

hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

NEWS

VANCOUVER: FREE HEROIN

A program began in February that is giving free heroin so that addicts will hopefully stop selling their bodies or stealing for drugs. Under a clinical trial just approved by Health Canada, 158 Vancouver addicts will be given prescriptions for free, pharmaceutical-grade heroin for 12-15 months. Officials are hoping that, freed from their daily pursuit of money to buy their next fix, users will find time to make positive changes in their lives.

A second site is being planned in Montreal, to open in April, followed by another in Toronto.

Source: CTV.ca News Staff Feb 10, 2005, Free heroin program starts recruiting http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/1108041780767_12/?hub=CanadaAM

BEACH BOY CAMPAIGNS

David Marks, former Beach Boy and current HCV sufferer, unveiled a display of large portraits of HCV-positive people from across England, kicking off an awareness campaign during an event in Leicester Square on March 16, 2005. The star made himself available for interviews and photos, along with photographer Michele Martinoli, also living with HCV. The event in Leicester Square lasted for two days, to be followed by exhibitions in other major cities in England later in the year.

For further information or to set up advance interviews or to receive pictures by email, please contact Joanna York, Chris Duncan or Victoria Smith on 020 7815 3900 or email joanna.york@munroforster.com

Source: <http://www.hepc.nhs.uk> Original Beach Boy To Launch UK Government Hepatitis C Public Awareness Campaign 04 Mar 2005, GNNREF: 111827

(Continued on page 6)

STARBUCKS, HERE I COME!

Liver cancer (hepatocellular carcinoma or HCC) is found less in coffee drinkers than in those who abstain, say Japanese researchers. This includes people with or without hepatitis B and C, which together cause 90% of all HCC in Japan. It is believed that interferon treatment lowers the risk of liver cancer. In Japan and Brazil, recent decreases in the incidence of liver cancer led researchers to investigate the possibility that it might be related to increased coffee consumption, so they studied the habits of 90,452 people, and found 334 cases of HCC. Among those who drank coffee daily, 51% had a lower HCC risk than those who drank little or no coffee. The finding was more significant in those with HCV than with HBV, and was not affected by alcohol or tobacco intake. The authors have no explanation. (Editor: Hmmm...Who paid for this study?)

Source: Inoue M, et al, Journal of the National Cancer Institute. 2005;97:293-300. Influence of coffee drinking on subsequent risk of hepatocellular carcinoma: A prospective study in Japan.



INSIDE THIS ISSUE:

Starbucks/News	1
Cupid's Corner	2
Treatment	3
How to Start a Support Project part VI	4
Recipe/Research	5
Conferences/Quilts	7
Compensation	7
Coming Up	8



Caravan of Hope Road Report Jan. – Feb. 2005

The Caravan can report that the grassroots hepatitis C community is out there and wants to make contact with information, support and care givers. The toll free line installed early September 2004 has been ringing off the hook since the ads went out for the Hep C 101 workshops. People are looking for information and we are sending out info pacs regularly. Please help to support the Toll Free Helpline (1-888-HepCURE) by calling in a donation. Grassroots support is much appreciated.

Liver Disease Center of Excellence?

The brain child of Dr. Yoshida and seeded by PWA's past powerhouse Paula Bratstein, the Liver Disease Center for Excellence idea has steamed ahead and now is in its 3rd draft. Advisory committee meetings have been held in November and February, with a final strategy document due in March. The main thrust would be to have a liver disease center of excellence where all involved with liver disease can share the same expertise and resources. Dr. Yoshida's statistics indicated that liver disease prevalence breaks down as follows: HCV 45%; HBV 35%; Autoimmune/PBC 10%; and all other liver disease 10%, with alcoholic liver disease being represented across the board. Some notable advisory committee members are chairman Dr. Eric Yoshida; Dr. Durhane Wong-Rieger, writer/consultant CHCN; Ken Thomson, HepC Council; Dr. Mark Tyndal, HIV Center of Excellence; Dr. Chris Sherlock, St. Paul's Virology; Terry Howard, PWA (sponsor organization); Marjorie Harris, HepCURE; and Dr. Mel Kraiden and Gail Butt from BCCDC. —Marjorie Harris

