



# hepc.bull

## Canada's Hepatitis C News Bulletin

www.hepcbc.ca

### HEPATITIS C AWARENESS IN MAY

#### PROCLAMATIONS, DECLARATIONS, RECOGNITION, PERSPIRATION May 2003 is National Hepatitis C Awareness Month

May 1<sup>st</sup>, 2003 will mark the 4th Annual Hepatitis C Candlelight Memorial Ceremony, and is the first day of Hepatitis C Awareness Month in Canada and in other parts of the world. May 1<sup>st</sup> will also mark the first year that the majority of Canada's provincial governments, through proclamation, declaration, or some other form of official recognition, will acknowledge a month to honor Canadians living with Hepatitis C.

#### History In The Making

The 1<sup>st</sup> Candlelight Ceremony (May 1<sup>st</sup>, 2000) was inspired and instituted in British Columbia by a small group of friends, including Sue White, Carol Romanow, Bob Edwards, and Marjorie Harris, as a hepatitis C awareness event. Thousands of people in 16 cities across North America gathered in unity that first year to share and remember together.

Meanwhile, on the other side of the country in Nova Scotia, Bruce DeVenne (HepCAN) was still working with his MP to have "The Hepatitis Awareness Act" act passed through Parliament and made law.

#### HEPATITIS AWARENESS MONTH ACT Excerpts from Hansard

Monday, October 18, 1999 - House of Commons, Ottawa - Mr. Peter Stoffer (Sackville-Musquodoboit Valley-Eastern Shore, NDP) moved for leave to

### UPDATE ON HYPERTHERMIA TRIAL

by Darlene Morrow

Hi Everyone,

I know that I said I would e-mail after I stopped the high dose interferon therapy but it took too much out of me. I am now in my second week of the once a week Pegylated interferon injections. It is going much better. The less said of the high dose therapy the better :-)

At the moment my white count is very low (1). We are hoping this is a result of the high dosages and it will come up soon. Otherwise, I will be taken off therapy until it normalizes and will be put back on half the dose. This is not preferable as it can allow the virus to mutate and escape treatment. The next couple of weeks should tell the story.

Fortunately the Doctor is very up to date and willing to consider the whole picture and not just the white count. I met him Wednesday and he gave me the good news I am an early responder to the treatment. That means the chance of success (the virus remaining unde-

(Continued on page 5)

### LETTERS TO HEALTH SANTE IN THE MERRY MERRY MONTH OF MAY OR MORE TREATMENT APPROVAL DELAYS

#### Is There Really A Choice?

On May 31, 2002 (the last day of Hepatitis C Awareness Month), when Health Canada approved Schering's pegylated interferon bundle (PEGETRON) for sale in Canada at the federal level, I never imagined that, almost a year later here in BC, we would still be waiting for provincial approval by BC Pharamacare. Yet here we are, almost a whole year later, and BC still cannot tell me when approval will occur, citing paperwork errors as a reason for delay. According to Schering, at the time of this writing, BC is the last province to approve PEGETRON. Here in the West, following The Yukon's example (The Yukon Approved PEGETRON in December 2002), Alberta and Saskatchewan approved PEGETRON April 1, 2003, and Manitoba will offer Schering's "PEG" effective May 1, 2003.

"Only a year, and 9 out of 10 provinces... that's not so bad," you might say, if you disregard the fact that BC leads the rest of the country with 4 times the national average for hepatitis C infection, and the fact that anyone with genotypes that are hard to treat, like genotype 1a, who decided to treat before PEGETRON, had a less than 50% chance of successfully clearing the virus. In BC this is still the case unless you can get into a study. Hoffman-La Roche is presently offering their pegy-

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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:

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## HOW TO REACH US:

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## 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 both include 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, Chris Foster, Ian Campsall, Darlene Morrow, Will Lawson, Judith Fry, Rebekah Coopsie, Inar Hansen and D&D friends, Ron Comber, and Stacey Boal. 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, #5-915 Glen Vale Rd, Victoria BC V9A 6N1

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.*

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.

