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Canada's Hepatitis C News Bulletin

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NEWS

BIOPSY ALTERNATIVE

Researchers are trying out a breath test that they hope can replace most biopsies. Advantages would be the avoidance of some pain, risks and hospitalization. In the breath test, the patient drinks a carbon-tagged caffeinated drink. When it is processed by the liver, it passes through the blood and then is exhaled, where the remaining carbon tag is measured. Healthy people still have a lot of carbon in their breath. This non-invasive test, like a biopsy, seems to be able to indicate cirrhosis or advanced fibrosis. It should be available in Sydney, Australia, by next year.

Source: *Kylie Walker, Australian Associated Press, Oct. 7, 2004 "Fed: Breath Test a Pain-Free New Alternative to Liver Biopsies"*

VIRAMIDINE LAWSUIT

Linda Iacovetta is suing Valeant, a drug company, and California Pacific Medical Center (San Francisco) for failing to disclose the possibility of harmful side effects of a clinical trial combining Pegasys and Viramidine. The patient suffered brain damage and is permanently disabled.

The clinical trial hoped to show that Viramidine, causing fewer anemias, was a good replacement for ribavirin. Apparently the risks of combining it with pegylated interferon were already known to the defendants. Iacovetta now suffers memory loss, difficulty concentrating, depression and migraines.

Source: <http://biz.yahoo.com>, January 12, 2005, *Hersh & Hersh Files Lawsuit Against Drug Maker Valeant for Brain Injury Sustained by Plaintiff During Hepatitis C Clinical Drug Trial*

WORK-RELATED CLAIM

An anonymous Hep C sufferer has been awarded more than \$100,000.00 when a judge ruled that he was infected while work-

ing at Prince Edward Heights institution in Picton, ON, an institution for the disabled, making it a workplace injury. A regular blood donor, he worked there from 1980 to 1995, and was scratched many times and bitten at least once. He was exposed to bodily fluids, including blood. He tested positive in 1994. The plaintiff had no history of transfusions or IV drug use. He is asking that the government warn other employees of the risk of infection. His request for benefits was turned down, but he appealed and won.

Source: *Tracey Tyler, GTA Columnists, Jan. 13, 2005. Hepatitis victim wins cash ruling Provincial employee infected at work*



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TO THE MINISTER:

Jan 11th, 2005

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

Dear Minister Bond:

We the Hepatitis C Community of British Columbia wish to welcome you as our new Minister of Health Services and we hope to continue the most excellent and helpful relationship established with your predecessor the Hon. Colin Hansen. Your government has declared May as Hepatitis C Awareness month for 4 years in a row, and as the Hepatitis C Caravan of Hope, we met with Minister Hansen May 17th, 2004 and with your Health Caucus on Oct. 6th 2004. Both meetings yielded excellent dialogs and outcomes.

Minister Bond, we would like to draw your attention to the fact that hepatitis C is both a preventable and treatable disease already infecting at least 44,000 British Columbians.

Of the 250,000 Canadians estimated to have hepatitis C, an estimated 30% live here in British Columbia.

Many people with hepatitis C are running out of time and need to access treatment within the next 5 to 10 years. Your four pilot treatment projects have demonstrated that the best medical outcomes for patients taking hepatitis C treatment occur in an integrated clinic setting providing expedited referrals to other medical professionals, and to community-based service and support organizations. We hope that long term funding is put in place for these treatment clinics, and that more clinics are funded quickly.

Other imminent needs include formulary listing of Pegasys RBV, by Hoffman La Roche, which was given final recommenda-

(Continued on page 3)

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SUBMISSIONS: The deadline for any contributions to the hepc.bull® is the 15th 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 12th 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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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.

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

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: Jay P. and Diana L. 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 15th 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/>
<http://groups.yahoo.com/group/PS-Hep/>
<http://groups.yahoo.com/group/HepCingles2>
<http://groups.yahoo.com/group/NewHepSingles/>

CHAT: <http://forums.delphiforums.com/hepatitisen1/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.

Hepatitis Magazine

Management and Treatment
A Practical Guide for Patients, Family
and Friends

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elsewhere in BC)



A TASTE OF THIS LIFE
Cookbook

Project Background:

PACE Society was granted financial support from Health Canada's Hepatitis C Prevention, Support and Research Program to work with individuals living with hepatitis C. These individuals living with hepatitis C who are actively involved in or have experience in survival sex and injection drug use created this cookbook: **A Taste of This Life: Recipes and Reflections from People Living with Hepatitis C.**

Project participants consist of individuals who are forced through external factors to sell their bodies, as their skills are not seen marketable or are underutilized by traditional markets. Faced with poverty, homelessness and malnutrition, individuals involved in survival sex also battle social stigma as a result of their involvement in sex work. Historically, those involved in sex work and survival sex have been treated as 'vectors of disease' regardless of any such disclosure.