SUBSCRIPTION/ORDER FORM

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

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

Name: _____

Address: _____

City: _____ Prov. ____ PC _____

Home(____) _____ Work(____) _____

Email: _____

- Membership + Subscription (1 year) **\$20.00**
- Membership Only **\$10.00**
(for those already receiving the bulletin)
- Subscription Only **\$10.00**
(for those already members of HepCBC)
- Peppermint Patti's FAQ **\$6.00**
- Resource CD **\$10.00**

TOTAL: _____

- "I cannot afford to subscribe at this time, but I would like to receive the bulletin."
- "I enclose a donation of \$ _____ so that others may receive the bulletin."
- "I want to volunteer. Please contact me."

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: Maximum 4 per issue, if space allows. \$20 for business card size ad, per issue. Payments will be refunded if the ad is not published.

HOW TO REACH US:

EDITORS: _____
PHONE: _____ TEL: (250) 595-3892
FAX: _____ (250) 414-5102
EMAIL: jking@hepcbc.ca
WEBSITE: www.hepcbc.ca
HepCAN List <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

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 at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD: The CD contains back issues of the hepc.bull from 1997-2004; the FAQ V6; the slide presentations developed by Alan Francis; and all of HepCBC's pamphlets. The Resource CD costs \$10, including S&H. Please send cheque or money order to the address on the subscription/order form on this page.

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

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: Jack M. 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!



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

e-mail: info@pacificcoast.net
web: www.pacificcoast.net

250 380 7322 TOLL FREE 1 888 239-7172

CUPID'S CORNER



This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad: Write it up! Max. 50 words. Deadline is the 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>

LEXMARK

Passion for printing ideas™

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

TO SUBSCRIBE CALL
800-792-6397

or visit us online @

www.hepatitismag.com

DIAL-A-DIETITIAN

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

HOOKED?

Subutex (buprenorphine hydrochloride) is a new, safe oral medication that treats opiate addiction (heroin, pain medication), and it has just been approved in Canada. It lessens drug cravings, reduces withdrawal symptoms, and blocks the effects of further abuse of drugs. It will be available at the end of this year, after the corresponding physician education programs have been given. Only 25% of more than 100,000 addicts in Canada are currently being treated. The cost to Canada of untreated addiction was around \$1.4 billion in 1992 alone, not counting treatment for IVD-caused HCV and HIV. There is some reluctance of addicts to use methadone, since relapse is great, there is stigma attached, and there is a risk of overdose. Subutex is less risky, even at high doses. Patients must be closely monitored in a treatment program.

The training program consists of training the doctors in the use of Subutex, maintaining a list of trained physicians, and daily supervised dosing by a trained professional. Like other opioid agonists, there is some risk of respiratory depression.

Source: Doctor's Guide February 14, 2005
<http://www.docguide.com/dg.nsf/PrintPrint/B1C1F5BD8C2B356485256FA8004B9BCC>
 Title: *New Opiate Addiction Treatment, Subutex (Buprenorphine Hydrochloride), Approved by Health Canada*

DIABETES INCREASES HCC RISK

Patients with diabetes are three times more likely to develop liver cancer, according to a new study in the journal *Gut*. Researchers looked at a database of 2061 diabetic patients aged 65+ who had liver cancer, and 6000 other diabetics of the same age group without cancer. They checked for risk factors such as HCV and HBV, alcoholic liver disease and diabetes. They took into account other risk factors, as well, and found that diabetes tripled the risk of liver cancer. They found that HCV infection could act together with the diabetes to increase the liver cancer risk.