AD 25: SF, Indo-Cdn., 35 years old. 5'7", heavy-set. Hep C+, but I still enjoy life, and try to stay active. I love movies, pets, music, traveling, and reading. I occasionally take self-improvement courses. Searching for SM who is confident, caring, would benefit from my company, and can keep me happy. Richmond.

## Got Hep C? Single? Visit:

<http://nationalhepatitis-c.org/singles/list.htm>  
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Yo. Well, hey, guess what...It ain't fun!!!!. I take my injection on Wednesdays and this week the sides kicked in on Thursday nite. Never can tell with this peg stuff.

I've also developed a bit of Ribavirin-related asthma (that happened on Rebetrone, so I know what it is).

Other than that: I have lost the ability to read, and I'm mostly too tired to follow a movie through, so it's splog splog splog and splog some more, when I'm not sleeping, which is about 12 hours a day MINIMUM

I'm almost always nauseated. I really don't want to eat; but I find that if I eat something good I like it; trouble is I don't want to eat. I am almost always bloated; I do not sleep well, and I have lots of headaches.

Just got my Week 4 results back: AST 57, ALT 73, and my WBC is slightly low at 3.8 and my neutrophils are slightly low at 1.7.

Other than that, to tell you the truth, life could be a lot worse.

To all of you on treatment: Hang in there.

Squeeky

### 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.

### DIAL-A-DIETITIAN

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

### HCV FROM POLIO SHOTS?

The rate of HCV infection in southern Italy is very high. A recent study suggests that this may be due to polio vaccination from 1956 to 1965, because of the use of improperly sterilized glass syringes. People born between 1940 and the early 1960s are infected three times as often as younger people in that area.

*Source: Montella M, et al, Assessment of iatrogenic transmission of HCV in southern Italy: Was the cause the salk polio vaccination? J. Med. Virol. 70: 49-50, 2003 PMID: 12629643*

### PEGETRON TO BE COVERED IN MANITOBA

HCRC, Inc., reports that Pegatron will be covered under provincial pharmacare as of May 1, 2003. The price will be the same as Rebetrone. All genotypes will have access to Pegatron, and HCRC says Schering does not anticipate any problems about providing treatment to everyone. HCRC wants to thank those who participated in the letter writing campaign to the provincial and federal governments.

*Source: Hepatitis C Resource Center, Inc hrcrc@smd.mb.ca*

### SHOULD HE?

Dr. Michael Hall, a heart surgeon in Manhasset with hepatitis C is still opening and closing patients' chest cavities, despite being advised the pro-

cedures have already infected his patients. The riskiest parts of an operation for injuries or glove punctures during heart surgery are when the breastbone is cut, or when the sternum is sewed back together and the wires are tied. Dr. Hall prefers to complete the operation by himself. He is one of the best surgeons in the state. He is required to inform his patients of his infection and the slight risk of contracting Hep C from the surgery if he should nick himself and bleed into an open cut. He now uses double gloves, and blunt needles to close the sternum, and announces the use of sharp instruments during the operation. The health department suggested that the doctor let someone else close the chest, or that he use clamps rather than wires, but later his technique was evaluated by an expert and pronounced "exemplary" with "a very low risk" of viral transmission. Other evaluators, though, said the doctor sometimes tied stitches with needles attached, and put his fingers next to the needle when closing the sternum. Other surgeons commonly let a trainee open and close patients, but Dr. Hall has a very low complication rate. A 1988 study in *The Lancet* said 40% of surgeons experienced glove punctures, a rate which has now gone down to 12%. Dr. Hall has not infected any patients since modifying his techniques.

*Source: Newsday, Inc., March 30, 2003, Surgeon Declines Safety Advice: LI doctor with hepatitis C still opening, closing chests, by Roni Rabin*



### TRIALS

#### NM283

Idenix Pharmaceuticals presented pre-clinical results of its HCV drug candidate, NM283, an oral ribonucleoside analog, at the 11th International Symposium on Viral Hepatitis & Liver Disease in Sydney, Australia. One week of treatment reduced viral load by more than 90% in a primate infected with HCV. The company hopes to find a better treatment than the present standard treatment, interferon combined with ribavirin, which often improves laboratory results and sometimes symptoms, but almost 50% of patients relapse after treatment ends. Side effects are frequent, and since IFN has to be injected, many patients drop out. NM283 is taken orally, once a day, and seems to be well-tolerated. Idenix scientists have found several nucleoside analogs that should be effective against several HCV genotypes, even genotype 1, the most resistant and the most common. The FDA approved the evaluation for NM283 late last year, and it is now in phase I/II trials in naïve Hep C patients, and non-responders. Safety and effectiveness will be tested in adults with genotype 1 HCV, and determine the best dose for future trials.