This project focuses on the creation of empowerment strategies and direct support to individuals with HCV. Based on the general benefits of nutrition, it is evident that nutritional health will help persons with hepatitis C infection feel stronger and improve their quality and enjoyment of life. The creation of this cookbook was appropriately chosen to allow us to focus on health enhancement strategy for individuals living with HCV.

The purpose of this cookbook is two-fold: firstly **to enhance the wellness of individuals living with hepatitis C, and those involved in survival sex and drug use.** This as the primary goal of the project ensures that those most impacted by hepatitis C, survival sex work and injection drug use benefit directly from this project. Secondly **to expand the degree of knowl-**

edge and sensitivity of community members pertaining to issues of hepatitis C, survival sex and drug use. This is the element of the project that shares knowledge and experiences with the larger community. Survival sex workers living with hepatitis C were involved in recipe planning, food preparation, cooking, sharing lived experiences and their knowledge around a kitchen table.

This cookbook along with presentations to local groups will provide opportunities for project participants to share what they have learned through this project and participate in existing dialogue surrounding Hepatitis C. Also, and most importantly, this cookbook is a tool to reduce the social stigma experienced not only by survival sex workers, but also by those living with hepatitis C in our communities.

To preview this cookbook log on to our website: www.pace-society.ca (select SERVICES then drop click HEALTH SERVICES).

Free copies of cookbook will be distributed upon filling the requisition form on our website. We offer cookbook presentations and provide hepatitis C educational workshops to service providers and their clients. For inquiries please contact:

Effie Savoy at 604-872-7651 or e-mail: pace-admin@telus.net

FROM THE E.D.'S DESK

Greetings and Happy New Year to all!

The new year is upon us. I am hoping the opportunity for funding initiatives will be a part of this! I would like to find out what people may want or what kind of ideas everyone has for services for HepCBC, This includes prevention, awareness and direct services. One of my goals is to obtain the funding to be able to keep our office open more than 8 hours a week, as we have such a great library which is constantly updated with information. If anyone has any ideas, please feel free to email them to me at karendennis@shaw.ca or call me at 595-3892!

Thank You!

*Sincerely,
Karen Dennis,
Executive Director, HepCBC*

(LETTER—Continued from page 1)

tions by CEDAC on Oct. 14th, 2004. Also, the Pegetron Redipen by Schering has been reported under review since the Sept. 24th, 2004 issue of the Pharmacare newsletter. Please give us a written update as to the formulary listing dates for these two products. We hope that you can report their approvals to us.

Minister Bond, please instruct those members of your staff responsible to adopt and bring into force the new Health Canada guidelines for the care and treatment of hepatitis C contained in the Management of Viral Hepatitis 2004 Consensus Document (a copy is enclosed).

There is no time to lose. Predictions are that \$1 spent now will save \$4 to the health care system by 2010. So many of our friends, family and communities are affected by this terrible disease who can now be cured 50–60% of the time, guaranteed! We have treated less than 6% of infected patients to date. The need for liver transplants will increase by 246% over the next few years.

We need a coordinated, cost-effective, multidisciplinary approach that utilizes community-based organizations and peer supports in addition to specialists, nurse-practitioners, primary care physicians and other health professionals.

Treatment for hepatitis C can be complicated and difficult to tolerate. Cross-education and expedited referral pathways need to be in place to deal with treatment complications such as neuropsychiatric disorders, malnutrition, dental problems, addiction issues, financial issues, etc., in a timely manner so as not to jeopardize treatment outcomes. Some of these interventions require specialized expertise. Much of the basic information, education and support can be provided very cost-effectively by community-based organizations and peer supports.

Please do your part to help save lives by updating treatment guidelines, approving life saving medications and putting in place long term funding for treatment clinics and community based support systems.

Sincerely,

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

Phone: (250) 546-2953
www.hepcure.ca hepcure@sunwave.net

CC: MLA Randy Hawes
MLA Lorne Mayencourt

HOW TO START AN HCV SUPPORT PROJECT:

PART 4

Alan Franciscus, Editor-in-Chief
HCV Advocate

Facilitation

A peer led support group is very different from a therapy group that is led by a therapist who is educated and professionally trained to guide people through complex emotional issues. A peer led support group is usually led by someone who has not been professionally trained as a therapist. While peer led support groups should not be intended as a substitute for professional therapy, members may find emotional support from the group members that is therapeutic in nature. It is not overly difficult to learn how to run a support group. Some people are born with the talent to become a support group leader; but with education, experience and help from others, almost anyone can become a support group leader if their heart is in the right place.