Source: Health News Mar 08, 2005 Diabetes triples liver cancer risk

LOW-DOSE: EFFECTIVE OPTION

A study, done by Dr. Nezam Afdhal,

which included 550 HCV+ non-responders with advanced fibrosis, now confirms what many doctors believed: Progression of Hep C can be delayed and maybe prevented by using low-dose IFN, such as Peg-Intron, as maintenance therapy for full-dose therapy non-responders. The subjects have now done 2 years of the 4 year study, testing low-dose (0.5 mcg/kg/week) Peg-Intron against colchicines (an anti-inflammatory/antifibrotic). Those in the PEG arm have proven to have a 50% reduction in progressing to liver failure or transplantation compared to the colchicine arm.

Source: Deutsch, Nancy
http://www.medicalpost.com/mpcontent/article.jsp?content=20050110_193853_5588
 January 11, 2005 Volume 41 Issue 02, *Interferon slows hep C progression*

CAN A BIOPSY DIAGNOSE LIVER CANCER?

Early diagnosis of liver cancer (hepatocellular carcinoma or HCC) would improve the chance of successful treatment. Currently, doctors screen for smaller nodules, and treat larger ones. The researchers in this study wanted to know if ultra-sound (US) guided, fine-needle biopsy (FNB) could diagnose small nodules, so they selected patients newly diagnosed with cirrhosis with no sign of liver lesions. US and alphafetoprotein (AFP) levels were done every 4-6 months to detect new nodules. Patients with high AFP levels were excluded from the trial. All nodules were biopsied using FNB. In the case of a cancer diagnosis, the patient was treated. If the findings didn't indicate cancer, a CT or MRI was done. If the results were indecisive, the biopsy result was accepted, and the patient wasn't tested again for a year. The researchers concluded that US FNB diagnoses HCC correctly in 90% of nodules, even very small ones.

Source: Nature Clinical Practice Gastroenterology & Hepatology, http://www.medscape.com/viewpublication/1167_index. Is Ultrasound-Guided Fine-Needle Biopsy Effective for Diagnosis of Early HCC in Liver Cirrhosis?

HOW ACCURATE IS MELD?

MELD (Model for End-Stage Liver Disease) is a way to measure how livers are distributed for transplants, producing a score according to the severity of the disease and the quality of life (QOL). A new

study shows it is not very accurate as an indicator of QOL.

The MELD score is based on three lab test results, but complications like hepatic encephalopathy (brain inflammation) and ascites (fluid in the abdomen) aren't considered in that score. Even so, MELD has replaced an earlier model which does consider these complications related to QOL. In this study at UCLA, 150 patients on the transplant list were tested by both scores, and also completed two QOL questionnaires, which showed that QOL scores don't correlate with disease severity as shown by MELD. The authors believe that QOL must be assessed because of the long waiting list for transplantation. Dr. R.B. Freeman of the Tufts-New England Medical Center reminds us that we must take into account severe organ shortage. It is more a case of which of many should get the few livers available, and that should take into account mortality risk.

Source: <http://www.interscience.wiley.com/journal/livertransplantation> Liver Transplantation, Feb. 2005, Severity of Liver Disease Not a Reliable Indicator of Quality of Life. Original source: Saab, Sammy, et al, Liver Transplantation; February 2005; 11:2."MELD Fails to Measure Quality of Life in Liver Transplant Candidates."

CURED? FOR HOW LONG?

According to a new study from Japan, those who have a sustained viral response (SVR) to IFN can maintain their "non-detectable" status for up to 12 years. To get that coveted SVR, you must test negative 6 months after stopping treatment. People sometimes relapse after those 6 months, and some even get liver cancer, and there is some question as to whether SVRs might have hidden HCV and/or HBV. A unique form of HCV can live in the liver and not be found in the blood. In some Hep C patients who are co-infected with HBV, their Hep B virus can act that way, as well.

