

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

MORE DYING OF HEPATITIS C THAN AIDS; BABY-BOOMERS AT GREATEST RISK

Every year since 2007, more Americans have died from complications of chronic hepatitis C than from HIV/AIDS, and those born 1945 through 1965 are most at risk (CDC, Feb. 20, 2012). There is no vaccine against HCV, and as of yet, no 100% cure. The good news is that the rate of new HCV infections is decreasing steadily, and more effective new treatments for this 'silent killer' are becoming available. In Canada, the picture is similar. There are about 250,000 HCV+ Canadians, of which almost 55,000 live in BC. Sadly, Vancouver Island has one of the highest rates of infection in Canada (BCCDC, Aug. 18, 2010).

Many HCV+ people don't know they have it, as HCV commonly does its deadly damage to the liver and other organs 'silently' over 3 to 4 decades. Suddenly, a 60-year-old grandmother may discover she has advanced cirrhosis and won't survive without a liver transplant, or that she has liver cancer. The minor fatigue, rashes, stiffness, or digestive complaints she'd occasionally experience were all the warning she ever got that the transfusion or medical procedure she'd forgotten about, or that once-in-a-lifetime party that included IV drugs, or use of a cocaine straw, or that unsterile tattoo or piercing, had infected her with HCV back in her teens or twenties. Or maybe she was a nurse or dental assistant, always at extra risk of accidental needle-stick injury.

Fortunately for the spouses of those infected with hepatitis C (and contrary to other forms of hepatitis), HCV is only very rarely contracted during normal sexual activity. HCV is spread only by direct blood to blood contact, such as when skin is penetrated by an object contaminated with another's blood.

Current BC guidelines require patients to provide proof of considerable liver damage to get PharmaCare to cover HCV treatment. Some patients have even attempted to further damage their livers so as to qualify. Howev-

er, current research shows that treatment is more likely to work the earlier it is provided, which would mean fewer lives and families devastated by disability, liver cancer, and transplant. Against this rapidly-shifting background, concerned voices with competing needs--the medical profession, patients and caregivers, pharmaceutical companies, policy-makers who administer health insurance and disability benefits, and taxpayers -- are starting to be heard.

HepCBC, a charity run by and for people infected and affected by HCV, is offering a free, all-day, interactive public forum in Victoria, BC at Begbie Hall, Royal Jubilee Hospital (2101 Richmond Ave.) on Friday, March 2nd (9 AM to 4 PM), where these various stakeholders can meet to hear and consider one another's perspectives. Five Canadian liver specialists will present new recommended guidelines for managing HCV. Each of their presentations will be followed by a public Q&A and comment period. The public is invited, but as seating is limited, online pre-registration is required via our website, www.hepcbc.ca.

Here are the quest per answer:

(1) Would you or a member benefit in a come of this review? tail.

(2) Describe how chrotype 1, affects your da (3) If you have tried what effects did you experience with each to be a public Q&A and comment period. The public is invited, but as seating is limited, online pre-registration is required via our website, www.hepcbc.ca.

This is a particularly critical time for BC's Ministry of Health and PharmaCare policy-makers responsible for addressing the prov-

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URGENT: PATIENT INPUT FOR INCIVEK NEEDED

Call for Patient input on TELAPREVIR (IncivekTM) by March 5

On February 17, 2012, BC PharmaCare began its "Your Voice" patient group review of Vertex's IncivekTM (telaprevir) for chronic hepatitis C (GENOTYPE 1 ONLY). HepCBC needs individual patient input by March 6th in order to meet their deadline. Input requested **only from HCV+ patients with genotype 1 in BC**, thanks.

Here are the questions. 200 words max. per answer:

- (1) Would you or any immediate family member benefit in any way from the outcome of this review? If "yes" explain in detail.
- (2) Describe how chronic hepatitis C, genotype 1, affects your day-to-day life.
- (3) If you have tried IncivekTM (telaprevir), what effects did you experience?
- (4) What drugs or other treatments have you used (or are currently using) for chronic hepatitis C, genotype 1? Briefly describe your experience with each.
- (5) Do you believe Telaprevir (IncivekTM) should be included in the BC Pharmacare program, and if so, why?

Please email your answers to these 5 questions by midnight, March 6th to HepCBC (cherylreitz.hepcbc@gmail.com) Thank you! Anything that might identify you will be removed from our group submission. NOTE: The "Your Voice" website is still experiencing technical difficulties as of press time, but that will not affect HepCBC's patient group submission.