A support group requires that someone lead or oversee the entire group process. The role can be defined as total or limited, depending on how much time and energy the individual wants to invest. Most people starting a group take on the role of facilitator, but it is not required. Some people prefer to work behind the scenes and leave the leadership to another member. Others may set up the group (by agreement with other members) to rotate facilitation among the members of the group. There are also groups that have no leader and rely on a true peer led support concept in which there is equal power and decisions are made by consensus of the group members. Alcoholics Anonymous (AA) is an excellent example of a peer led support group where specific principles and rules have been developed and applied and where the leadership role is rotated between the members.

The Role of the Facilitator

If you have decided that you would like to facilitate a support group or mentor someone else to become a leader there are some important steps to take before the first meeting. The first step is to understand the role of the facilitator. Basically, a facilitator's job is to help guide and support the entire support group.

There are certain traits that a good facilitator possesses. Many of these traits can be learned from experience or from reading and attending seminars on group facilitation. Some people take naturally to the role while

it may be more difficult for others to be an effective group leader.

Qualities of an effective group leader include:

- Knowledge of hepatitis C: A person does not need to be an expert on hepatitis C, but should be knowledgeable about HCV to some extent to help correct inaccurate information.
- Compassion: Feeling empathy for people.
- Conflict: Able to deal with conflict and effectively manage potential conflicts between group members.
- Communication skills: Be able to listen and to convey that you understand what is being said.
- Real: Express your feelings in an honest and open way.
- Present: Be in the moment and not thinking about situations outside of the group.
- Positive: A healthy outlook on life so that the group can always draw from your positive traits.
- Boundaries: Set clear goals about what steps are needed to help, and be able to set your emotions aside. Not internalize or take on the emotional needs of the other members.
- Non-Judgmental: Always open to someone's experience and not making any judgment calls based on what they have done or tell you.
- Open mind: Be able to look at ideas and situations openly and honestly.
- Observant: Be aware of others in the group in regard to verbal and non-verbal language—vocal intonations, facial expressions and body language.
- Energetic: Positive energy for other members to draw upon.
- Look for the positive in people instead of the negative.

Of course we are not all saints, but these characteristics are important to have or to strive or work toward. It may seem like a monumental list of characteristics, but you may be surprised how many you possess or how easy they are to obtain.

Is There a Need for a Co-Facilitator?

A co-facilitator is highly recommended for groups that have a large membership. In fact, the responsibilities of facilitation can be shared on a rotating basis. A co-facilitator can take off some of the pressure on the facilitator and monitor the other group members while the lead facilitator is busy interacting with the members. A co-facilitator can also monitor the other group members and intervene if there are times when things are stuck or when there are potential problems. If you should decide to seek out a person to

co-facilitate, look for the same traits that would make a good facilitator and for someone with whom you feel comfortable working in the support group environment.

Membership

How do you get people to join the support group? Sometimes, it can actually be difficult to recruit members. This can be for a variety of reasons, but probably the most important reason is that since it is an emotions based support group it takes a leap of faith for people to trust that the group will be a safe environment for people to discuss their very private feelings, especially at first when all the group members are strangers.

Strategies for recruiting members:

- Develop a flyer for the support group that would motivate people to want to join a support group – proactive, positive and caring.
- Post the flyer in doctors' offices, medical institutions, community-based organizations, public health departments or any other agency that may serve and support people with hepatitis C. It would help to personally talk to organizations about the new group, and to get permission to post the flyer.
- Newspaper advertisements can be a good way to attract members. Look for community based or local papers that cater to various communities or to a specific population that you would like to attract.
- Develop a press or media kit (a general press kit is available on the HCV Advocate Web site) and send it to local newspapers, radio, television or any other media that may be available.
- Contact a national or local self-help clearing house. A clearing house may be able to list the support group in their directory.

Flyers

Develop a flyer that is upbeat and positive:

- List the objectives or mission of the support group: be clear and concise in your objectives:
*“The mission of HepCats is to provide peer support and education for hepatitis C positive people.”
- List the affiliations on the flyer, such as medical providers that endorse the group:
*“The HepCats support group is endorsed by the Sunnybrook Medical Center.”
- List the approximate location time, duration or any other important information.
*“Title: HepCats Support Group
Time: Every Wednesday of the month from 6:30 – 8:00PM
Location: 1225 Market Street, San Francisco, CA 04112

(Continued on page 5)

(SUPPORT—Continued from page 4)

Purpose: To provide peer support to people with hepatitis C. Please call: 555-1212 for more information.”