This study followed 75 patients (38 with SVR, and 37 who normalized their ALT but still had detectable HCV) for 12 years. After 12 years, there were still 15 patients available for testing in each group. None of the SVRs had evidence of HCV and all had normal ALT levels, but 87% still had mild inflammation. Of the other group, only one was undetectable. Fibrosis improved in the SVR group, but not in the other. In the non-SVR group, almost half had flare-ups,

(Continued on page 5)

HOW TO START AN HCV SUPPORT PROJECT:

PART 6

Alan Franciscus, Editor-in-Chief
HCV Advocate

Ground Rules

In order for a community to survive, it must enact certain laws or rules to govern everyone in the community. If all the people in the community ignore the law, the community would falter and it would be thrown into a state of chaos. In many ways, a support group can be compared to a community, and, like a community, a support group must have certain rules or the group meetings will be chaotic—the members would not feel safe enough to talk about personal issues or offer advice to others. Setting the ground rules is one of the most important steps to take before the first meeting. Start by drafting a list of ground rules to be discussed at the first meeting. Discuss the reasons for the ground rules, and ask for comments from all the group members. The members may also have additional rules or changes to the ones that you suggested. After a discussion about the rules, they should be adopted by the entire group membership. It is much easier for people to obey rules if they feel that they have taken part in the approval process. In the future, the ground rules can be changed as long as a majority of the members agree to the changes.

Example of ground rules:

- I will always arrive on time – this is a courtesy to other group members.
- I will attend every meeting if possible. The group is not the same if I am not there.
- I will not inflict physical or verbal violence. It is ok to get angry and to disagree, but it is also important to respect one another's individual differences and points of view.
- I respect the confidentiality of all group members. What is said in the support group stays in the support group.
- I respect that only one person speaks at a time.
- I will not interrupt others. It is disrespectful to the person speaking and to the other group members.
- I will not have side conversations. These are disruptive to the group and disrespectful to the person who is talking.
- I will not monopolize the conversation.
- I am willing to talk, but it is also ok if I decide not to talk if I do not feel like it.
- I will accept other group members without judgment.

- I will accept other members' feelings, whether positive or negative.
- I will keep any discussion in the first person. Always use "I."
- I will give advice with care.
- I will listen carefully.
- I will not attend a meeting if under the influence of any non-prescribed drugs or alcohol.

As they say, rules are made to be broken, but some of the rules described above should be followed to the letter. As a facilitator you will develop strategies to help you remind the members about the ground rules that you and they have approved and implemented.

Funding

In general, a support group leader does not need very much money to run a meeting, especially if other agencies are able provide free meeting space or donate materials and other services. However, if a support group decides to expand its mission to provide more support groups or services to the community, a fundraising strategy should be well thought out and in place before the first group meeting takes place. Regardless of whether you decide to go large or small, a budget of possible expenses is recommended at the beginning of the planning stage.

Non-Profit Status

In order to receive grants, an organization must apply for commercial or non-profit status with both the federal and the local state government. A support group or any advocacy organization will usually apply for non-profit status, since they do not intend to make money from running a support group or advocacy organization. Applying for non-profit status is not too difficult, but the application process can be time-consuming and the day-to-day business operation has to be carefully managed. In addition, all of the revenue and expenses have to be carefully recorded and tax returns have to be filed with both the state and the federal government. If you decide to apply for non-profit status, check with your local, state or federal government to learn more about the application process.

Another option would be to find a non-profit agency that would be willing to act as your fiscal agent. Some agencies will act as your fiscal agent for free, but usually the agency will charge you a small percentage of the money you generate to provide this service. This is a very good option for many smaller advocacy groups because they will not have to devote precious time to the "business" of running a non-profit, and can therefore spend more time running and maintaining the support group.

Budget

The first step to managing money is to develop a budget. Try to estimate all the possible expenses, such as postage, copying, snacks, beverages, telephone or any other charges you might incur for the first year of operation, well before the first meeting. Once the expenses are estimated, you will have a better idea of the amount of fundraising you will need to keep the group running for one year. Many times, the expenses you budgeted for can be covered by volunteers and/or in-kind donations; but it is important to have a realistic picture of the support group expenses.