*Sources: <http://www.idenix.com/press/030409.html>, Idenix presents positive hepatitis C and hepatitis B results [http://www.idenix.com/hcv/hcv\\_treatment.html](http://www.idenix.com/hcv/hcv_treatment.html), Current HCV Treatment, <http://www.idenix.com>.*

*(DELAYS—Continued from page 1)*

lated product (PEGASYS) to selected patients while they wait for approval at the federal level.

So how long does federal approval take? According to Louise Binder of CTAC (The Canadian Treatment Action Council), it took Health Canada's Therapeutic Products Division (TPD), the department responsible for federal approval of prescription drugs, 653 days to approve PEGETRON from its filing date on August 15, 2000. That's almost 2 years. By comparison, in 1999 it took only 316 days for Canada's TPD to approve REBETRON, PEGETRON's non-pegylated predecessor. Also by comparison, it only took the FDA in the US 182 days to approve Schering's pegylated treatment.

It gets worse. A new layer of bureaucracy has been introduced between the federal and provincial levels called The Common Drug Review (CDR), and it is expected to slow down the process of getting prescription drugs to patients even longer. It seems that everyone "gets in on the act". So where do we as patients fit in? Nowhere in the approval process, it seems!

Despite the efforts of treatment advocacy groups concerned with hepatitis C drugs, like CTAC, the Consumer Advocare Network, and the Best Medicines Coalition (BMC), there continues to be a lack of transparency (openness) between the consumer (patient) and the government drug approval process. Drug manufacturers like Schering or Hoffman-La Roche will not share this information, since the information they provide is proprietary and held as competitive intelligence between companies. Because of this, the information we can get from the drug companies is spotty at best. The only transparency in the whole drug approval process in Canada seems to be between different levels of government.

With new drugs like Novartis-IDENIX nucleoside antiviral NM283 soon to be coming down the "pipeline," we are looking at waits of 3 years or longer under the current system. A cure could be discovered tomorrow, and patients would be made to wait and worsen for 3 years.

## **Pegylated Interferon Treatment for HCV**

Treatment for hepatitis C is a bundled combination of two drugs—a long-acting form of interferon (IFN) called pegylated IFN, and another drug called ribavirin. In Canada, the combination is bundled. The long-acting IFN is taken by injection once weekly, while ribavirin comes in the form of capsules and is taken twice daily. Side effects from combination therapy include fever, headache, tiredness and sometimes depression.

IFN is a chemical messenger, or cytokine, made by cells in your body. This cytokine protects your cells from infection by HCV, and helps your immune system fight HCV. The "peg" in pegylated IFN stands for polyethylene glycol (antifreeze).

When peg is attached to IFN, it provides a protective barrier that shields the interferon from being broken down, thus prolonging the time it remains in the blood. Regular IFN needs to be injected at least three times weekly. Pegylated IFN only has to be injected once a week and appears to be stronger than regular IFN.

Ribavirin is a type of drug called a nucleoside analogue, or simply a "nuke." When taken by itself, ribavirin is a weak drug. However, when taken together with pegylated IFN, the combination is powerful.

Although potent, combination therapy for HCV with pegylated IFN and ribavirin can create a series of problems that include Mental Health Issues like anger and depression, including suicidal tendencies, and tiredness, nausea, abdominal pain and shortness of breath. The depression may require treatment while you are taking pegylated IFN. Heart and blood problems like anemia and vision problems are also common side effects. Both pegylated IFN and ribavirin can temporarily weaken the bone marrow.

But when you cannot wait or you don't want to wait, these harsh treatments do offer a better than 50% chance of clearing the virus if they are available.