• For a drop-in type of support group, list the exact address:

* “Would you like to meet others with hepatitis C and learn how they live positively with HCV? A support group meets every Wednesday from 6:30-8:00 at 1255 Market St., San Francisco, CA 04127. Check us out!”

• If you decide to name your support group – make it upbeat or specific to the members you would like to attract to the group: * “The HepCats: For living positively. Being well,” or

* “The Positive Partners meet to support partners of people with HCV

• List a phone number or another means of contacting you if you want to interview people before they attend a meeting. If you are listing a personal phone number you may want to consider adding a new telephone line or a new voicemail box to your existing voicemail options. A word of caution—if you list your home phone, you may want to make sure that you have an option for turning the ringer off in case you receive calls at odd hours of the day or night. Some people prefer having a voicemail box separate from their personal or home phone.

• Talk with other support groups that are currently serving the needs of the HCV community – you may have a particular type of support group that they can support or endorse. For instance, a current support group may endorse and send people to your group if it is a support group for family and friends.

HEPCBC INFO SESSIONS

HepCBC in Victoria, BC, is offering moderated 8-session pilot groups for those who are infected with hepatitis C. Please sign up, leaving your name and phone number at 250-595-3892, or email info@hepcbc.ca. Space will be limited.

ATTENTION: ARTISTS

We at HepCBC are looking for a new, bold logo. We are prepared to offer \$100.00 for any logo that is used on our website or bulletin as a result of this contest. To enter, please send your logo design to info@hepcbc.ca



CLINICAL TRIALS

BAY 43-9006

Bayer AG and Onyx are holding Phase II trials with BAY 43-9006, a drug which shrank liver cancer tumors by 9% and stabilized 43% of patients for at least 4 months, according to their mid-stage reports. The pill is designed to stop the tumor from growing by starving it of RAF Kinase, which the tumor needs to survive. It also inhibits one of the proteins necessary for blood-vessel growth. The average survival time of patients in the trial was 9.2 months, and the side-effects were mild, such as fatigue and diarrhea.

Source: Reuters, September 29, 2004, Bayer, Onyx Drug Shrinks Some Liver-Cancer Tumors http://healthnews.orb6.com/stories/nm/20040929/health_bayer_onyx_dc.php

MX-3253

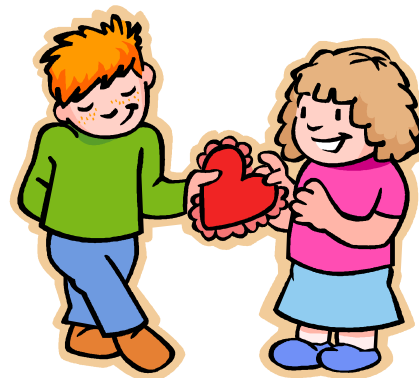
Migenix, Inc., is enrolling about 60 genotype 1 patients in a Phase II trial of its antiviral drug MX-3253, to be administered for 12 weeks in 5 sites in Canada. The drug is an Alpha-glucosidase I inhibitor. It will assess safety and efficacy, and will be used combined with other drugs, which will include IFN and possibly ribavirin.

Source: PRNewswire-FirstCall, Oct 13, 2004, MIGENIX initiates Hepatitis C Phase II clinical study

MEDUSA IFN

Flamel Technologies has begun to enroll patients in its Phase I/II of a long-acting IFN-alpha called Medusa, to test safety and determine dosage. It will also compare the product to Schering's Viraferon. The company has obtained exciting results in monkeys, and believes their product may be safer than existing treatments.

Source: <http://uk.biz.yahoo.com/041221/241/f8yrn.html>, Dec 21, 2005, Flamel moves hepatitis product into phase I/II



HCV-796

Pharmaceutical company partners ViroPharma and Wyeth have applied for an evaluation of HCV-796, a polymerase inhibitor. They are planning a clinical trial later this year in healthy volunteers to check for safety and side-effects. Studies so far have shown this to be probably the most powerful anti-HCV drug the two companies have. Their drug HCV-086 is already in clinical trials.

www.viropharma.com

Source: ViroPharma Incorporated, Jan. 6, 2005, ViroPharma Announces Submission of Investigational New Drug Application for HCV-796

MBI-3253

Micrologix Biotech, Inc., now has the rights to one of Virogen's products, which is known as celgosivir, or MBI-3353. In Phase II trials, and evaluated in more than 600 humans, the drug is an oral antiviral. An alpha-glucosidase inhibitor, it is derived from the Australian Black Bean chestnut tree. It attacks a mammalian enzyme rather than a virus, hopefully avoiding viral mutation. The company plans to use it in combination with current treatments.