Cash

Raising cash for the support group operations is one of the easiest ways to run a support group if your expenses are minimal. There are many ways to generate cash to help with any of the support group costs.

Cash Donations

At the beginning or end of the support group, pass around a jar or can for donations. Don't be afraid to tell the members that certain items cost money and that there is an expectation that all the members help offset the expenses. Also, try asking the members to bring in food and beverages on a rotating basis or to be responsible for copying educational materials for the support group meetings.

Garage or Sidewalk Sales

One of the easiest ways to raise cash is to have a garage or sidewalk sale. Enlist the help of the support group members, their family and friends to help organize and staff the sale, and ask them to donate items for the sale. You would be surprised how much money a sidewalk sale can bring in to help offset support group expenses. Ask the support group members if they live in an area that is highly trafficked and see if they could host the sale.

Donations from Agencies

As the saying goes, it never hurts to ask! Approach agencies or companies and ask them to donate services or food for the meeting. This may include bakery shops, coffee houses, local physicians' offices or any other group you think might be willing to support your group meetings.

Donations from Pharmaceuticals

Pharmaceutical companies that sell hepatitis C drugs may be willing to help defray some of the expenses of a support group. Contact your local pharmaceutical represen-

(Continued on page 5)

(SUPPORT—Continued from page 4)

tatives and ask if they would be willing to donate food, beverages or even speakers for your group. If you do not know the local representative, contact the national office for a referral to the local representative. They may also be able to provide speakers and materials for the meetings.

A word of caution: It is very important to make sure that information presented or given at the meeting is free of bias. Pharmaceutical representatives should always disclose their affiliations.

Resources:

- Guidestar – National Database of Non-profit Organizations: <http://www.guidestar.org/>
- Internet Non-Profit Center <http://www.nonprofits.org/>

Next Steps

Now that you have the information you need to start a support group or maintain an existing group, the next steps are up to you. HCV support groups can have a tremendous positive influence in people’s lives. Almost every support group leader I have ever talked with has commented that leading a support group has been one of the most rewarding experiences of their lives. As well, the vast majority of people with hepatitis C who attend support group meetings have commented that the experience of attending a support group and being supported by their peers is the one event in their lives that transformed them from ignorance, fear and anger to acceptance. This process also helps people develop strategies to move forward in their lives and to become better self-advocates.

I hope this series of articles has helped you to become a more effective support group leader. I look forward to working with many of you to improve the guide and bring more support and care to people affected by hepatitis C. Any suggestions to improve this guide or our services would be greatly appreciated. Please send comments to alanfranciscus@hcvadvocate.org



(TREATMENT—Continued from page 3)

which could be controlled by retreatment in 70% of them. Only 2 showed persistently normal ALT. Four of the SVRs developed liver cancer, discovered 1 month to 5 ½ years after treatment. None of the non-SVR group did. Only one of the patients had HBV in the liver, and that patient was infected prior to treatment. The non-SVR group on a whole were older than the SVR group

“Thus, the present study showed that the SVR [patients] were completely free of occult HCV and HBV up to a decade after therapy withdrawal.”

These researchers say that SVRs at 6 months may have achieved a “virological cure,” but are asking for larger studies.

Source: John C. Martin, *Hepatitis Neighborhood* 11-24-04, http://www.hepatitisneighborhood.com/content/in_the_news/archive_2152.aspx, *SVR Can Last*

FRIJOLES BORRACHOS

- 2-3 tablespoons sauté liquid
- 1 cup tomatoes, chopped
- 2 large scallions, chopped
- 4 cups pinto beans, cooked
- 1/2 cup alcohol-free beer
- 1/3 cup fresh cilantro, chopped
- 1 jalapeno pepper, seeded and minced
- Salt and pepper to taste



In a large skillet over a high heat, heat the sauté liquid. Lower the heat and sauté the scallions and the tomatoes until they begin to soften, about 2 minutes.