**Patient Action = Treatment Access**

As I sit here pondering the dilemma that we as hepatitis C patients face in accessing treatments, including intake capacity problems (there are too few treatment facilities), and the fact that treatment in provinces like BC is based on LFT's (Liver Function Tests), which are not by themselves conclusive criteria, the future seems pretty grim for increasing our community's treatment options, unless we "turn-up the heat" and get our governments to make these drugs available to doctors and their patients alike.

While it is true that groups like Durhane Wong-Rieger's Consumer Advocare Network have written politicians and bureaucrats alike in their efforts to assure a patient voice in the drug approval process, governments need to hear from the patients themselves, as well as the advocacy groups. Maybe they will begin to respond to the advocacy groups if we hold the governments accountable for hiding behind ever-increasing layers of delay mechanisms cloaked in the secret interests of safety and economics.

The latest "hold-up" at the federal level is PEGASYS, the Hoffman-La Roche pegylated bundle, which may prove in some patients to be the best alternative, and which is currently being "fast tracked" by the TPD after being submitted October 15, 2002. PEGASYS may be approved by early summer (that's monotherapy, not combination (COMBO) therapy, which means that Hoffman-La Roche will still need to give away COPEGUS brand ribavirin to treat patients until COPEGUS is approved as well.)

I am suggesting that it is time for the entire hepatitis C community to take time to write the Federal Health Minister and indicate our concern every time we discover that some bureaucratic delay is keeping us from accessing the best medicines for our disease.

Below is a letter that I have written to the Minister of Health about my concern. I would ask anyone who supports the issue that I have taken over this delay and the sad series of historical delays over HCV treatment drugs to either write a letter of their own or simply sub-

*(Continued on page 5)*

(DELAYS—Continued from page 4)

stitute my name with their own and email, snail mail, or fax it to the Health Minister. Let's see if we can get better results than what we have now.

### Letter of Complaint - Templates

Hon. A. Anne McLellan  
Minister of Health  
Minister's Office - Health Canada  
Brooke Claxton Bldg.,  
Tunney's Pasture, P.L. 0906C  
Ottawa, Ontario, Canada  
K1A 0K9  
Fax: 613-952-1154  
Email: McLellan.A@parl.gc.ca

Dear Health Minister,

I am writing you today out of concern for the slow approval times for hepatitis C treatment drugs at the federal level in the Therapeutics Products Division (TPD) of Health Canada.

As a case in point, many Canadians living with Hepatitis C are aware that Hoffman-La Roche is giving away their PEGASYS pegylated interferon product while waiting for Health Canada to approve PEGASYS.

What many aren't aware is that Canadians with hepatitis C have been waiting for 3 years for this approval. It will take another year after this approval before PEGASYS is put on the provincial pharmacare programs. This constitutes a 4 year wait.

Of special concern to me is the possibility of continued delays for patients who can't take the existing treatments or who stand a better chance with PEGASYS?

It is unfair that our doctors are under-prescribing by staying with existing treatments when better treatments like PEGASYS are being approved too slowly.

What does this mean for other drug companies who have new treatments and who can't afford to give away product like Hoffman-LaRoche and what does this mean for people who fail both treatments?

I don't think a monopoly is good for Canadian patients with hepatitis C, and what if those who have been treated experience a rebound and their HCV returns and Canada has discour-

aged competition?

There are 240,000 Canadians with hepatitis C and only a few thousand have been treated to date. Many are waiting for better drugs like PEGASYS to begin treatment and are disappointed and frustrated at the delays. We will continue to bring these issues forward until delays for drugs like PEGASYS no longer exist.

Sincerely,

Bill Buckels, Secretariat  
CHCAN (The Canadian  
Hepatitis C Activist Network)  
104 - 3340 Wood Ave.  
Armstrong, BC V0E 1B4  
Phone: (250) 546 - 2146  
Email: chcan@sunwave.net



## PROLONGED IFN THERAPY FOR 1b

In this study, only 10% of patients with HCV genotype 1b and a high viral load (more than 1 Meq/ml) had a sustained viral response to a 6-month course of interferon (6 MU of natural IFN-alpha a day for 8 weeks and then three times a week for 16 weeks.). Prolonged IFN therapy was tested in 51 of these patients. During the trial, the patients were divided into two groups. The first group was given 6 MU of natural IFN-alpha three times weekly for 24 weeks. The second group was treated with 6 MU of IFN-alpha three times a week for 48 weeks.