Source: <http://www.prnewswire.com/cgi-bin/stories.pl?ACCT=104&STORY=/www/story/02-03-2004/0002101599&EDATE=> Micrologix acquires clinical-stage hepatitis C drug candidate

ACTILON

Coley Pharmaceutical Group has announced results from a Phase Ia study in 40 healthy volunteers and a Phase Ib dosing study of hepatitis C patients with Actilon (CPG10101), a Toll-like receptor 9 (TLR9) agonist. The Phase Ia trial of Actilon showed the compound to be well tolerated in several doses, and that it induced immune responses. The same range of doses was given in the second trial in patients who had relapsed or couldn't tolerate earlier IFN treatment. A 1.0 log reduction of viral load occurred in one-third of the patients. Antiviral activity occurred even in genotype 1 patients. Side-effects were mild.

Source: PRNewswire, Jan 06, 2005, Coley Reports Results from Phase I Studies of Actilon (TM) for Hepatitis C Antiviral Activity Demonstrated in Interim Phase Ib and Consistent with Phase Ia Dose Tolerance, Pharmacokinetics and Immune Response
Web site: <http://www.coleypharma.com/>

Hepatitis C Research BC North is a new support network for Northern British Columbia, Canada. This is a one way information only group. The latest Hepatitis C research and management information will be posted here, as well as information of interest to people living within the Northern Health Authority area. Membership is confidential and the members list will remain hidden from view. <http://health.groups.yahoo.com/group/HepatitisCResearchBCNorth/>

Hepatitis C Connection Northwest is an ongoing two way discussion group providing peer support for people infected with or affected by hepatitis C who are living in the northern areas of British Columbia. <http://health.groups.yahoo.com/group/Network-NW/>

Both sites are managed by Wendy at Hepatitis C Support Northwest B.C. <http://www.island.net/~wmm> Please visit Wendy's Northwest site for the latest happenings in our regional area

Robin Tomlin is a volunteer for the BC Transplant Society and is undergoing a personal battle with hepatitis C.

"The goal for the BC Transplant Society is to get everybody registered. It doesn't mean that we want everyone to become a donor but find out if they would be willing to donate."



Robin says that when you pre-register your choice, it will automatically be programmed into your health care number, which will put less stress on family members in time of death. Robin explains that during this winter season, the BC Transplant Society will team up with the Counter Attack Program to hand out their registration forms. This combination is a first for the area, and is acting as a pilot program elsewhere. If all goes well this technique may be tried province-wide.

Robin received a blood transfusion in 1974 and was diagnosed with hepatitis C in February of 1996. At the moment he has advanced stage cirrhosis and his liver is only 35% functional. He is on the waiting list, and has been since September of 2003. Robin does not want compensation or sympathy but wants to raise awareness about this disease and stop it in its tracks.

"There is no vaccine or medication to help hepatitis C. Most people get it through sharing needles or blood transfusions. In BC alone, there are 44,000 people who have it and it is estimated that number is actually 65,000 because they're simply not aware that they have it. It's also called the silent killer. Those are big numbers especially if you compare them to the 20,000 in BC who have diabetes."

In response to the topic of government funding, help or involvement, Robin says underlying health care is there, but there is no funding to cover the cost of medications, new procedures or anything else that might help ease the pain, such as physiotherapy.

The government has compensated people who were infected through tainted blood from 1986-90 but many gaps lie in place. Concerning the issues around hepatitis C, Robin explains that the Red Cross knew it was in the blood system years before they told the public.

They identified it first as hepatitis non-A/non-B. After they identified it, they still didn't know what to do about it and held off telling the public for a number of years. Eventually the Red Cross admitted they had tainted blood with hepatitis C and HIV within the system.

During that time HIV got most of the publicity because of all the stigmas attached. And hepatitis C was left in its shadow. Out of five people who received tainted blood, four contracted hepatitis C and one got HIV. Recently the government discovered that there is a surplus of \$1.8 billion that could be used within the system. Robin thinks that now the government is stuck in denial because if they compensate everyone, they would be admitting guilt.

He, along with others, are trying to set up a council to help victims and to find the best way to use some of this surplus. They hope to see focus on education, prevention and research for a cure. Robin recently found himself volunteering in Vancouver's East Side, which is notorious for its IV drug users. He admits the main stumbling block is prevention.

"Ninety percent of IV drug users are hepatitis C positive as well as 40% of the prison population."