Add the remaining ingredients and mix well. Simmer the mixture covered over a low heat for about 30 minutes. After the half hour, check the skillet. If there is too much liquid, uncover and cook until the mixture thickens up a bit.

Serve hot.

<http://www.fatfree.com/recipes/mexican/frijoles-borrachos>

RESEARCH

If scientists have their way, we shall be using glass livers and models of HCV, to figure out exactly what is happening in our bodies, then be able to attack the virus effectively and use stem cells to re-construct our livers. We can only hope.

HCV MODEL

Finally HCV has been replicated in the lab! This feat, produced at the National Institutes of Health (NIH) in the US, will let investigators study the virus and generate possible antiviral compounds, leading to new therapies to treat infection and liver disease. The lack of a test tube model has been holding back research. This model produces “particles that have all the properties of the whole virus,” in this case, genotype 1. The model has only the genetic material of the virus, not the envelope which protects it. The “naked” virus was placed into human cultured liver cells. The virus replicated itself. It is not yet known if the new viral particles are infectious. This model represents only the end of the life cycle of the virus, and another model is needed to replicate the beginning stage of the life cycle.

Source: Heller, Theo, et al, *Proceedings of the National Academy of Sciences*, Vol. 102, No. 7, pp. 2579-2583. "An in vitro model of hepatitis C virion production." <http://www.eurekalert.org/pubnews.php>

GLASS LIVER

A glass liver model is being developed at the University of Leeds to help understand how the organ is actually constructed, how it works, and how the liver tissue may be engineered to replace damaged cells. It is hoped that the glass liver may be used in place of animal testing. It may work as a dialysis machine, and will be made of little six-sided glass plates with tubes under 1/200 mm. wide, lined with liver cells going from the edges to the centre. The tubes will link with a central “vein”. One of the major obstacles is making sure there is enough oxygen in the blood at the end of the process. Another problem lies in the fact that liver cells don’t last long outside the body. The artificial liver is still being simulated on a computer before being built.

Source: <http://news.bbc.co.uk/2/hi/health/3430525.stm> *Glass liver may aid disease fight*

(Continued on page 6)

CONFERENCES

May 1—4, 2005

3rd National Aboriginal Hepatitis C Conference

Regina, SK

All Nations Hope AIDS Network

Toll free: 1-877-210-7622

allnationshope2@sasktel.net

www.allnationshope.ca

November 3, 2005

Royal College of Physicians of Edinburgh
- Hepatitis C

Edinburgh, Scotland

www.sign.ac.uk/events/index.html

<<http://www.sign.ac.uk/events/index.html>>

November 11-15, 2005

56th Annual Meeting of the American Society for the Study of Liver Diseases (AASLD)

San Francisco, CA

<https://www.aasld.org/eweb/>

DynamicPage.aspx?

webcode=05_Annualmeeting

March 25--28, 2006

Shanghai - Hong Kong International Liver Congress 2006

Shanghai, China

Web Site: <http://www.livercongress.org/en/news/20041015.htm>

(NEWS—Continued from page 1)

CLASS ACTION AGAINST BC EAR BANK

A Health Canada investigation in 2003, showing that the BC Ear Bank at St. Paul's Hospital in Vancouver, operating under the direction of UBC, had "sloppy record-keeping practices," leaving it unclear as to whether there was a correct screening of tissue donors or even sterilization of tissue. All unused donor tissue has been recalled, and recipients of tissue from the Ear Bank are asked to get tested for HIV, HCV and HBV. A class action has now been filed. The Ear Bank supplied tissue and bone to 87 hospitals in Canada and to two cities in the US. Then B.C. Minister of Health, Colin Hansen stated, "This is not acceptable to me, to the Premier or to our government as a whole. And I know it is not acceptable to the people of British Columbia."

