ca/>

**Boundary Hep C Support.** Contact Ken 250-442-1280 [ksthomson@direct.ca](mailto:ksthomson@direct.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. Contact Dianne Morrissett 604-517-6120 [dmorrissett@excite.com](mailto:dmorrissett@excite.com)

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

**Prince George Hep C Support Group** 2<sup>nd</sup> Tues. monthly, 7-9 PM, Prince George Regional Hospital, room 1356 (former Chapel) Contact Gina 963-9756, [gina1444@yahoo.ca](mailto:gina1444@yahoo.ca) or Ilse 565-7387 [ikuepper@northernhealth.ca](mailto:ikuepper@northernhealth.ca)

**Prince Rupert Hepatitis C Support** Contact Ted Rogers (250) 624-7480, [Ted.Rogers@northernhealth.ca](mailto:Ted.Rogers@northernhealth.ca)

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

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

**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, 12 noon, **3862 Broadway (behind Panago).** Contact Deb 877-0042 or Doreen 847-2132, [deb@plnw.org](mailto:deb@plnw.org)

**Sunshine Coast—Sechelt:** 1<sup>st</sup> Wed. monthly, 6:30 pm at Sechelt Indian Band Health Unit. Contact 604-885-9404

**Pender Harbour** – 3<sup>rd</sup> Thurs. monthly, 6:30 pm at Pender Harbour Paper Mill. Contact Myrtle 604-883-0010 or Bill, pager 604-740-9042

**Vancouver: Healing Our Spirit**—Offering HCV and HIV education, support to Aboriginal People in BC. 100 - 2425 Quebec St. Contact 1-800 336-9726, [info@healingourspirit.org](mailto:info@healingourspirit.org) [www.healingourspirit.org](http://www.healingourspirit.org)

**VANDU Vancouver Area Network of Drug Users** Each Mon., 2 PM, Bus fare & snack. 50 East Hastings St. Bus fare & snack. Contact Cristy or Ann 604-683-8595 (ask for VANDU). Space limited. [vandu@vandu.org](mailto:vandu@vandu.org) [www.vandu.org](http://www.vandu.org)

**Vancouver:** Pre/post liver transplant support Contact Gordon Kerr: [sd.gk@shaw.ca](mailto:sd.gk@shaw.ca)

**YouthCO AIDS Society HepCATS #205-1104** Hornby St., Vancouver. Contact for info, Caitlin Padgett [caitlinp@youthco.org](mailto:caitlinp@youthco.org) Support, contact Matt Lovick 604-688-1441 or 1-877-YOUTHCO [www.youthco.org](http://www.youthco.org)

**Vernon HeCSC HEPLIFE** 2<sup>nd</sup> & 4<sup>th</sup> Wed. monthly, 10 AM-1 PM, The People Place, 3402-27<sup>th</sup> Ave. Contact Sharon 542-3092, [sgerant@telus.net](mailto:sgerant@telus.net) <http://www.hepc.vernon.bc.ca/>

**Victoria Support & Info** Contact The Needle Exchange 384-2366

**Victoria HepCBC & INFO line**—Contact (250) 595-3892 [info@hepcbc.ca](mailto:info@hepcbc.ca), [www.hepcbc.ca](http://www.hepcbc.ca) Library open M-F 306-620 View St. Private appointment either for phone support or interviews.

**Works Without Words Yukon Hep C Support Group** Every Thurs. at 7 p.m., Grace Community Church, 8<sup>th</sup> & Wheeler St. Contacts: Harry & Debbie 867-667-2402 [harry.mckenzie@klondiker.com](mailto:harry.mckenzie@klondiker.com) Brian: 867-668-4483 P.O. Box 31216, Whitehorse, YK.

### QUEBEC:

Arundel Contact Andy Aitken [chcn\\_alexander@sympatico.ca](mailto:chcn_alexander@sympatico.ca) Canadian Hepatitis C Network <http://www.canhepc.net/>

**Quebec City Region** Contact Renée Daurio 418-836-2467 [reneeaurio@hotmail.com](mailto:reneeaurio@hotmail.com)

## OTHER PROVINCES

### ATLANTIC PROVINCES:

**Fredericton, NB** Contact: Bob, 453-1340

**Saint John & Area:** Information and Support. Contact Allan Kerr [kerrs@nbnet.nb.ca](mailto:kerrs@nbnet.nb.ca)

**Cape Breton Island, N.S.** The Hepatitis Outreach Society Support Group 2<sup>nd</sup> Tues. monthly 150 Bentick Street, Sydney, N.S. 7:00 - 9:00 PM. Call Cindy Coles 1-800-521-0572, (902) 733-2214 Fax (902) 733-2043 [hosc@ns.sympatico.ca](mailto:hosc@ns.sympatico.ca)