Robin understands there may be little help for him and others already infected, but knows at the moment the best way to retain control is to prevent infection in the first place. He also wants to focus on changing stereotypes that follow the disease and educating people that it is not just the addicts' or prostitutes' problem. Robin has lived in the Castlegar area for over twenty years and believes that the more people he can educate, the better.

Karlie Shaughnessy
For the Castlegar Citizen
Reprinted with permission

Anyone having concerns or questions about transplants can contact me at (250) 365-637.

—Robin Tomlin



WARNINGS

CIRRHOSIS AND DRIVING

People with cirrhosis can suffer a brain disorder (minimal hepatic encephalopathy or MHE) that can hinder their ability to drive, according to a recent study in Germany. The disorder can cause problems in "behavior, intelligence, consciousness and neuromuscular function." The study used a standardized driving test for brain-injured patients and found that 29% of cirrhotic patients had MHE on neuropsychological tests, and when given the 90 minute driving test by an instructor unaware of their diagnosis, only those with MHE did noticeably worse, especially when checking mirrors, merging, and parking. There was no difference between cirrhotic patients without MHE and healthy drivers. The authors propose studies concerning the safety records of these patients.

Source: <http://www.interscience.wiley.com/journal/hepatology>, March 2004, *Brain Dysfunction in Some Cirrhotic Patients Impairs Driving Ability Significant Driving Deficits Seen in Patients with Minimal Hepatic Encephalopathy*, from "Minimal Hepatic Encephalopathy Impairs Fitness to Drive," by Christian Wein, Horst Koch, Birthe Popp, Gerd Oehler, and Peter Schauder; *Hepatology*; March 2004; 39:3.

STRATTERA

Watch out if you have liver disease and are taking a drug called Strattera, which is approved in cases of attention deficit hyperactivity disorder (ADHD). Severe liver damage was found in two patients who had been taking the drug for several months. Both recovered.

Source: <http://www.fda.gov/medwatch/SAFETY/2004/safety04.htm#Strattera>
MedWatch - The FDA Safety Information and Adverse Event Reporting Program

WANTED

Wanted-volunteers for the inaugural Hepatitis C Council of BC Working Group

We need people with planning, writing, and strategizing skills who are willing to contribute one to three hours a month to making the great ideas and plans that were developed at the Victoria conference a reality.

In case you haven't seen them yet, the meeting notes and most of the workshop notes are available at <http://www.bchepecouncil.ca> Click on the 'Conference' link.

The key tasks that we need to accomplish over the next few months are to:

- Create a one page fact sheet.
- Create a 3-4 page background.
- Create a question sheet for provincial election candidates.
- Create a general strategy/framework document (we are working on securing the funding to have a professional writer involved on this).
- Encourage widespread HCV awareness raising in BC.
- Create a draft framework for how the Hepatitis C Council of BC will operate.

Most of the communication regarding this work will be done by e-mail and the occasional teleconference.

You can volunteer for the Working Group by sending an email to ken@bchepecouncil.ca

Thank you for your willingness to contribute a bit of time and energy to improving services for people with, and at risk for, hepatitis C in BC.

Don't forget to sign up for membership in the Hepatitis C Council of BC

Some of the advantages of membership are:

- Having a voice in the creation and on-going activities of a dynamic province-wide organization.
- Staying up to date on funding and treatment issues and coming events.
- The ability to share and access the knowledge and expertise of people from across the province.
- A free six month subscription to the hepc.bull newsletter.
- The opportunity for scholarship subsidies at future Hepatitis C Council of BC conferences.

Apply for your free membership at <http://www.bchepecouncil.ca> Click on the link in the top right-hand corner.

We have a winner!: Lisa Mortell of Kelowna has won the \$25 gift certificate. Big thanks to everyone who took a few minutes to complete the regional meetings/conference evaluations. The feedback was very helpful.

TRAIN THE TRAINER

We are pleased to announce our next peer educator's train-the-trainer workshop of the 2004-2005 project. It will be February 18th from 6-9pm, and February 19/20th from 10am – 5pm.

This workshop is designed to provide in-depth peer education training to youth, ages 15-29. In addition to the information of Hepatitis C 101 and 202, this workshop provides skills in effective listening, communication, facilitation and support. The workshop also addresses social issues such as poverty, street-involvement, incarceration, drug use and stigma. Upon completion of this workshop, the participants will have the skills to provide peer education and support around hepatitis C and related issues to their peers, and will be provided with a certificate of completion. They will also have the options of continuing volunteer training at YouthCO by completing the Core Training, which will enable them to become YouthCO volunteers if they so choose.

We would like to extend this wonderful training opportunity to any youth interested. We also welcome any invitations to do this training with a group or organization already formed that would like to schedule one specifically for them at no cost.