Source: <http://www.kleinlyons.com/bcear/intro.html> Feb. 22, 2005 B.C. Ear Bank Class Action



(RESEARCH—Continued from page 5)

CANADIAN DISCOVERY

A team of Canadian researchers reports that the Hep C virus escapes detection because its external coat changes to mimic immunoglobulin, one of the immune system's warriors. The team studied the blood of a newly infected man beginning in the Spring of 2000, observing the process and charting it over time. The 47 year old man cleared the disease in 2003 after two treatments with antiviral drugs.

Dr. Brown (virologist at U of Ottawa, and senior author of the paper) was quoted "It's going to change the way scientists think in research of Hep C and a bunch of other diseases..." However he was cautious as to the value of the research, saying, "A vaccine for hepatitis may be an elusive, even dangerous target that could backfire by prompting the immune system to attack itself."

Several members of the medical profession were not convinced that these observations of the process of "mimicry" were of great importance with respect to conquering the disease: e.g., Dr. Krajden of the BC center for Disease Control commented, "I'm sure it's more complex than just this".

Source: *Branswell, Helen, Canadian Press February 22, 2005, Canadian scientists may have found why hepatitis C triggers chronic infection*

STEM CELLS REPAIR LIVERS

Using mouse tissue cultures, scientists have found that stem cells can be developed into healthy liver cells. When transplanted into mice with liver injuries, the stem cells helped restore liver function in seven days or less. The discovery resolves a debate in the scientific community.

Source: *Journal of Nature Cell Biology, June 1, 2004, Saul J. Sarkis Bone Marrow Stem Cells Help Restore Damaged Liver Tissue*

INTERNATIONAL HEP C QUILTS

The Hep C quilts are made up of patches submitted by people from all over the world with hepatitis C. They are sewn together by Marie Stern in her spare time. Marie possibly contracted the Hep C virus in 1978 and auto-immune hepatitis several years later, and this is her way of helping the Hep C community to be heard and seen. The first quilt was created in 1996. It became so large that Marie started a separate one a year later. There are now four quilts for display, with the fourth one having blank squares to be filled in at functions. The quilts are available for display at various public and private functions. Due to grant changes, LiverHope Inc., based in Minnesota, now sponsors the mailing of the quilts by a grant from Roche.

Reserving the Hep-C Quilts

To reserve the Hep-C quilts for an event, email Marie at mlstern@pacbell.net. Several months' notice is required to secure your reservation. (I do make exceptions for last minute requests if it's possible.)

There are currently four quilts that can be displayed separately or together. If several requests are made for a specific date, I will try to accommodate everyone with at least one.

Adding a Square

If you have or know of some one who currently has hepatitis C or has died from Hep C (a black ribbon will be added) and would like to add a square to the next quilt, here are the requirements:

On a 12" x 12" red or yellow cotton cloth trace your hand in the opposing color of the background and apply it in any medium you like. (Make sure it's waterproof!) Please write your name, state you live in, date you think you contracted the disease and the date you were diagnosed with Hep C. Feel free to write anything else you'd like and be as creative as much as you'd like. If you want to eliminate the hand and do something different, please do so. I will do the backing. I will not turn anyone's square away. When you are finished send it to the following address:

Marie Stern

14119 Via Corsini

San Diego, CA 92128

If you'd like a picture of your square after it's put on the quilt please include an email address to send it to or let me know in your letter if you'd like a hard copy. I may need reminding several times, since I do have a habit of forgetting things.

<http://www.geocities.com/hepcquilt/>

SHOULD YOU GET COUNTED?

The law firm Kolthammer, Batchelor & Laidlaw in Alberta is asking for Canadians infected outside the January 1, 1986 to July 1, 1990 "window" to please contact them if they have not yet done so. Options for compensating these victims are being discussed with representatives of the Federal Government. There is not, at this date, a compensation program. Those involved in the discussions are trying to determine the number of victims involved. Do be careful of what you sign.