Viral response occurred in 16.6% of the patients in the 48-week-group and in 20% in the 72-week-group. The researchers concluded that prolonging IFN therapy could be a good strategy for patients with genotype 1b and a high viral load.

*Source: Arase Y, et al, Efficacy of prolonged interferon therapy for patients with chronic hepatitis C with HCV-genotype 1b and high virus load. J Gastroenterol. 2003;38(2):158-63.PMID: 12640530*

## DENIED

March 17, 2003

(From Pacific Blue Cross to "Ms. Anonymous")

Dear Ms. A,

This is in reference to your recent letter regarding the eligibility of Pegetron and Rebetrone under your Extended Health Care Plan.

According to the terms, conditions and benefits of this Extended Health Care Contract, we will provide reimbursement for drugs and medicines that legally require a prescription from a Physician and are eligible under the British Columbia provincial government's Pharmacare program. Any medication not eligible through the Pharmacare program will not be covered by this Contract.

Our records indicate that Pegetron and Rebetrone are not eligible under the Pharmacare program. Therefore, they are not eligible medication under the terms of this Contract.

If you have any questions, please call us at 604 419-a2600 or 1-888-4672 (toll free). Our Service Representative will be pleased to assist you.

Yours truly,  
(Illegible signature)

Extended Health Care  
Pacific Blue Cross

(HYPERTHERMIA—Continued from page 1)

tectable and staying that way) is very high. Needless to say I am jumping for joy at this news. The last time I was on treatment it took me nine months to respond. Here's hoping my white count behaves.

I am able to enjoy my daily walk but find that any additional activity can be difficult. Fortunately there is a library close by and I have been doing a lot of reading. I have also been able to visit my mum several times a week and talk with her on the phone which compensates for being away from 'home'.

My weekly checkups will change to monthly as of April 23rd. so I have a flight booked on the 24th to go home. Needless to say I am looking forward to being at home if only for 18 days. I had hoped to be able to do some visiting when I am home, but I think it unlikely at this point. The fatigue is really horrendous and I am not trying to be anyone's hero. :-)

Take care,  
Dar



(HANSARD—Continued from page 1)

introduce Bill C-232, an act to provide for a Hepatitis Awareness Month.

He said: Mr. Speaker, I am reintroducing a bill that I introduced last year which basically calls for the month of May to be known as Hepatitis Awareness Month.

Friday, March 30, 2001 - Mr. Peter Stoffer (Sackville-Musquodoboit Valley-Eastern Shore, NDP) moved that Bill C-243, an act to provide for a Hepatitis Awareness Month, be read the second time and referred to a committee.

He said: Madam Speaker, it gives me great pleasure after three and a half years of researching, studying and working with activists to finally bring the bill for debate before the House of Commons.

I will ask again at the end of the debate to make the bill votable.

Mr. Yvon Charbonneau (Parliamentary Secretary to Minister of Health, Lib.): Madam Speaker, I take this opportunity to speak about the important issue of hepatitis.

Health Canada already supports the Canadian Liver Foundation declaration of "Help Fight Liver Disease Month" for the month of March.

**Excerpts From Hansard Monday  
April 30, 2001**

Mr. Yvon Charbonneau (Anjou-RiviÈre-des-Prairies, Lib.): Mr. Speaker, I would like to recognize the diligent efforts of the hon. member of parliament for Sackville-Musquodoboit Valley-Eastern Shore in promoting Hepatitis C Awareness Month. Although Bill C-243 was dropped from the order paper, I am nevertheless pleased to inform the House that the Minister of Health has designated May as Hepatitis Awareness Month. Increased public awareness is essential if Canadians are to be better informed about hepatitis. Hepatitis Awareness Month is a good means of achieving this.

