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Canada's Hepatitis C News Bulletin

www.hepcbc.ca

BC PAYS FOR PEGASYS

Thank you to all who wrote letters!

Patient Access Update – BC Pharmacare now reimbursing Pegasys RBV

Since receiving a positive listing recommendation from the Canadian Expert Drug Advisory Committee (CEDAC) in October, 2004, Pegasys® RBV™ for the treatment of hepatitis C (HCV) has been added to a number of drug plans in Canada.

Effective February 7, 2005, Pegasys RBV is eligible for reimbursement through BC Pharmacare's Special Authority Program. This combination therapy is also currently being reimbursed in Ontario, Quebec, Nova Scotia and Saskatchewan. Federal payers including the Non-Insured Health Benefits Program and Corrections Canada are reimbursing Pegasys RBV and approximately 90 per cent of people covered by private insurance companies are covered for Pegasys RBV. Criteria vary from payer to payer.

In related news, Health Canada in December 2004, granted priority review for Pegasys RBV for the treatment of patients co-infected with HIV and hepatitis C. In Canada, approximately one-quarter of people living with HIV are co-infected with HCV.¹ HIV co-infection aggravates and accelerates the progression of liver disease in patients with HCV, resulting in a more rapid progression to cirrhosis and end stage liver disease.

¹Management of Viral Hepatitis: A Canadian Consensus Conference 2004, p. 23. Available on-line at

<http://www.hepatology.ca/cm/FileLib/ViralHepatitisCanadianConsensus2004.pdf>



NEWS

NEWS FLASH: REDIPEN

Schering Redipen is now covered by BC Pharmacare! The Redipen's innovative technology which prevents mixing mistakes and ensures a high quality standard for the medication is now available under most provincial drug plans. The unique engineering safely, simply and hygienically mixes the water and powdered pegylated medication for you in one easy step. In addition the Redipen comes with an excellent patient guided learning and demonstration kit with CD, VHS, book, handouts, placemat, carrying case and freezer packs for ease of travel.

—M. Harris

WHAT ABOUT HCV+ DOCTORS?

In January 2004, a hospital in Montreal was in the process of testing 2614 children operated on by an HIV+ surgeon. The policy of

(Continued on page 6)

Congratulations Community Writers!

The Caravan of Hope would like to thank the hundreds of you who got on board the bus and took the time to send in a letter to your Health Minister or MLA requesting that Pegasys RBV (Roche) or the Redipen (Schering), be made available on your provincial formulary. Every letter makes it happen more easily, so keeps those letters going.

—M. Harris

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Caravan of Hope: Surrey HepC101 Project
January 22nd, 2005

Marjorie Harris, President, HepCURE

The day was most auspicious as The Caravan of Hope HepC101 Project attracted an astounding standing-room-only crowd to hear Dr. Siegfried Erb, hepatologist, as lead speaker for the full afternoon educational event designed for hepatitis C patients and held in the Surrey Memorial Hospital Annex. On a Saturday afternoon, braving travel through cold, unseasonable torrential downpours and flooding hitting the Lower Mainland, seventy-five citizens infected or affected by hepatitis C demonstrated with acute clarity in their gathering that this workshop was answering an overwhelming need for information and education on hepatitis C care, treatment options, grassroots community supports, and how to access them.

Dr. Erb was well received, delivering a power packed, interactive two hour presentation covering hepatitis C basics with an in-depth discussion on the current pegylated IFN combination treatment options and some new drugs in clinical trial development. Questions abounded and the knowledge-hungry group hung in for the full four hour session while the speakers continued with Lori Fortier, liver transplant dietitian, giving sound advice on how the nutritional aspects of living with liver disease and hepatitis C can affect improvement in quality of life. Dr. Erb indicated that he tolerated cannabis use in light of the rapid, fivefold increase in liver damage caused by alcohol consumption in the hepatitis C infected liver, however, Lori Fortier cautioned that you would NOT qualify for a liver transplant if cannabis were detected in your system during the transplant assessment.

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LETTERS TO THE EDITOR:

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

NEW!!!!

Peppermint Patti's FAQ

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

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

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

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Management and Treatment
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DO TRY THIS AT HOME
An Interview with Alan Franciscus
H CSP, San Francisco

HCV Advocate is based in San Francisco, CA. Their "Train the Trainer Program" is being used by many state organizations. See

<http://www.hcvadvocate.org/hepatitis/hepC/commforum.html> where you can find maps showing where they have held trainings. The sessions are for peers, but also, many people who work professionally in health fields, such as nurses, CDC coordinators, corrections people, drug and addictions counselors come to these and receive recognized certification.