*Kolthammer, Batchelor & Laidlaw LLP
#208, 11062 - 156th St.
Edmonton, Alberta
T5P 4M8
kkoltham@telusplanet.net
Tel: (780) 489-5003
Fax: (780) 486-2107*

BRILLIANT IDEA!

The Irish government is going to aid tainted blood victims so that they may get mortgages and insurance, a proposal developed by Health Minister Mary Harney. Normally the cost of insurance for those infected with HCV or HIV would be prohibitive, or the insurance would be unavailable. With this decision, the State will pick up any cost beyond that which an uninfected person of the same age and sex would pay. They are looking at ways to cover travel insurance, as well.

The plan will offer life insurance up to age 75, and mortgage insurance to the same age. There are limits on the amounts insured. Victims will have 12 months to apply (or 3 years from the date of diagnosis)

There would be a waiting period depending on the age of the victim, and an open period for those under age 30 who cannot yet afford insurance.

Source: Ireland Online 10/02/2005 Insurance help for transfusion victims planned

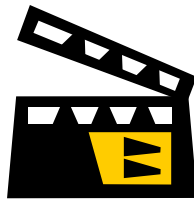
FILM TO BE RELEASED

A documentary film called "Factor 8: The Arkansas Prison Blood Scandal, had not been available to the public because of a dispute, which has now been resolved.

The parties involved are Michael Galster of Pine Bluff and Kelly Duda of Little Rock. Duda now has the film and will be able to distribute it soon. Galster sued Duda in 2003, saying Galster hired Duda to help with the film, but Duda took Galster's raw footage and used it for a different film with an-

other focus. Duda said that Galster contributed little to his film. After a 3 day hearing in 2004, Duda was prohibited from showing his film, based on Canada's discovery of tainted blood from Arkansas prisons, at a festival in Utah. There has now been a settlement, and the case has been dismissed, and Duda is pleased that the story will go public. The film will include credit to Mr. Galster, and will include some of his interviews.

Source: Satter, Linda, Arkansas Democrat-Gazette; Date: Saturday, 19 February, 2005; Section: Arkansas; P.17, 2 men settle case blocking prison-blood film's release



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>

HEPCBC SUPPORT

HepCBC in Victoria, BC, is starting a new, open support group for those who are infected with or affected by hepatitis C. Please sign up, leaving your name and phone number at 250-595-3892, or email info@hepcbc.ca. The first meeting will be on **April 6, 2005**, 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St.

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



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 ambrrose@sunwave.net www.hepcure.ca

AIDS Vancouver Island Hep C support.
♦ **Campbell River:** Mon-Thu 9AM-4 PM, 1249 Ironwood. Contact Jeanette/Leanne: 830-0787, leanne.cunningham@avi.org, jeanette.reinhardt@avi.org
♦ **Comox Valley** 355 6th St. Courtenay Contact: Phyllis 338-7400 phyllis.wood@avi.org

Castlegar Contact Robin 365-6137

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Support Group Monthly meetings. Contact Katerina 417-2010, heccsc-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@silks.net or 1-866-766-5132.

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

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, or lise 565-7387 lise.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@methop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy 557-2487, www.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, 3862F Broadway Contact 1-866-877-0042 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

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, ssgrant@telus.net <http://www.hepc.vernon.bc.ca/>

Victoria Support & Info Contact the Needle Exchange 384-2366

Victoria HepCBC New Support group Apr 6th Contact 595-3892 info@hepcbc.ca www.hepcbc.ca Library open M-F 306-6020 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

Hepatitis C Network of Windsor & Essex County, Last Thurs. monthly, 7-9 PM. Contact (519) 562-1741 Fax (519) 256-1383 hepc@hepcnetwork.net, <http://hepcnetwork.net>

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, hepcnfi@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 (Brampton Mississauga, Caledon) Hep C Support Group. 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@hepcvorkregion.org www.hepcvorkregion.org

QUEBEC:

Arundel Contact Andy Aitken chen.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 hoscb@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