# hepc.bull

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

# 5<sup>TH</sup> ANNUAL HEPATITIS C CANDLELIGHT MEMORIAL CEREMONY MAY 1<sup>st</sup> 2004

# National Hepatitis C Awareness Month

May 2004 is National Hepatitis C Awareness Month in Canada and in other parts of the world. May 1st is National Hepatitis C Awareness Day. That is the day for holding the 5<sup>th</sup> Annual Hepatitis C Candlelight Memorial Ceremony.

It will also mark the second year that the majority of Canada's provincial governments, through proclamation, declaration, or some other form of official recognition, will acknowledge a month to honour Canadians living with Hepatitis C.

### The Candlelight Ceremony

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



### The Candle of Hope

The stained glass Candle of Hope was created in B.C. for the 2<sup>nd</sup> Annual Candle-

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# WHAT ABOUT NON-RESPONDERS?

In June 2003, Health Services Minister Colin Hansen approved Pegetron for the treatment of hepatitis C. While at the time I welcomed the Minister's decision, I have now become infuriated that coverage was not extended to patients who have relapsed following treatment with other therapies. This means that patients in British Columbia are being denied treatment, which can improve their quality of life.

In this era of cost constrained health care budgets, we must always make decisions based upon the available evidence. While the published evidence is limited, there are several ongoing clinical trials, which point to response rates of 30 to 50 percent for HCV-infected patients who have relapsed following treatment with previous, less effective therapies.

In addition, one has to ask why the provinces of Ontario and Quebec have approved the treatment specifically for those same patients. It creates a situation where access to treatment for patients with hepatitis C depends on your postal code.

Pegylated interferon and ribavirin combination therapy for chronic hepatitis C is not a lifetime treatment, but rather a one-time cost. If just five patients who have relapsed

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# **CAN YOU BELIEVE IT?**

Can you believe it? We've been reading about Pegasys for years now. Many Canadians have been involved in clinical trials. We've been waiting a year and a half for federal approval of Pegasys with Copegus (ribavirin) - and that's with it having a priority review status. Health Canada approved Pegasys monotherapy last August. And yet, it is still not available through most provincial formularies.

Without coverage under formularies such as Pharmacare, most Canadians cannot afford to pay up to \$20,000 for a course of treatment.

Several issues need to be addressed:

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# **HOWARD LANGLOIS**

May 29, 1931- May 12, 2002

We have lost another long-time member, "Sir Howard", and would like to pay



" Until we meet again "

tribute to him. Howard is survived by his wife of 44 years, Helen, who is still a subscriber, 2 sons, 2 daughters, 6 grandchildren, 2 brothers, 3 sisters, and many nieces, nephews, cousins and in-laws.

As a member of the Royal Canadian Navy and

reserves, Howard visited many countries and received many medals. In 1953, he served in Korea on the HMCS *Iroquois*. He worked as the Market Food Service Manager for the T. Eaton Company.

He is remembered for his smile, humour, generosity, and class. His hobby was cooking, and his recipes were in much demand.

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# SUBSCRIPTION/ MEMBERSHIP FORM

Please fill out & include a cheque made out to **HepCBC** - Send to our **NEW ADDRESS**:

HepCBC #306-620 View Street Victoria BC V8W 1J6

Address:				
City: Prov PC				
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Email:				
☐Membership + Subscription (1 year): \$20.00				
☐Membership Only \$10.00 (for those already receiving the bulletin):				
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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, (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: PHONE: FAX: EMAIL: WEBSITE: HepCAN List Joan King, Will Lawson, Smilin' Sandi TEL: (250) 595-3892 (250) 414-5102 jking@hepcbc.ca www.hepcbc.ca

http://health.groups.yahoo.com/ group/hepcan/messages

HepCBC 306-620 View Street Victoria BC V8W 1J6

### 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.

# Peppermint Patti's FAQ Version 5.6

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 postage—but if you can afford more, we'll take it. Contact HepCBC: (250) 595-3892, info@hepcbc.ca

HepCBC Resource CD: The CD contains back issues of the *hepc.bull* from 1997-2003; 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.