Their fact sheet series, written by a team (Lucinda Porter, who is a hepatology nurse, Liz Highleyman who is a professional medical writer, and Alan Franciscus) and checked by medical editors for accuracy, is really appreciated. There are various levels of fact sheets to meet different levels of literacy.

Their Guidebook is translated into many foreign languages, and their websites (which get well over 1 million hits a month) reflect the international demographics of their visitors.

Ah, and did I mention that our own Squeaky (CD Mazoff) works with them?

JK: Hi Alan, We have been hearing all about the Hepatitis C Support Project or HCSP and the HCV Advocate, and have been wondering how we can do something similar here in Canada. Can you tell us a bit about your educational program and how you got it going? First of all, what do CEU and CME mean?

AF: CEU means Continuing Education Units, and CME means Continuing Medical Education. CEU is a credit for education to re-certify drug and alcohol counselors. The CME is required from most agencies for re-certification or licensing of medical providers.

JK: How did you start this up?

AF: We have hired vendors who have put together programs accredited by the University of New Mexico and National Association of Drug and Alcohol Abuse Counselors.

JK: Where did you get the vendors?

AF: For the CME program, a personal friend and colleague put me in touch with a vendor who has contacts with the University of New Mexico Medical Center that does accreditation. In Canada, you should look for a doctor willing to help you. In the US, most univer-

sities and research hospitals have a process in place to issue credits.

JK: How did you go about setting up the courses?

AF: We will launch a pilot module on HCV diagnostic tests for the CME program within the next couple of months. We plan to develop two or three modules a year on HCV topics. Our vendor is designing and coordinating them in cooperation with the University of New Mexico. HCSP works with the vendor on the course content, and the University issues the accreditation. We advertise through our website, our various newsletters, postcards and our national, one-day HCV training workshops. Our trainings attract many people in the substance abuse work and medical professionals who have direct contact with hepatitis C positive individuals. The trainings are a result of collaboration between many agencies including Centers for Disease Control, Hepatitis Coordinators, public health officials, HIV organizations, community-based organizations, support group leaders and HCV positive individuals.

JK: How do you gain credibility? Why do these medical people work with you? Do you have a medical degree?

AF: No, I don't have a medical degree. Establishing your credibility is a slow process. At first we developed a comprehensive overview of hepatitis C and we recruited a respected HCV medical thought leader. Through this process and with all of our medical publications, we have worked with many medical professionals. We deal with solid medical information for our publications, but if there is a gray area, we note that the information is anecdotal, and we make it clear that it may not be backed up by scientific data. For instance many of the symptoms of HCV are not well documented, so we would say, "Patients report that they have this or that symptom." We also try to steer clear of any controversial issue unless it is backed by good, solid scientific data.

Another important step was the development of our fact sheet series and other publications in easy to copy format. For instance many health officials tell us that their source for information is our web site, and particularly our fact sheets. We regularly receive between 300-400 downloads from our web site for the fact sheets each week. HCSP's *Guide to Understanding Hepatitis C* is

downloaded between 100-150 times a week. We also have many of our publications in English, Spanish, and even some in Russian, Traditional Chinese, French, Tagalog, and Vietnamese.

I think one of our most successful programs is HCSP's national Train the Trainer program. Since the program's inception we have certified (through our agency) over 2200 people all across the country. These are truly collaborations with many different organizations attending the workshops. The workshops provide a thorough basic understanding of hepatitis C and opportunities to network with other organizations. We conservatively estimate that, if every HCSP trainer impacts 50 people, in just one year alone the trainers will reach 110,000 people! Another key to our success is looking for areas where there is a need for services. For instance our trainings were developed because we saw a serious need and tried to fill this gap in education and support.

Another important component of gaining credibility is to produce measurable outcomes when we report back to our contributors.

Of course, the most important reason we have become so successful is because of everyone who works or volunteers for HCSP. Every person that works for HCSP is very passionate about making a difference in the lives of people living with hepatitis C. We all take that extra step or effort to make sure that we produce the highest quality information and tools to better serve the HCV community.

JK: That's truly inspiring, Alan. One last thing--speaking of funding, where do you find it?