The profile of hepatitis C will be raised at the upcoming Canadian conference on this disease which will take place in Montreal this week. Health Canada is a major sponsor of this conference. By designating May as Hepatitis C Awareness Month, our government

is providing clear proof of its commitment to fight this disease through prevention and information.

**Hansard Thursday, May 17, 2001**

Hon. Allan Rock (Minister of Health, Lib.): Mr. Speaker, Health Canada has designated the month of May as Hepatitis Awareness Month in Canada. I thank colleagues in the House for encouraging that step to be taken. Just last week Health Canada organized and financed a national conference on hepatitis C to have researchers come together, share information and enlarge both public understanding and scientific discoveries in hepatitis treatment. We are focusing on supporting those in the community who work in this area and on assisting scientists across the country developing new methods of treatment and hopefully one day a cure.

On May 1, 2001 HepCURE and the Hepatitis Foundation of Quebec were in Montreal at the 1st National Conference on Hepatitis C and led the May 1st ceremony with groups and individuals from across Canada. Health Canada designated May 2001 as Hepatitis Awareness Month in Canada.

It should be noted that Health Canada never did place either Hepatitis Awareness Month nor Hepatitis Awareness Month on their Calendar of Events website. I have been working with them to get this rectified this year (2003), and by the time you read this, Hepatitis C Awareness Month may hopefully be recognized along with the other disease months. Hope is what Hepatitis C Awareness Month is really about anyhow, and remembrance, of course.

It is a time to celebrate the lives of those who have died, and those who continue to live and who are affected by this disease.

**TIP OF THE MONTH:**  
**Make a  
Difference:  
Write a letter**



**The Month of May  
Forever**

**A Hepsong (Hepatitis Song Parody)  
About the Killing of Bill C-243,  
May, Hepatitis Awareness Month,  
Sung to the Tune of  
The Maple Leaf Forever**

On Commons floor,  
From Scotia's shore  
Stoffer's legislation fell!  
He tried to pass the month of May  
Hepatitis Awareness Bill.  
But Charbonneau,  
With blustering pride  
And Liberals joined together,  
With petty politics they killed,  
The Bill of May forever.

[CHORUS]

The Month Of May,  
We stand as one,  
The Month of May together.  
Of hepatitis be aware,  
The Month of May forever.

From Red Cross blood and fellow man  
We became infected,  
Yet because of Liberals' pride,  
The remembrance was rejected.  
And so our rights which they ignore,  
We swear to yield them never.  
Our watchword ever more shall be  
"The month of May forever!"

[CHORUS]

Hepatitis now extends  
From Cape Race to Nootka Sound  
May Canada forever be aware  
Of how this killer now abounds  
And may we work towards a cCure,  
Which Causes cannot Sever  
And with yellow and red we'll be aware  
The Month of May forever

[CHORUS]

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**THE FIRST PROVINCIAL  
PROCLAMATION -  
MAY 2001  
MANITOBA PROCLAIMS MAY  
HEPATITIS AWARENESS  
MONTH**

In 2001, while preparing to attend the First National Conference on Hepatitis C, a group of internet friends who were doing community based support across Canada gathered together around Marjorie Harris, HepCURE's president, and decided to focus on hepatitis C awareness in the month of May as one of the priorities in this brave new pre-treatment, post-treatment world of hepatitis C. It was then that I got the idea, inspired by Marjorie's civic proclamation from the previous year, that I should approach the Province of Manitoba for a Hepatitis Awareness Month proclamation at the provincial level. Manitoba was in the process of announcing its tainted blood traceback program.

And Presto! We got a proclamation, and I hung it on the wall, and the following year (2002) we got another, and it is hanging in the office of a community-based group in Winnipeg. This year (2003) it has gone to a different group, David Hartung's HepSEE WPG.

**The Second and Third  
Provincial Proclamations  
May 2002**

On May 1, 2002 in British Columbia, in partnership with many other groups including HepCBC, HepCURE (Marjorie Harris and I) held a Hepatitis C Awareness day event on the steps of the Victoria Legislature. HepCURE had received proclamations declaring May as Hepatitis Awareness Month from the provincial health ministers of two provinces; British Columbia and Manitoba (for 2 years in a row).