### **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!

epCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, 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: Megan, Nicole, Kelly, 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!



# 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, (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://nationalhepatitis-c.org/registration.htm http://clubs.yahoo.com/clubs/ontariohepcsingles http://forums.delphiforums.com/HepCingles/ start

http://clubs.yahoo.com/clubs/hepcingles http://groups.yahoo.com/group/PS-Hep/ www.hepcmeet.com

### **CONFERENCES**

#### March 17th, 2004

Hepatitis C Prevention
Peer Education Workshop
Vancouver, BC
Tel: 604-688-1441 Fax: 604-688-4932
cindyw@youthco.org

#### March 27-30, 2004

The 2nd Canadian Conference on Hepatitis C Vancouver, Canada New Knowledge, New Hope <a href="http://www.cvhn.ca/hepc2004/">http://www.cvhn.ca/hepc2004/</a>

> February 26 - March 5, 2005 Canadian Digestive Disease Week Banff, Alberta

### **September 12, 2005**

WCOG Conference - 14th Annual Meeting -World Congress of Gastroenterology: Montreal. Quebec

March 4 - 12, 2006

Canadian Digestive Disease Week Quebec City, Quebec

# DIAL-A-DIETITIAN

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

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# **TREATMENT**

by Nicole O'Farrell

# THE IMPACT OF ANTIVIRAL THERAPY ON CHRONIC HCV

A retrospective study was done to evaluate the HCV clearance after interferon treatment, and also to evaluate the rate of progression from hepatitis to cirrhosis and hepatocellular carcinoma in responders and non-responders.

The study showed that patients who go into remission during the first six months after antiviral treatment was concluded have a high chance of remaining in remission for the rest of their lives. Relapse occurred in 13 per cent of patients who achieved a "sustained virological response", but progression to cirrhosis was uncommon. There was also a significant reduction in the development of hepatocellular carcinoma and cirrhosis in responders as compared to non-responders.

Persistent HCV replication is a major factor in hepatic deterioration caused by hepatitis C. Because of this, treatment is aimed mainly at suppressing viral activity in the long-term.

The authors concluded, "...[S]ince factors predictive of sustained response to interferon are independently associated with less frequent and/or later development of decompensation or HCC, the beneficial effects of antiviral therapy may be probably overestimated."

Source: Panminerva Medica. Sept 2003; 45(3): 175-82.

# SPLENIC AND NODAL MARGINAL ZONE LYMPHOMAS (MZL)

Splenic and nodal marginal zone lymphomas are a subtype of marginal zone-derived neoplasms. Because there is little known about MZL's, a study was done to analyze the lesional tissues from 43 patients (34 with splenic MZL and 9 with nodal MZL).

Results showed that out of the 34 patients with splenic MZL, 26 patients had enlarged spleens with or without involvement of lymph nodes, and 7 patients showed extension to superficial lymph nodes. The HCV serology was positive in 35% of the patients and 3 out of every 4 of those HCV positive patients produced a lymphoma response from interferon treatment. Out of 27 treated patients, 13 had a complete response,

and only 12 had a partial response. The median event-free survival (EFS) was 3.3 years.

Out of the 9 patients with nodal MZL, HCV serology was positive in 2. Only 5 patients responded to chemotherapy and the median EFS was 2.8 years.

Although splenic and nodal MZL have different presenting features, they have common morphologic and biologic characteristics and both have high HCV seroprevalence.

Source: Cancer. Arcaini L; Paulli M; Boveri E; Vallisa D; BernuzziP; et al. Jan 1, 2004; 100(1): 107-15.

Division of Hematology, IRCCS Policlinico San Matteo, University of Pavia, Italy.

# APPROVAL OF REBETOL LIQ-UID FOR KIDS WITH HCV

Schering-Plough Corporation has approved a treatment for pediatric chronic Hep C. This treatment consists of Rebetol ® Oral Solution (ribavirin, USP) in combination with Intron ® A Injection (interferon alfa-2b, recombinant). Until now there has been no treatment for children with Hep C even though there are 160,000 children with Hep C out of four million people in the United States infected with the virus. The dose for this treatment can be tailored to a child's body weight and size and is available for children as young as 3 years old.