AF: Funding is very difficult to find. We have been lucky to have various funding bases such as pharmaceutical companies, donations from individuals and private foundations.



HOW TO START AN HCV SUPPORT PROJECT:

PART 5

Alan Franciscus, Editor-in-Chief
HCV Advocate

Sample Support Group Format

The following is a sample of a group format: The support group meets on the first and third Monday of every month from 7:00-8:30PM.

Starting the Group (the first 45 minutes)

The first order of business—each member should check-in with the group. The members usually talk about any important issues or just a general “where they are at.”

This allows all members to speak and it is an important part of the meeting for establishing group unity. The check-in for each member is usually 2-3 minutes each, but should not last longer than 5 minutes. During the check-in, group members may ask for additional time to talk about topics or problems they would like to discuss with the entire group. The member checking in should not be interrupted with questions or comments.

The facilitator may also introduce a question into general check-in such as: “When you check-in, please define how you are feeling” (Discourage members from using “Fine” or other one word simplistic descriptions.)

“When you check-in, please tell us one thing that you feel good about or grateful for.” (It helps group members to start out with a positive instead of a negative comment. This can also be used for the check-out.)

Education or Specific Topic Section (35 minutes)

The second part of the group is ideal for discussing a wide range of topics. It is important to talk about the various topics and to have the group prioritize and decide which topics should be discussed at each meeting. You may even want to arrange for a speaker to address the group.

Check Out

It is important that each member is able to bring closure to the group meeting. Allow about 5-10 minutes at the end of the meeting for the members to check-out. This is the time for members to have a final word or thought. This could be a simple goodnight or a comment about the meeting. The person checking out should be allowed to talk without interruption.

The ending of the group is important to give the members a positive feeling about group unity and hope for their future. Many groups perform a closing ritual to bring about a sense of group unity and hope. The closing can be a prayer, mediation, poem or holding hands with a moment of silence. Ask the group members what they prefer to close the meeting. Ask the group members to share any prayers or poems they find that helps them.

Examples:

- Serenity Prayer: God grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference.
- Silent meditation: All the members form a circle and silently say to themselves: May I be well (breathe in) May Others be well (breathe out)
- Repeat

Strategies for Challenging Situations

Every support group is unique. Support group members bring a wide variety of issues and emotions to every group based on the members’ personalities and viewpoints.

At times, personalities and viewpoints will clash with the facilitator and other group members. The facilitator will need to help resolve any potential problems that might arise during the meeting. Try not to worry too much about potential problems – trouble is generally infrequent and by referring to the ground rules and developing strategies beforehand you can avoid or handle most of the problems that may surface during a meeting.

Support Group Members

Since the ground rules (to be discussed in part 6) have been adopted by the other group members, most of the problems can be resolved by referring to the rules. It is also important to remember that the entire group is responsible for maintaining the harmony of the support group – not just the facilitator.

No one likes to be directly challenged by the facilitator or other group members. If you must interrupt or challenge a member, try using a calm and reassuring voice in a non-threatening way. Always try to reassure the person with a positive comment when interrupting or when attempting to refocus the group.

Common Problems

- Member repeatedly shows up late for the support group meeting
 - Acknowledge that the member is late and remind him or her that the member is responsible for showing up on time. Of course,

there are always situations that prevent people from arriving on time, so be careful that you are not too rigid.

◦ “I have noticed that you have been late for the last 2 meetings – is there anything we can help you with to make sure you show up on time?”

- A member is talking too long at check-in
 - Remind the member of the ground rules – there is a time limit so that everyone can talk
 - “It sounds like you may need some time during the group – is there an issue you would like help with from the group after checking-in?”

- A member is monopolizing the conversation. A good strategy before this happens is to discuss the dangers of one member monopolizing the group with the entire group and include it in your group rules.
 - If the member is monopolizing, rambling or gets side-tracked:

- Bring the member back to the main points by summarizing the key points and asking the other group members to comment.
- Interrupt the member: “You bring up some interesting points. Do any others have any comments or would others like to share how this relates to them?”

- Avoid direct eye contact with the person monopolizing – it is harder for people to monopolize the conversation if the leader is not actively engaged.