The training will take place at YouthCO's offices, suite 205, 1104 Hornby St. There is no cost, and we will be providing breakfast and lunch, and covering transportation costs (bus tickets) to youth traveling here.

Please feel free to contact Brandy Svendsen at YouthCO if you or the youth you work with have any questions or wish to register. I can be reached at 604-688-1441 or via e-mail brandys@youthco.org Thank-you,

Brandy Svendsen
Hepatitis C Project Coordinator
YouthCO AIDS Society www.youthco.org
205-1104 Hornby Street
Vancouver, B.C V6Z-1V8
ph:604-688-1441 fax:604-688-4932

CARE-LINE

A limited patient assistance program, called CARE-Line, is available in Canada for some people receiving Pegatron. Patients can call 1-800-603-2754 extension 2121 to find out if they are eligible for help from this program. Health care providers who wish to make inquiries about their patients access to CARE-Line may call 1-800-463-4636 extension 346.

Source: <http://www.hepcyorkregion.org/docs/352,1,Slide 1>

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
<http://www.kpmg.ca/en/ms/hepatitisc/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

David Harvey
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204

Lauzon Belanger S.E.N.C. (Quebec)
www.lauzonbelanger.qc.ca

Goodman and Carr LLP
pre86hepc@goodmancarr.com
www.goodmancarr.com

Kolthammer Batchelor & Laidlaw LLP
#208, 11062 – 156 Street,
Edmonton, AB T5P-4M8
Tel: 780.489.5003 Fax: 780.486.2107
kkoltham@telusplanet.net

Other:

William Dermody/Dempster, Dermody, Riley & Buntain
Hamilton, ON 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
Look back 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, ON 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/

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-877- 434-0944.
www.hepc8690.com info@hepc8690.com
<http://www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf>

MISCELLANEOUS

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



COMING UP IN BC/YUKON:

Armstrong Hepatitis C United Resource Exchange Contact: 1-888-HepCURE ambrorse@sunwave.net www.hepcure.ca

AIDS Vancouver Island Hep C support in Courtenay, Campbell River and Pt Hardy. Contact Jeanette/Leanne: 830-0787, leanne.cunningham@avi.org

Castlegar Contact Robin 365-6137

Comox Valley AVI Hep C Community Support Mon.-Thurs. drop-in support 9-4 PM. 355 6th St. Courtenay Contact 338-7400 Del: dgregmstad@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Support Group Monthly meetings. Contact Katerina 417-2010, hecsce-ek@shaw.ca Leslie 426-6078, ldlong@shaw.ca

Kamloops AIDS Society of Kamloops (ASK) 372-7585 for support or referral. ask@telus.net

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 768-3573, eriselev@shaw.ca or Lisa 766-5132 lmortell@silksilk.net or 1-866-766-5132.

Kootenay Boundary: Individual support & info Contact Brian Reinhard 364-1112 reiny57@yahoo.com

Mid Island Hepatitis C Society 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Sue 245-7635, mihepc@shaw.ca

Nakusp Support Group Meetings: 3rd 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 1-800-421-2437, 505-5506, info@ankors.bc.ca www.ankors.bc.ca/

Boundary Hep C Support. Contact Ken 250-442-1280 ksthomson@direct.ca

Mt Waddington Harm Reduction Each Tues. 10-12 8635 Granville, Pt. Hardy. Contact Dan 250-902-2238 mtwreduc@hotmail.com

New Westminster Support Group 2nd 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

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 Regional Hospital, Rm. 107. Contact Gina 963-9756, gina1444@yahoo.ca or Ilse 565-7387 ilse.kuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Contact Ted 624-7480 Ted.Rogers@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Contact Brad 295-6510, kane@nethop.net

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

Salmo Hep C Support Group 2nd Wed. monthly 6 PM, 926 Davies. Contact Giselle Rogers 357-9511, Alex 304-3448 alex@ankors.bc.ca

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 Healthy Livers Support Group 2nd Monday monthly, 6:30 PM, Sechelt Health Unit, 5571 Inlet. Contact Brent or Bill 604-740-9042 brent.fitzsimmons@cgh.bc.ca

Pender Harbour Hep C Support & Info Contact Myrtle Winchester 604-883-9911 or 604-883-0010, waterspider@telus.net

Vancouver: Healing Our Spirit—HCV and HIV education, support for 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: Satellite Hep-C group, each Thurs. 2 PM, HCC, 166 E. Hastings.. Bus fare & snack. 604-658-1224. **H.A.R.M. group** each Mon., 10 AM, 50 East Hasting St. Bus fare & snack. Contact 604-683-8595 vandu@vandu.org www.vandu.org