### ONTARIO:

#### Barrie Hepatitis Support

Contact: Jeanie for information/ appointment 705-735-8153 [hepcsupportbarrie@rogers.com](mailto:hepcsupportbarrie@rogers.com)

#### Durham Hepatitis C Support Group

2<sup>nd</sup> Thurs. monthly, 7 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contacts: Smilin' Sandi [smking@rogers.com](mailto:smking@rogers.com) "Sandi's Crusade Against Hepatitis C" <http://creativeintensity.com/smking/> 1-800-841-2729 ext. 2919 re: HCV testing, free Hep A and Hep B Vaccines and group info. Next Meetings: Aug. 12, Tai Chi Sept. 9<sup>th</sup> Speaker: Dr. Durhane Wong-Rieger, PhD "Living Well with Hepatitis C" <http://health.groups.yahoo.com/group/hepc-info/>

#### Kingston Hep C Support Group

1<sup>st</sup> Wed. monthly, 5:30 PM, - 9 p.m. St. George's Cathedral, King and Johnson St. (Wellington St. entrance) Contact: HIV/AIDS Regional Service 613-545-3698

#### Unified Networkers of Drug Users

Nationally [undun@sympatico.ca](mailto:undun@sympatico.ca)

#### 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) No meetings in July or August.

#### Niagara Falls Hep C Support Group

Last Thurs. monthly, 7 PM excluding July and Dec., Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact Rhonda (905) 295-4260, [hepcnf@becon.org](mailto:hepcnf@becon.org)

#### AIDS Committee of North Bay

Bi-weekly HCV Support meetings Shannon (705) 497-3560

#### Peel Region Hep C Support Group

[www.peel-hepc.com](http://www.peel-hepc.com) Contact (905) 799-7700 [healthlinepeel@region.peel.on.ca](mailto:healthlinepeel@region.peel.on.ca)

**St. Catharines** Contact Joe (905) 682-6194 [jcolangelo3@cogeco.ca](mailto:jcolangelo3@cogeco.ca)

#### Hepatitis C Network of Windsor & Essex County

Contact Andrea 250-5399 or Michelle 256-1878, [hepcnetwork@mailcan.com](mailto:hepcnetwork@mailcan.com) <http://hepcnetwork.cjb.net>

#### York Chapter HeCSC

3<sup>rd</sup> Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact (905) 940-1333, 1-800-461-2135. [info@hepcyorkregion.org](mailto:info@hepcyorkregion.org) [www.hepcyorkregion.org](http://www.hepcyorkregion.org) No meetings in July or August.

### PRAIRIE PROVINCES:

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

#### Hep C Edmonton

HCV, pre/post liver transplant support Contact Fox 473-7600, or cell 690-4076, [fox@kihewcarvings.com](mailto:fox@kihewcarvings.com)

#### Fort McMurray, Alberta

Hepatitis C Support Network 1<sup>st</sup> Wed. monthly 12:00-2:00 p.m. Lunch included. #205, 10012A Franklin Ave. Contact: Lyn (780) 743-9200 Fax (780) 943-9254 [wbbas@telus.net](mailto:wbbas@telus.net)

#### Medicine Hat, AB Hep C Support Group

1<sup>st</sup> & 3<sup>rd</sup> Wed. monthly, 7 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Phone (403)527-7099 [bettyc2@hivnetwork.ca](mailto:bettyc2@hivnetwork.ca)

#### 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, [here@smd.mb.ca](mailto:here@smd.mb.ca)

Note\* Some support groups do not have meetings in the summer months or other seasonal holidays-contact the group for clarification.

If you have a Canadian HCV Support Group to list on this page, please send the name of the group, day, time, place, contact name/phone, and email address to [smking@rogers.com](mailto:smking@rogers.com) PLEASE inform me of any changes, or of any special events/speakers, etc., in your area, well in advance of the date. —Smilin' Sandi



## BE PART OF THE TEAM!

We need people to summarize articles, and HepCBC needs office staff. The HepCAN list needs a moderator trainee. Please contact Joan at 250-595-3892 or [info@hepcbc.ca](mailto:info@hepcbc.ca)