The combination of Rebetol and Intron A can be used for any pediatric patient 3 years of age or older with chronic hepatitis C that has compensated liver disease previously untreated with alpha interferon. Rebetol is dosed according to weight (15mg/kg daily in divided a.m. and p.m. doses) and comes in a bubble gum flavor liquid or a capsule and Intron A is dosed according to patient size (3MIU/m2 three times weekly). This combination therapy is recommended for a 24 week duration for children with genotype 2 or 3 virus and 48 week duration for children with genotype 1 virus.

Source: Schering-Plough Corporation 01/20/2004 http://www.schering-plough.com

# TREATMENT, NOT TRANSPLANTS!

-Ken Thomson

# HEP C PEER EDUCATION WORKSHOP

Hepatitis C Prevention
Peer Education Workshop
Wednesday, March 17<sup>th</sup>, 2004
10 AM - 5 PM
535 Hornby Street, Vancouver
4<sup>th</sup> Floor, Welsh Room
Free event
Light breakfast and lunch provided

This workshop on youth HCV prevention and peer education will allow youth and youth service providers from throughout the Lower Mainland the opportunity to meet and share best practices. The focus of the workshop will be on providing people working in the field with "hands on" peer education learning opportunities that will allow them to more effectively work with at-risk youth in their home communities.

To register, contact:

Cindy Weeds, Administrative Coordinator Tel: 604-688-1441 Fax: 604-688-4932 cindyw@youthco.org

Registration deadline: Friday, March 5<sup>th</sup> Enrolment is limited and will be on a first come, first serve basis.

Maximum of 2 people per agency

# **SEXUAL TRANSMISSION?**

A team of San Francisco researchers has concluded that "HCV is inefficiently spread through sexual contact."

A 3-year retrospective study of 754 gay men, 135 women, and 92 HIV-positive heterosexual men found no cases of sexual transmission of HCV, even in the case of insertive or receptive unprotected anal sex.

The study did find 6 new cases of herpes and 10 new cases of HIV. Those who had injected drugs were 33 times more likely to have Hep C than those who hadn't. There was an association between Hep C and increasing age, but not with the number of lifetime sexual partners.

Source: Michael Carter, No sexual transmission of HCV seen in repeat in San Francisco, 14

2004

HIV testers
January

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# (CANDLELIGHT MEMORIAL—Continued from page 1)

light Ceremony and introduced at the 1st Canadian Conference on Hepatitis C, May 1st, 2001, in Montreal.

The Candle of Hope was commissioned by Marjorie Harris of HepCURE (The Hepatitis C United Resource Exchange). It was donated to the hepatitis C community by Okanagan artists Deborah Wilson and Pat Lightfoot-Doyle as a symbol of Hope and Awareness.

The two purple eagle feathers at the centre of the burning flame of hope to represent both the spirituality of aboriginal peoples and the two-spirit people 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 for the preciousness of life. The red and yellow Hepatitis C Ribbon, which stands front and centre, represents the tainted blood that carries this blood-borne pathogen.

### What you can do

During May 2004, groups and individuals from across Canada and around the world will participate in a Hepatitis C Awareness Day event in their own community.

This year, in addition to approaching our provincial and federal governments for proclamations, groups and individuals will approach our city councils to proclaim May 1<sup>st</sup> as the fifth annual Hepatitis C Awareness Day.

You might want to start a Hepatitis C Awareness Event of your own or help out with one.

For instance, intravenous drug users might want to do a Safe Injection Day. A support group for shut-ins and persons with cirrhosis might advocate for 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. A tree planting is always appropriate.

An effective way to hold a press release is to do it at your provincial legislature, city hall, or other high profile community location with the cooperation the newspapers and TV. This is a good way to invite the people of your community to your Hepatitis Awareness Day Event.

May 1<sup>st</sup> is the preferred day, but might not be practical in every community. The

community where you live will dictate the type of awareness event needed for your community needs.

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. Do some brainstorming. The idea is just to do something for Hepatitis C Awareness.