The BC HepC Circle (our provincial network) signed a petition that year in support of the first BC Proclamation. At that time I was reluctant to change the disease month to Hepatitis

C from Hepatitis because I was afraid of deviating from what I had done in Manitoba in 2001. Not now though... Canadians Living With Hepatitis C need their voices heard during a disease specific awareness Month.

**Back To The Present - Hepatitis C  
Awareness Month - May 2003**

Well, there you have it... the historical perspective. Which brings us back to the present. So what's happened so far this year?

I got a late start on my Awareness Month Proclamations so it "touch and go" and I worked many long hours sending out email in any direction I thought would help. It is a full time job for a month or two.

I am pleased to report that at the time of this writing, the BC Proclamation for Hepatitis C Awareness Month has already made it to Cabinet and will likely be approved by the time this goes to print. (The BC Attorney General's Office has also indicated that we are to deal directly with their office in future years after we have established May as Hepatitis C Awareness Month in British Columbia.)

This brings the count of the provinces who have proclaimed, declared, or otherwise recognized May as Hepatitis C Awareness Month to eight.

Nova Scotia, New Brunswick, Newfoundland, and PEI have unanimously recognized May 2003 as Hepatitis C Awareness Month.

Premier Roger Grimes proclaimed May, 2003 as Hepatitis C Awareness Month in Newfoundland and Labrador. With no hepatologist in Newfoundland, Hepatitis C patients must go to other provinces to seek the advice of a liver specialist.

After 3 years of trying Debi Ripley of HepC Moncton took forward the proclamation in New Brunswick. Premier John Hamm of Nova Scotia signed his proclamation and faxed it to Cindy Coles of The Hepatitis Outreach Society Thursday, April 3rd.

Manitoba provided a proclamation joining Saskatchewan and Alberta in recognizing May as Hepatitis C Awareness Month.

The Yukon has also proclaimed May as Hepatitis C Awareness Month and May 1st as Hepatitis C Awareness Day. There has been no word from the other territories, though, despite several emails to their governments.

**Other Provinces**

Quebec and Ontario continue to be the only provinces in Canada who are not officially recognizing May as Hepatitis C Awareness Month. Efforts are strong in both provinces to convince the respective governments that citizens of those provinces living with hepatitis C deserve recognition in this national effort.

Even with the election in Quebec, we still expect to receive a proclamation. We are not certain in Ontario, and efforts by community groups in Ontario, both at the provincial level and civic level, are continuing!

**Civic Proclamations**

In the Month of May 2003, groups and individuals from across Canada, from British Columbia to Newfoundland, and around the world, will participate in a Hepatitis C Awareness Day event in their own community.

You might want to start a Hepatitis C Awareness event of your own or help out with one. For instance IDU's (Intravenous Drug Users) might want to do a "Safe Injection Day", or a support group predominated by "shut-ins" and persons with cirrhosis might advocate awareness through fax and letter writing campaigns to local and national politicians and the media. Groups, and individuals with strong roots in schools and churches might want to schedule hepatitis C awareness information seminars or workshops as part of regular classes or community activities. You are encouraged to do what you can to raise awareness. The community where you live will dictate the type of awareness event needed for your unique community needs.

This year, in addition to approaching our provincial and federal governments for proclamations, groups and individuals will approach our City Halls (City Councils) to proclaim May 1<sup>st</sup> as Hepatitis C Awareness Day for the 4th year in a row.

*(Continued on page 8)*

*(PROCLAMATIONS—Continued from page 7)*

It is an effective way to do a press release event at your Provincial Legislature or City Hall or another high profile community location. A press release at City Hall or at a Community Centre, with the cooperation the newspapers and TV, will allow you to invite the people of your community to your Hepatitis Awareness Day event, whatever that be, a tree planting, letter writing campaign, Safe Injection Day or Candlelight Ceremony.

Toronto Mayor Mel Lastman, living with hepatitis C himself, is in the process of providing a scroll recognizing May 1st as Hepatitis C Awareness Day. Also in Ontario, Jeanie Villeneuve of HepSEE BARRIE had her city proclaim May 1st Hepatitis C Awareness Day. Smilin' Sandi will likely get a proclamation for Durham region.