- A group member frequently makes comments or ask questions only to the facilitator
 - Look away from the member

- Pass the questions back to the group
- After the group, talk with the group member about directing comments or questions to the entire group

- Silent moments

- Silent moments can be a positive sign that members are feeling comfortable with each other. It can also mean that people are digesting information or may be trying to process some feelings. If the silence runs on for too long ask the members “Does anyone have any other thoughts about what was just discussed?” Or you can simply move along to the next topic.

- The silent member

- It is ok for members to sit quietly and not participate. If you feel that someone wants to talk but may be shy, you can make direct eye contact with the quiet member. Check out their body language for hints that they may want to jump into the discussion. You can also ask them: “Do you have anything you want to share about the discussion?” “It’s ok if you don’t want to comment, but do you have any feelings about what we discussed?”

- ◆ Incorrect information

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(SUPPORT—Continued from page 4)

°Nothing is to be gained by directly or aggressively challenging a member when they state incorrect information. Instead try to speak in a calm and soothing voice: °“Hmm...that’s not what I have heard or read. Maybe we can talk about it after the group.” You can also say (in a non-threatening way) “I have heard differently, let’s talk after group about how we can research this issue and share it with the group at a later time.”

• Humor – appropriate and inappropriate °Humor is a wonderful tool to use to break the tension in the group when the conversation becomes too filled with emotions. However, it can also interfere with members coming to terms with emotions and may impede a discussion that is important. Try these strategies:

°Ignore the humor and move on.
°Make a comment such as, “That was really funny, but I think we need to stick with our discussion.”

°If a person continues to interject inappropriate humor say, “This is a serious issue and we really need to concentrate on working through this issue.”

• Anger

°Anger is a necessary part of the support group process, especially for people with a potentially life threatening illness. However, it is important that anger be released in a non-threatening way and that it is not directed against anyone in the group. Once anger is verbally expressed a member should be able to move on. However, prolonged anger can sabotage a support group meeting by making people feel that the group is unsafe. If anger continues to dominate a meeting try these approaches:

°Acknowledge the feelings being expressed by the member

°“You have expressed some powerful emotions. What does this bring up for the other members?”

°Ask for a time-out so that you and the other members can deal with the anger.
°“I can see that you are really upset. Let’s take a couple of minutes before we continue with the discussion.”

°Acknowledge the feeling of the member and reassure the member that everyone wants to help.

°If the member becomes too angry, ask them to step outside for a minute and try to calm them down.

°Try moving on to another topic, but make sure you come back to the member and check in when the emotions have calmed down a bit.

• Crying

°Crying is an essential part of the grieving process. If someone starts to cry reassure them that the feelings are normal. If the person is unable to continue to talk, move on to another topic or ask the other members to check-in. Be sure to always come back to the member after they have stopped crying to check in and ask if they would like to continue talking about the issue.

• Side talk

°Side talking is very disruptive to the group and it leaves other group members feeling like they are being left out of a personal conversation instead of creating an atmosphere of sharing information and feelings. The best advice is to remind the members at the beginning of the meeting of the ground rules and enforce the rules when appropriate. A facilitator may have to stop the group for a moment to make the point or interrupt the members and ask them if they want to share.

MULTICULTURAL HEPATITIS C SYMPOSIUM

March 18th 2005 9 AM-3 PM
Plaza 500 Hotel | 500 West 12th Ave
Vancouver, B.C.
Granville Room

The B.C. Multicultural Health Services Society through the Multicultural Hepatitis C Prevention Project is hosting a Symposium to provide participants with information on HCV issues, to promote awareness of the multicultural communities among service providers and institutional representatives and to strengthen HCV existing support network in BC.

Agenda: Registration and continental breakfast; Introduction and the Multicultural Hepatitis C Prevention Project; Coffee break; Panel Discussion: Hepatitis C in diverse population. Ann Livingston (VANDU), Ken Winifki (Healing Our Spirit), Brandy Svendson, (Youthco), Dr. John Farley and Peer Outreach of DTES; GIS Mapping-A bird’s eye view of services.- Steven DeRoy; Lunch provided; Treatment and Co-infection.- Dr. Rolando Barrios; Keynote Agenda: Presentation; Certificate of Attendance, Evaluation, and Closure.

The registration for the Symposium is free.