# Better to light one candle than curse the darkness

Remembrance and Hope are what Hepatitis C Awareness is about. It honours those who have passed from this disease, and those who survive with and who are affected by it. When we share our memory of them, we also share in the hope for a cure and an end to the Hepatitis C epidemic.

We are encouraging as many groups as possible to do proclamations and Candle-light Ceremonies. At sundown on May 1<sup>st</sup>, 2004, please join us and light your own Candle of Hope.

#### Contacts:

We support all awareness activities. Let us know the particulars.

- ♦ http://hepcure.junction.net/may1 Hepatitis C awareness events, proclamation information, and links can be posted and accessed here. Events are listed for each province and territory.
- ◆ Bill Buckels, Hepatitis C survivor National Hepatitis C Awareness Month Co-ordinator, HepACT (The Hepatitis Activist Group)

Voice Mail: (204) 222-6020 E-mail: bbuckels@escape.ca

Awareness Month website: http://www.hepcure.ca/may1



# PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

# NOTICE

# HepCBC ANNUAL GENERAL MEETING

TUES. APRIL 9, 2004
7 PM
PWA Office
330-1105 Pandora
(back door)
Victoria, BC

(Non-Responders—Continued from page 1)

with this disease experience advanced cirrhosis or scarring of the liver and require a liver transplant, the surgery and a lifetime regimen of antirejection drugs could cost the healthcare system up to \$250,000 per patient. So where is the economics in all of this?

Hepatitis C is a debilitating disease, which can destroy people's lives. It has a devastating impact on families. Many of us have suffered job loss, marriage breakdown, personal bankruptcy and lengthy battles to obtain disability benefit payments. It is indefensible and discriminatory that a certain group of British Columbians will not have access to the best treatment available for hepatitis C because of a seemingly arbitrary decision made by their government.

BC leads the country in the number of new cases of hepatitis C being reported. According to Health Canada, there were 1,142 new cases of hepatitis C in BC from July 1 to September 30, 2002. That is about one-third of all the new cases in the entire country for the same three-month period. More people are contracting the disease everyday. This province should be leading the way in treatment and services for patients.

By withholding funding for hepatitis C patients who have relapsed following treatment with other, less effective medicines, the BC Ministry of Health is denying these patients access to the care they need and that could potentially benefit them.

I strongly encourage you to write to the Minister of Health Services or to call your MLA today and ask them to reconsider the decision on Pegetron and make the therapy available to this group of patients.

Joan King

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# LETTERS TO THE EDITOR

Dear Joan and all,

I have been studying herbology off and on for over 30 years. I would like to add an additional note to the warning about comfrey. I very strongly encourage people to know the Latin name of a herb to be taken orally, and to look for it on the product. It is very easy to make a mistake when you rely only on a common name.

Comfrey is *Symphytum officinale* (Boraginaceae) and is commonly known as "knitbone". I advise no one to take this herb orally, as it has long been known to be potentially very toxic to the liver.

However, there is a herb named *Eupato-rium perfoliatum*, which is commonly known as "boneset". It can be used to treat a cold with fever, as it induces sweating, and has some analgesic action. But there are cautions to its use as well.

Stephen Harrod Buhner describes "boneset" as stimulating to the immune system, so I do not recommend it as an alternative to echinacea for people with autoimmune conditions secondary to HCV. Also, take a product containing only the aerial parts (no root), and take it only briefly, following the instructions on the bottle. In excessive doses, this herb can be toxic too.

Thank you so much for your newsletter. I count it an important source of information, and read every issue.

Cheri Collins, in San Francisco

Jan. 2, 2004

I just discontinued IFN treatment after the first six weeks. My reactions to the IFN were severe, and more than my body could handle. I have reactions to many medications because I also suffer from fibromyalgia.

My concern is that the government should take more responsibility for monitoring patients and giving them the personal support they need while on treatment. Cancer patients get this through the availability of hospices, community nurses, and so on.

This is especially important for people like me who live alone and lack the support of family and friends. There were days when I was too sick to make it across the street to the walk-in clinic, and I found that the doctors there didn't know much about it anyway.

I am still suffering from after-effects.