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

Vancouver Hepatitis C Support Group Meetings: 3rd Tues monthly, 7-9 PM, Lauener Room JPP 2809, Sassafras Cafeteria, Jim Pattison Pavilion, South Level 2, Vancouver General Hospital, and 1st Tues monthly, 5-8 PM, Java Express, 3420 Cambie St. Contact Robert, CLF: 1-800-856-7266

YouthCO AIDS Society HepCATS #205-1104 Hornby St., Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Program Coordinator: Brandy Svendsen brandys@youthco.org Support Worker: Matt Lovic mattl@youthco.org

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

Victoria Support & Info Contact the Needle Exchange 384-2366

Victoria HepCBC Support group and Info Contact 595-3892 info@hepcbc.ca, www.hepcbc.ca Library open M-F 306-620 View St. Phone support or private interviews.

Works Without Words Yukon Hep C Support Group Every Thurs. at 7 PM., Grace Community Church, 8th & Wheeler St. Contacts: Harry & Debbie 867-667-2402 harry.mckenzie@klondiker.com. Brian: 867-668-4483 P.O Box 31216, Whitehorse, YK.

OTHER PROVINCES:

ONTARIO:

Barrie Hepatitis Support Contact: Jeanie for information/ appointment 705-735-8153 hepcsupportbarrie@rogers.com

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contacts: Smilin' Sandi smking@rogers.com Sandi's Crusade Against Hepatitis C <http://creativeintensity.com/smking/> <http://health.groups.yahoo.com/group/hepc-info/> 1-800-841-2729 ext. 2919

Kingston Hep C Support Group 1st Wed. monthly, 5:30-9 PM 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

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Kitchener. Contact: Bob bc.cats-sens@rogers.com

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, hepcnfl@becon.org

North Bay HCV Support Group 2nd Monday monthly 7 PM, 269 Main St. West, Suite 201, North Bay. Contact: Gabe Giroux, Hep C Education and Support Coordinator 705-497-3560 ggiroux@vianet.ca

Peel Region Hep C Support Group 1st Tues. monthly. 7-8:30 PM, Mississauga Office, 3038 Hurontario St. (Hwy 10 & Dundas), 3rd floor, Brampton. Contact (905) 799-7700 healthlinepeel@peelregion.ca

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

Hepatitis C Network of Windsor & Essex County Contact Andrea 250-5399 or Michelle 256-1878, hepcnetwork@mailcan.com <http://hepcnetwork.cjb.net>

York Chapter HeCSC 3rd 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

Victoria and Area S.O.L.I.D. Society of Living Intravenous Drug Users

Consumers Support Group Wednesdays (except welfare week) 7-9 PM

1947 Cook St, Health Unit (Cook and Pembroke) Past and Current IDU's welcome, support, info, & referrals Contact: momma@ven.bc.ca

QUEBEC:

Arundel Contact Andy Aitken chn.alexander@sympatico.ca Canadian Hepatitis C Network <http://www.canhepc.net/>

Quebec City Region Contact Renée Daurio 418-836-2467 reneedaurio@hotmail.com

ATLANTIC PROVINCES:

Fredericton, NB Contact: Bob, 453-1340

Saint John & Area: Information and Support. Contact Allan Kerr kerrs@nbnnet.nb.ca

Cape Breton Island, N.S. The Hepatitis Outreach Society Support Group 2nd Tues. monthly 150 Bentinek Street, Sydney, N.S. 7-9 PM. Call Cindy Coles 1-800-521-0572, (902) 539-2871 FAX (902) 539-2657 hosc@ns.aliantzinc.ca

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

Fort McMurray, Alberta Hepatitis C Support Network—Info and support. #205, 10012A Franklin Ave. Contact Lyn, (780) 743-9200 Fax (780) 943-9254 wbhas@telus.net

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Contact (403) 527-7099 bettyc2@hivnetwork.ca

The Life with Hepatitis Society of Central Alberta Support group meets each Wed. 7 PM Turning Point Agencies 4611-50th Ave., Red Deer. Contact: Chris (403) 341-6026 crthomas@shaw.ca

Winnipeg Hepatitis C Resource Centre 1st Tues. monthly 7-9 PM. # 204-825 Sherbrook St. (south entrance—parking at rear) Contact 975-3279, here@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 info@hepcbc.ca Please inform us of any changes by the 15th of the month —Joan King



BE PART OF THE TEAM!

We need people to summarize articles. HepCBC needs office staff and 6 people to help with our website. The HepCAN list needs a moderator trainee. Please contact Joan at 250-595-3892 or info@hepcbc.ca