For further information please call Berta: 604-725-8058 or Byron: 604-315-7725

Funded by Public Health Agency of Canada

RESEARCH

HEMOPURIFIER

Aethlon Medical, Inc., says it has a technology called the Hemopurifier, which can treat people infected with both HIV and HCV. It uses a regular kidney dialysis machine, together with affinity chromatography, filtering viruses and toxins from the blood with a unique cartridge. A recent development allows it to attack HIV and HCV specifically. The cartridge removes only the undesirable particles. Some agents are bound to the filter to stop them from entering the bloodstream. The HIV Hemopurifier is able to eradicate 55% of HIV in 3 hours, and more than 85% in 12 hours. The HCV-Hemopurifier eradicated 58% of HCV in 2 hours. This technique can give the liver a chance to heal itself.

Source: Aethlon Medical Discusses Potential to Treat Patients Co-Infected With Both HIV/AIDS and Hepatitis C, Dec 15, 2004 http://home.businesswire.com/portal/site/altavista/index.jsp?ndmViewId=news_view&newsId=20041215005550&newsLang=en http://www.corporate-ir.net/ireve/ir_site.zhtml?ticker=AEMD&script=2100

NEW MEDICATIONS

Since current Hep C treatment only works in some patients, and can’t be used in others, the search for better treatment continues. The following categories of drugs are being investigated:

Drugs That Attack Viral Enzymes

HCV has some enzymes in its RNA, which help it to replicate. Researchers hope to inhibit these enzymes.

NS3 Serine Protease Inhibitors: Boehringer Ingelheim’s BILN 2061; Vertex’s VX-950; Schering-Plough’s SCH6.

Polymerase Inhibitors: Idenix’s NM283, Japan Tobacco’s JTK-003, Rigel Pharmaceuticals’ R803, Roche’s R1479, ViroPharma’s HCV-086, BioCryst, Roche’s R1626, Medivir/Chiron’s MIV-210. Enanta/Chiron.

Drugs that target the proteins on the virus’ surface

HCV has a protective protein shell and an “envelope”. Researchers are trying to attack the envelope’s proteins so it can’t attach to cells.

Monoclonal Antibodies: XTL Pharmaceuticals’ HepeX-C (formerly XTL-002), Genmab’s HuMax-HepC

Immunoglobulin: Nabi Pharmaceuticals’ Civacir

Imino Sugar Derivative: Migenix’s (formerly Micrologix) MBI-3253, United

(Continued on page 6)

(RESEARCH—Continued from page 5)
Therapeutics' UT-231B

Drugs That Attack Viral RNA

These drugs are expected to attack the replication process of the RNA once it is inside the host cell:

PTC Therapeutics' IRES (Internal Ribosomal Entry Site) Inhibitor; Sirna Therapeutics' Hepatzyme—a Ribozyme; Isis Pharmaceuticals' ISIS 14803, an Antisense Oligonucleotide; AVI BioPharma's Antisense Oligonucleotide; Hybridon's Antisense Inhibitor; InterMune's Protease Inhibitor; Atugen Biotechnology GmbH's Antisense Oligonucleotide

Interferon-based Drugs Under Investigation

Human Genome Sciences's Albuferon--Long-Acting IFN alpha; BioMedicines's Omega Interferon--Genetically Engineered Type 1 IFN; Viragen's Multifera--Natural Human IFN alpha; Maxygen/Roche's optimized IFN alpha; Serono's r-Interferon beta; Maxygen/Roche's IFN Beta; InterMune's IFN Alfacon-1 + Ribavirin and Consensus IFN + Ribavirin; InterMune's IFN Alfacon-1 + IFN Gamma-1b and Consensus IFN + IFN Gamma; InterMune's PEG-Alfacon-1--Pegylated Consensus IFN; InterMune/Maxygen's "Next Generation" IFN Gamma; Amarillo Biosciences' Oral IFN Alpha; Nautilus Biotech's Belerofon--IFN Alpha; Hemispherx Biopharma's Alferon--IFN alfa-n3; Mochida Pharmaceutical's Alpha IFN-alpha Mochida500--"Natural" IFN; Intarcia Therapeutics' Omega IFN-- Human Type 1 IFN and OMEGA DUROS, an IFN delivery system.

Ribavirin-based Drugs

Vertex's Merimepodib (VX-497)--IMPDH Inhibitor; Valeant Pharmaceuticals' Viridamine--Ribavirin Pro-drug; Koronis Pharmaceuticals' Viral Mutagen; Roche's R1518--Levovirin Pro-drug

Immunomodulating, broad-spectrum antiviral and antifibrotic drugs

SciClone's Zadaxin (thymosin alfa-1); Anadys Pharmaceuticals' Isatoribine (ANA245).