Anonymous in Victoria

(CAN:YOU BELIEVE IT?—Continued from p. 1)

The older (non-pegylated) interferon/ribavirin treatment has failed for over half of all people who have taken it. Under the current Pharmacare criteria in B.C., these people have no second option. For people with serious liver damage, not having access to medication could be a death sentence. It is not acceptable that patients get only one chance at treatment.

Nor is it acceptable that they be limited to only one drug combination. Would we consider that an appropriate way to treat cancer, tuberculosis, heart disease or AIDS?

It seems logical that if you are going to try a second treatment, using a different type of interferon attached to a different polyethylene glycol (PEG) molecule makes sense. There is evidence that the Pegetron and Pegasys interferon formulations are different. They are different synthetic forms of interferon. They are attached to different sizes and shapes of molecules (PEG). They are excreted differently and, according to the literature, stay in the body for different lengths of time.

Pharmacare talks about its limited budget. Both PEG products cost about the same. A patient would be choosing one or the other. There would be no cost difference for increased choice.

There is a growing school of thought among physicians and researchers that viral eradication should not be the only goal for many patients. Slowing inflammation and the progression of fibrosis is also a medically valid goal because it can improve symptoms and give these patients the time they need until a better treatment becomes available. There are many illnesses where slowing disease progression and minimizing damage are seen as worthwhile therapeutic goals. Is the government trying to say that people with hepatitis C don't deserve the same therapeutic benefits?

The present Pharmacare criteria, based upon elevated ALT levels, are outdated and of dubious scientific validity. The National Institutes of Health Consensus Statement on Hepatitis C points out that a number of factors need to be considered when deciding whether and when to treat hepatitis C. This is a decision that should be made by the patient and the physician after carefully reviewing the risks and benefits.

The Canadian Association for the Study of the Liver (CASL) met recently. and it is

hoped that their treatment guidelines will soon be updated to reflect this new knowledge.

Treatment with interferon carries considerable risks and can be very unpleasant. Researchers are working on new approaches such as protease and polymerase inhibitors, but it is unlikely that any of these will be on the market for at least five years. Patients with few symptoms and little liver damage should discuss with their doctor the option of waiting for something new to come along.

However, many people are running out of time. The development of decompensated cirrhosis and certain other conditions can make treatment an impossible dream.

The nightmare is that these people have been doing all they can to maintain their health in the hope that Pegasys will work and give them the chance to return to a more productive and healthy life. Now they are being told, "Sorry, there is one drug available. We'll stop there."

Ken Thomson

PS: I just got confirmation today (Feb. 18) that Pegasys is available in Ontario through its Section 8 process.

# DON'T INTERFERE WITH MY INTERFERON!! -K. THOMPSON

# GRILLED ZUCCHINI FED WITH CORN

3 medium zucchini Vegetable oil spray (optional) 2/3 C. canned corn with red & green peppers, drained

Cut zucchini lengthwise in half. Scoop centre from zucchini; discard. Spray outside of zucchini lightly with oil or use fat free Italian dressing (Put zucchini on foil on the grill if not using

Spoon corn into zucchini shells.

Cover and grill zucchini, cut sides up, 4-6 inches from medium coals or until zucchini is crisp-tender and stuffing is hot.

6 servings

Source: www.fatfree.com/recipes/stuffed-veg/corn-stuffed-grilled-zucchini

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# CHINA DEVELOPS NEW ARTIFICIAL LIVER **MACHINE**

Doctors at the Southwestern Hospital in Chongging, China have developed a new generation of bio-artificial liver machines, a smarter device that automatically decides what treatment a patient needs.

The new machines perform all the treatments that were provided by the previous machines, but they can also perform more complicated operations, including plasma- and blood-to-blood contact than HIV, but less hemodialysis, imitating the detoxifying and metabolizing functions of the real liver, and providing interim treatment after liver trans-

The much smaller, cabinet-shaped machine. which will be put to clinical use in April, has an early warning device that detects potential system failures.

Artificial liver machines have been widely used in China to treat severe hepatitis and cirrhosis patients since Germany developed the world's first artificial liver in 1996 using pig liver cells.