Cindy Coles of the Hepatitis Outreach Society in Nova Scotia already sent me six civic proclamations that I placed on the website, and has sent over 50 faxed requests to towns throughout her province.

### **On or About May 1<sup>st</sup>, 2003**

May 1st is the preferred day, but might not be available to every community.

Andrea Monkman's group, The Hepatitis C Network of Windsor & Essex County, will hold a Candlelight Vigil on Friday, May 9th, in conjunction with Windsor, Ontario's proclamation of Hepatitis C Awareness Week, May 4th to 10th. Also during that week, Vancouver, BC hosts the 2nd National Aboriginal Hepatitis C Conference from May 4th to 7th.

There will be other Major Events both in Vancouver and Victoria in the month of May 2003. We will post these details as they become finalized on the website at <http://hepcure.junction.net/may1>

Whether we do our Awareness Day event May 1<sup>st</sup> or on another day close to the beginning of May, the important thing is that we all do our parts for hepatitis C awareness. We are encouraging as many groups as possible to do proclamations and candlelight ceremonies, and we support all awareness activities. Do

some brainstorming and come up with some ideas. Let us know the particulars.

From the website at <http://hepcure.junction.net/may1> events and proclamation information and links can be posted, and events are listed for each province and territory. Other hepatitis C awareness links and information are also available from the website.

### **It's Better To Light A Candle and Bless Awareness**

At sundown on May 1<sup>st</sup>, 2003, please join us and light your own Candle of Hope in honor of those who have passed from this illness. When we share our memory of them, share also in the hope that a cure will be found, and in the belief that through aAwareness in May and throughout the rest of the year, the citizens of Newfoundland and the rest of Canada can stop the spread of the hepatitis C epidemic.

May 2003 is National Hepatitis C Awareness Month in Canada. May 1<sup>st</sup> is National Hepatitis C Awareness Day. Light a candle on May 1<sup>st</sup>, and that's what it's all about.

Be Well,

Bill Buckels

*National Event Coordinator, Hepatitis C Awareness Month, May 2003*

*Awareness Event Website*

*<http://hepcure/may1/>*

*Vice President, HepCURE (Hepatitis C United Resource Exchange)*

*Box 195*

*Armstrong, BC V0E 1B0*

*Phone: (250) 546-2953*

*Cell: (250) 549-6511*

*Fax: (250) 546-8686*

*Website <http://hepcure.junction.net>*



*Penny (AVI), Marj and Bill (HepCURE), John Hasell (BC Circle), Joan King (HepCBC), Jim Lodge (Surviving Spouse) and Squeeky (David Mazoff)*



*The Candle of Hope by Deborah Wilson and Pat Lightfoot*

### **The Candle of Hope**

The Stained Glass Candle of Hope was created in British Columbia for the 2nd Annual Candlelight Ceremony, and introduced at the 1<sup>st</sup> Canadian Conference on Hepatitis C in Montreal, May 1<sup>st</sup>, 2001.

The Candle of Hope was donated to the hepatitis C community by Deborah Wilson and Pat Lightfoot-Doyle as a symbol of hope and awareness. The Okanagan artists placed two purple eagle feathers at the centre of the burning flame of hope to represent both the spirituality of aboriginal peoples and the twin spirits of the gay community. The radiance of the flame symbolizes the piercing of the darkness of ignorance, and the spreading of the light of awareness. The cobalt blue anchors us in solemn reverence of the preciousness of life, and the red and yellow hepatitis C ribbon, which stands front and centre, represents the tainted blood that carries this blood borne pathogen.

**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)*



## 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 Hepatitis C Conference. This is your opportunity to share your experiences, stories, and 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**

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)

**Abstract Deadline was February 15, 2003.**  
Scholarships are available.



### 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 Er-  
rands Grant Applications  
Board Member Other**

### Experience:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Time available:

\_\_\_\_\_

**SEX** M F

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

**Mo Day Year**

**Contact: HepCBC**

#5-915 Glen Vale Rd  
Victoria BC V9A 6N1

**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 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/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

**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>