Nucleoside Analogues/Immunomodulators: Anadys Pharmaceuticals' Isatoribine Prodrugs ANA971 and ANA975; Enzo; Biochem's EHC18; SciClone's SCV-07; Maxim's Ceplene

Coley Pharmaceuticals' Actilon, a TLR9 Agonist; Kemin Pharma's KPE02003002, a synthetic phytochemical and KPE00001133, a bicyclic carbohydrate derivative; Idun Pharmaceuticals' IDN-6556, a caspase inhibitor; InterMune's Pirfenidone, an anti-

brotic; Hemispherx Biopharma's Ampligen, an anti-viral.

Vaccines

Therapeutic Vaccines: Chiron, Intercell, Epimmune, ViRexx's HepaVaxx C, Merix, GenPhar, Innogenetics' Inno-101.

Prophylactic Vaccines: Tripep's ChronVac-C.

Source: V. J. Smith, RN, BSN, MA, *Experimental Medications for HCV* Oct 4, 2004 http://www.hepatitisneighborhood.com/content/treatment_options/medications_for_hepatitis_2082.aspx

(CARAVAN OF HOPE—Continued from page 1)

Fraser Hepatitis Services nurse Jane Carnahan-Schultz gave a snapshot of the Fraser Health Hepatitis Services Clinic and associated integrated services designed to assist the patient through the often debilitating course of treatment. Time flew by, the day was stacked full of information and in the last forty five minutes, Michael Barnholden, disability advocate from the BC Coalition of Persons with Disabilities, gave an update on the compensation project the coalition is spearheading, "The Hepatitis C Compassion Umbrella of Canada". The HCCUC has recommended to government to immediately expand compensation to include those outside of the pre-86/post-90 tainted blood transfusion window. To date the federal health minister Ujjal Dosanjh has indicated that he is open to reconsidering the compensation limitations, and has asked for his office to generate further information to be considered near summer. Michael also briefly outlined the federal and provincial disability benefit application process and highly recommends that anyone attempting to apply contact the BCCPD for professional assistance in filling out the lengthy and tricky forms.

Thank You to our sponsors: HepCBC, HepCURE, BCCPD, Hoffman La Roche & Schering. Special thanks are given to Diane Morissette for her super helping hands and excellent management of the registration table. Special thanks are also due to Effie Savoy and Sheri Kiselckback from PACE who brought us a wonderful assortment of refreshments. Well Done!

Dr. S. Erb: *Hepatologist: Hepatitis and Liver Diseases: (604) 875-5618*; Fraser Hepatitis Service: *Hepatitis Nurses Diane & Jane Tel: (604) 587-7900 or Toll Free 1-800-308-3318*; BC Coalition of People with Disabilities: *Tel. 604-875-0188*; PACE Society: *Effie Savoy, Hep C Coordinator: Tel. (604) 872-7651.*

NEWS—Continued from p. 1)

the College of Physicians and Surgeons, approved in late 1998, was posted on their website at that time, is due to be revisited in February 2005, and deals with physicians infected with HBV, HCV or HIV who perform invasive procedures. The policy states that such a physician is obligated to have his/her practice reviewed, and recommends that all physicians adhere to the principles of universal precautions and have Hep B vaccines.

Source: <http://www.cpso.on.ca/publications/dialogue/0304/policyexp.htm>, Members' Dialogue - March/April '04

NEW TEST

Ampligor GT HCV MONITOR is a test which determines both genotype (only types 1, 2 and 3) and viral load (how much of the virus you have). The test sensitivity was 0.5 KIU/mL. Comparing the results to another genotyping test, the results were the same in 97.2% of the samples. Treatment decisions can be based on genotype and viral load, and this combination test may make screening easier.

Source: Mukaide M, et al, *World J Gastroenterol.* 2005 Jan 28; 11(4): 469-75, *New combination test for hepatitis C virus genotype and viral load determination using Ampligor GT HCV MONITOR test v2.0*

HCV FIRING UNJUSTIFIED

A woman working in the kitchen of Little Chief's Place in Brandon, Winnipeg, was awarded \$2,000 because of being fired after she told her boss she was HCV positive.