Source: Xinhua, http://english.peopledaily.com.cn/200401/08/eng20 040108-132135.shtml

## **GOVERNMENTS FAIL TO CURB EPIDEMIC**

Hepatitis C is officially estimated at to have infected 200,000 people in the U.K. - four times as many as HIV – and more than 100 people are becoming infected each week.

Last month, the Health Protection Agency revealed that 5,901 cases of hepatitis C were diagnosed in 2002, compared with fewer than 1,000 in 1994.

Hepatitis C is already the main reason for liver transplants and is predicted to kill more people than AIDS by 2020, yet only a quarter of victims know they are infected and just 1 per cent are receiving treatment.

"The figures are horrifying. Over the next 10 to 15 years, liver disease and cancer rates will soar," said Graham Foster, professor of hepatology at the Royal London Hospital.

Most victims are unaware they are infected, but up to 30 per cent will suffer severe symptoms caused by chronic inflammation of the liver over two to three decades, including cirrhosis, liver cancer, and death.

William Irving, professor of virology at Nottingham University, said Britain was one of the few countries with a policy on hepatitis

"But it is disappointing we haven't seen an implementation plan or any funding for an implementation plan. There are a lot of people out there with hepatitis C, and there is a window of opportunity to treat them now before they develop liver disease.

"The Government is dragging its feet on this - there is a lack of political will and a fear of the cost implications," commented Charles Gore, of the Hepatitis C Trust.

The department of health promised an action plan, but a year later nothing has been

The virus is 10 times more infectious via infectious than HIV via sexual contact. Many victims became infected through experimenting with injecting drugs decades ago, although they now lead stable lives with families. Others were infected through blood transfusions or by snorting cocaine through a shared straw, skin piercing, tattoos, or shared razors or toothbrushes.

The virus was identified in 1989, but screening of blood was not introduced until 1991, and many do not know how they became infected.

Source: Jeremy Laurance, The Independent-UK From 'Silent Epidemic' of Hep C, Doctors Warn of Death Toll, 1-1-04. http://209.157.64.200/focus/fnews/1049599/posts

# **CONTROLLING DRUG CRAVINGS**

Dr. Greg Pidwirny of Kelowna, who proved flesh-eating disease is contagious. believes he has found a key ingredient to quitting drugs such as cocaine, crack, and "crystal meth".

Dr. Pidwirny noticed that, when he prescribed Seroquel to patients with bipolar disorder, the drug also helped control cravings for hard drugs. The drug acts on the same part of the brain as do crystal meth and cocaine.

Seroquel is a proven mood stabilizer and an antidepressant. This helps people to quit hard drugs. But counselling and support must be in place for an addict to quit.

Pidwirny claims to have successfully treated more than 25 persons in the past 18 months, and that he knows of several doctors who are also using Seroquel with success.

Consuming alcohol while taking the medication appears to negate its effects. Otherwise, Pidwirny added, "it's pretty sideeffect free".

Source: Canadian Press, January 25, 2004, Kelowna, B.C., Bipolar disorder medication may help control hard drug cravings, doctor says.

# **ALTERNATIVE TREATMENT**

### VITAMIN E

A small study has concluded that Vitamin E could reduce liver damage in Hep C patients with high ALT levels (over 70 IU/I), and is useful in these patients even after antiviral and anti-inflammatory treatment.

The researchers studied 17 patients with Hep C, non-responders to IFN, with an average age of 62. They were receiving anti-inflammatory drugs during the 6 months prior to vitamin E therapy years and still had elevated ALTs.

They were then given 500 mg/day of dalpha-tocopherol orally during 3 months. Thioredoxin was measured, since it is a protein secreted during oxidative stress.

Source: Mahmood S. et al. Free Radic Res. 2003 Jul; 37(7): 781-5. Effect of vitamin E on serum aminotransferase and thioredoxin levels in patients with viral hepa-PMID: 12911275 titis C. http://www.ncbi.nlm.nih.gov/



# DO YOU HAVE NICE HANDWRITING?

HepCBC needs a Volunteer thank you note writer. Please contact Joan at 250-595-3892 or info@hepcbc.ca



Passion for printing ideas:

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



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### **BE PART OF THE TEAM!**



Volunteers are required to contribute time and commitment to help keep the hepc.bull newsletter running smoothly. Thank you to the individuals who have already answered previous appeals for assistance.

Positions still needed to be filled:

People to summarize and "translate" articles.

Someone to do the Email version of the hepc.bull newsletter (MS Publisher required).

People to staff our office and answer phones.

Contact: info@hepcbc.ca





# **VOLUNTEER APPLICATION**

ADDRESS:				
CITY:				
PC:		_PROV:		
TEL: (	)_			
FAX: (	)_			
EMAIL:				

#### **ABILITIES OR AREA OF INTEREST:**

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

# HepCAN VOLUNTEER



The HepCAN Yahoo! List needs a person willing to be a moderator / replacement /trainee.

As HepCAN is an un-moderated group in regard to freedom of speech, this is a technical position only. However, the candidate would be encouraged to participate in group discussions and regular posting of relevant information.

The ideal candidate would have a good working knowledge of html and website administration, and be able to assist people experiencing difficulties with their browser, webmail and e-mail programs and configuration. As HepCAN is expanding, scripting knowledge (php, java, VB) is an asset.

This is a volunteer position and no renumeration is available, but the service is rewarding.

Interested individuals can contact hepcanowner@yahoogroups.com.

# **COMPENSATION**

#### **LEGALACTION**

**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

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

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.

Goodman and Carr LLP pre86hepc@goodmancarr.com 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-Ouebec 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-

**Quebec Red Cross Compensation**: 1-888-840-5764 1986-1990 Hepatitis C Class Actions Settlement 6/15/99 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 info@hepc8690.com

### MISCELLANEOUS

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

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# **COMING UP IN BC/YUKON:**

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

Campbell River Hep C Support Group Support and information, call 830-0787 or 1-877-650-8787 niacph@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 Support Group Monthly meetings- Call for details. Katerina (250) 417-2010, hecsc-ek@shaw.ca or Leslie (250) 426-6078

(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 or Lisa Mortell 766-5132 lmortell@silk.net or toll-free 1-866-766-

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

 $\begin{array}{ll} \textbf{Mid Island Hepatitis} & \textbf{C Society} \text{ Friendship} \\ \text{and support group, 2}^{\text{nd}} \text{ Thurs. monthly, 7 PM,} \\ \end{array}$ Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Sue for info 245-7635, mihepc@shaw.ca

Mission Hepatitis C and Liver Disease Support Group 3<sup>rd</sup> Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Contact Gina 826-6582 or Patrick 820-5576, missionsupport@eudoramail.com

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

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St. Contact Alex Sherstobitoff, 1-800-421-2437, 505-5506, info@ankors.bc.ca http://www.ankors.bc.ca/

Boundary Hep C Support. Contact Ken 250-442-1280

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 Morrissettie 604-517-6120 dmorrissettie@excite.com

Parksville Support Group Contact Ria, 248-

**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

Penticton Hep C Family Support Group Contact Leslie 490-9054, bchepc@telus.net

**Powell River Hep C Support Group** Next meeting: Contact the Health Unit 485-8850. Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Prince George Re- HeCSC Quebec City Region st Wed gional Hospital, room 1356 (former monthly, 7 PM, 876 rue D'Alençon, St. Chapel) Contact Gina 963-9756. na1444@yahoo.ca or Ilse 565-7387 ikuepper@northernhealth.ca

Prince Rupert Hepatitis C Support 1<sup>st</sup> Tues monthly, 8 p.m. North West Community Health Service Society, 300-3rd Ave. West Contact (250) 624-7480

Princeton 2<sup>nd</sup> Sat. monthly, 2 PM, Health Unit, 47 Harold St. Contact Brad 295-6510,

Queen Charlotte Islands/Haida Gwaii:Phone support. Contact Wendy 557-2487, wmm@island.net, www.island.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

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, 3862 Broadway (behind Panago). Contact Deb 877-0042 or Doreen 847-2132, deb@plnw.org