She lodged a complaint with the Manitoba Human Rights Commission. An adjudicator ruled that the boss had "misinformed assumptions about the nature of hepatitis C and cannot be justified," and is compensating her for "injury to dignity, feelings and self-respect." Hepatitis C cannot be spread other than direct contact with infected blood, not through food or water.

Source: *CBC News, Hep C no cause for firing, rules human-rights commission, Jan 28 2005*

HCV CAN CAUSE CANCER

The US Government has added hepatitis C, along with 16 other agents, including hepatitis B and some papillomaviruses, to its 11th edition of the Federal Report on Carcinogens, an official list of cancer-causing agents. This is the first time viruses have been included in the list. Hepatitis B and C can cause liver cancer. The report is published at least every 2 years.

Source: *17 Substances Added to Cancer Agents List, January 31, 2005, http://www.intelihealth.com/IH/ihtIH/WSIHW000/333/7228/412287.html*



BC FAIR PHARMACARE

Please make sure you are registered with this new program, effective as of May 1, 2003, especially if you will be taking Hep C treatment. The new program establishes a deductible and maximum payment per year based on net family income. For example, a family earning \$15,000 or less would pay a maximum of \$300 a year, while a family earning over \$100,000 would pay \$4000 a year. A family that has not registered would pay \$10,000 a year.

If employees do not register, it is possible that group insurers may not pay claims above a certain amount until the employee verifies his/her registration.

To register, you need your BC Care Card numbers, SIN numbers, and birthdates for your family members, and your 2003 net family income, your consent for CRA to release net income figures to PharmaCare. Then phone 1-800-387-4977 or register at <https://pharmacare.moh.hnet.bc.ca/>



QUACK, QUACK!

A quack is not necessarily involved in fraud. He/she may believe in what is being promoted. Many of us have been convinced by friends and relatives to try certain products. Sometimes the person is involved in a money-making scheme, but often is just trying to help. Before spending any money or risking your health, check out the product on the internet, or ask your doctor.

Source: Stephen Barrett, M.D., *Quackery: How Should It Be Defined?*
www.quackwatch.com
Another link: www.geocities.com/healthbase/anti_quack_sites.html

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.

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>

TOO SICK FOR TRIAL

Roger Perrault, 68, one of the big names in Canada's tainted blood fiasco, has asked that charges of three counts of criminal negligence causing bodily harm against him be dropped, since the trial could be too stressful for his health. (*Editor: I'm sure you all sympathize.*) Mr. Perrault is also charged with 7 counts of common nuisance by endangering the public during the 1980s, when he was in charge of the blood program. He now suffers from heart problems. This trial is scheduled for November, and could last a year. The Canadian Hemophilia Society has objected loudly. He is scheduled for another trial in Hamilton, as well.

John Furesz and Wark Boucher, former federal officials with Health Canada, were also charged, as were the Red Cross, Armour Pharmaceutical Co.—a U.S. firm that produced blood products, and Michael Rodell.

Source: Mark Kennedy, *CanWest News Service, February 12, 2005, Man at centre of tainted-blood scandal worried about his health Former head of Red Cross asks court to drop criminal charges.*

LIVING WITH LIVER DISEASE WORKSHOPS

FREE wellness and educational program for patients and their families..

Monday, March 7th: Living with Chronic Illness: Psychological Management: Joyce Barwis; Traditional Chinese Medicine and Liver Disease: Dr. June Beckford; Maximize Your Nutrition: Elizabeth Bergen
Monday, March 14th: Naturopathy and Liver Disease: Dr. Maria Boorman; Meditation, Hypnotherapy and Liver Disease: Georgia Foster.

James Bay Community Project
547 Michigan Street, Victoria
7:00-9:00PM

All workshops are free. To register, please contact the Canadian Liver Foundation at 1-800-856-7266

This workshop series was made possible through an unrestricted educational grant courtesy of Schering Canada.

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



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 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, 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@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 dmorrissettie@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 lse 565-7387 lse.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

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 306-620 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, 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 1st Tues. monthly. 7-8:30 PM. 3038 Hurontario St. (Hwy 10 & Dundas-Mississauga), 3rd floor. Contact (905) 799-7700 healthline-peel@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

Alternative Therapies for Hepatitis C

Masina Wright, ND

Monday, March 7, 2005, 7-8:30pm Metropolitan Hotel, Victoria Room 108 Chestnut Street, Toronto, ON
 RSVP to Meghan Cox at 416-924-3446.

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 reneedaudio@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 orthomas@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