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

**Pender Harbour** – 3rd 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 www.healingourspirit.org

VANDU Vancouver Area Network of Drug Users Each Mon., 2 PM, 412 East Cordova Bus fare & snack. Contact Cristy or Ann 604-719-5313, or 604-216-2776 (ask for VANDU). Space limited—come early. www.vandu.org

Vancouver: Pre/post liver transplant support Contact Gordon Kerr sd.gk@shaw.ca

YouthCO AIDS Society HepCATS Education & HCV info to youth #205-1104 Hornby St., Vancouver. Contact for info, Caitlin Padgett caitlinp@youthco.org Support, contact Matt Lovick 604-688-1-877-YOUTHCO o r 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, sggrant@telus.net

Victoria Support and Information Info about support groups & other services. Contact the Needle Exchange 384-2366, hermione.jefferis@avi.org

Victoria HepCBC & INFO line —Contact (250) 595-3892 info@hepcbc.ca, www.hepcbc.ca Meetings quarterly, 1st Tues. monthly 7 PM-9 PM. Place: TBA

Yukon Hep C Support Group PO Box 31216, Whitehorse, YK. Contact Brian: 867-668-4483

### **OUEBEC**

gi- Nicolas, QC. Contact Renée Daurio 836-2467, reneedaurio@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

Moncton. N.B. Contact Debi, email support only: hepcmonc@rogers.com

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 hoscb@ns.sympatico.ca

### **ONTARIO:**

Barrie Hepatitis Support, Hep-SEE Chapter Contact Jeanie for information/appointment 705-735-8153 hepseebarrie@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. Contact Smilin' Sandi smking@rogers.com "Sandi's Crusade Against Hepatitis C" http://creativeintensity.com/smking/ or Ken Ng (905) 723-8521 or 1 - (800) 841-2729 (Ext. 2170)

Canadian Hepatitis C Network http://www.canhepc.net/

Hamilton Hepatitis C Support **Group**, 2nd & 4th Wednesdays 7-9 p.m. at Self-Help Centre, 255 West Ave. Room 1. Contact Norman Frankum 905-379-2072 nfrankum@hamiltonhepc.net http:// www.hamiltonhepc.net/

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

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, hepcnf@becon.org

AIDS Committee of North Bay Bi-weekly HCV support meetings Contact Karyn (705) 497-3560

Peel Region Hep C Support **Group** www.peel-hepc.com Contact (905) 799-7700 healthlinepeel@region.peel.on.ca

St. Catharines Contact Joe (905) 682-6194 icolangelo3@cogeco.ca

Trenton ON support. Contact Eileen Carlton 394-2924 Hepatitis C Network of Windsor & Essex County Contact Andrea 250-5399 or Michelle 256-1878, hepcnetwork@mailcan.com http:// home.cogeco.ca/~hepcnet/

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 www.hepcyorkregion.org

### **PRAIRIE PROVINCES:**

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

**HepC Edmonton** Contact Fox 473-7600, or cell 690-4076. fox@kihewcarvings.com

Fort McMurray, Alberta Hepatitis C Support Network 1st Wed. monthly 12:00- 2:00 p.m. Lunch included. #205, 10012A Franklin Ave. Contact: Lyn (780) 743-9200 Fax (780) 943-9254 wbhas@telus.net

 $\begin{array}{ccccc} \textbf{M e dicine} & \textbf{Hat,} & \textbf{AB} \\ \textbf{Hep} & \textbf{C} & \textbf{Support} & \textbf{Group} \\ \textbf{1}^{st} & \textbf{\&} & \textbf{3}^{rd} & \textbf{Wed.} & \textbf{monthly,} & \textbf{7 PM,} & \textbf{HIV/} \end{array}$ AIDS Network of S.E. AB Association, 550 Allowance Ave. Phone (403)527-7099 bettyc2@hivnetwork.ca

Winnipeg Hepatitis C Resource Centre 1st Tues. monthly 7-9 PM. # 204-825 Sherbrook St. (south entrance-parking at rear) Contact 975-3279, hcrc@smd.mb.ca

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 PLEASE inform me of any changes, or of any special events/speakers, etc., in your area, well in advance of the date. -Smilin' Sandi



# **Order Your** "Hepper Bear" Now!

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