SUBSCRIPTION/ORDER FORM

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

HepCBC 2642 Quadra Street PO Box 46009 Victoria, BC V8T 5G7

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SUBMISSIONS: The deadline for any contributions to the hepc.bull® is the 15th of each month. Please contact the editors at jking2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

□"I want to volunteer. Please contact me."

to hepatitis on the envelope.)

□"I want to join a support group. Please call."

(Note: The hepc.bull is mailed with no reference

You may also subscribe or donate on line via

PayPal at www.hepcbc.ca/orderform.htm

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:

EDITOR: PHONE: FAX: EMAIL: WEBSITE: Joan King (250) 595-3892 (250) 595-3865 info@hepcbc.ca www.hepcbc.ca

HepCBC 2642 Quadra Street, PO Box 46009 Victoria, BC V8T 5G7

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!! FAQ version 9.0



Patti's FAQ Peppermint 9.0 NOW Version is AVAILABLE, Version 8 FRENCH available and SPANISH. The **ENGLISH**

version includes treatment information and research from 2012. Place your orders now. Over 160 pages of information for only \$15 each. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2012, the FAQ V9.0, the slide presentations developed by Alan Franciscus, 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 HERE.

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 <u>HepCBC</u>.

THANKS!!

HepCBC thanks following institutions and individuals for their generosity: The late John Crooks, The JackFM, Community Ocean, Victoria, Victoria Positive Living Centre, Provincial Employees Community Services Fund, United Way, the Victoria Foundation, Dr. C. D. Mazoff, Lorie FitzGerald, Chris Foster, Judith Fry, Allison Crowe, United Way, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Judy Klassen, and S. J.

Please patronize the following businesses that have helped us: Top Shelf Bookkeeping, Thrifty Foods, Samuel's Restaurant, 2 Guys & A Press, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, VanCity, Shoppers Drug Mart, Market on Yates, and Safeway.

Special thanks to Thrifty Foods for putting our donation tins at their tills in these stores: Greater Victoria: Quadra, Cloverdale, Hillside Mall, Tuscany, Broadmead, Fairfield, James Bay, Admirals Walk, Colwood, Central Saanich, and Sidney. Lower Mainland: Tsawwassen, Coquitlam, Port Moody. Also: Salt Spring and Mill Bay.

POSITIVE LIVING

Definition of "Tithe": (Christianity / Ecclesiastical Terms) a tenth part of agricultural or other produce, personal income, or profits, contributed either voluntarily or as a tax for the support of the church or clergy or for charitable purposes."

www.thefreedictionary.com

HepCBC was recently a beneficiary of the kindness and generosity shown by Victoria's Positive Living Centre. Their congregation fosters the custom of tithing. We were honoured to be one of their chosen charities. We were recommended to them by one of our loyal members, who wrote: "There are a total of 5 non profit organizations being presented with a cheque, and each speaks for a few minutes about their organizations and the good they do in the larger community."

Last January 8th, we sent our president, Stephen Farmer, accompanied by others from our group, and he spoke to them about hepatitis C and his experiences, and answered their questions. This was an excellent opportunity "to reach out to the community and break through the shame and stigma of the disease," and to impart information about prevention, as our kind friend pointed out.

We are grateful to have had the opportunity to participate in this congregation's tithing philosophy, which is most impressive and heart-warming, and we thank them for their generosity and support.

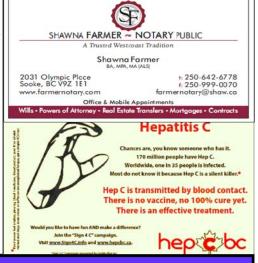
You can read more about this wonderful tradition at their website:

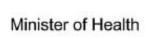
www.positivelivingcentre.com/

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Ministre de la Santé

Ottawa, Ontario K1A 0K9



I am pleased to send greetings to all delegates at HepC–BC's interactive forum on the 2011 Canadian Consensus Guidelines for the Management of Chronic Viral Hepatitis.

This forum provides you all with a unique opportunity to take a closer look at both the content and the implications of these new Guidelines for viral hepatitis care in British Columbia.

The Government of Canada acknowledges viral hepatitis as a significant public health issue, not only in B.C. and Canada, but also internationally. One in 12 people around the world live with either chronic hepatitis B or C. To change this, we need a comprehensive approach that emphasizes prevention, treatment, and safe public-health practices.

The Government of Canada is addressing hepatitis, and we invest about \$10 million a year in programs that focus on research and surveillance, care and awareness, and prevention and community-based support.

The Government of Canada also supports global efforts to address viral hepatitis. We are providing funding to establish the Global Hepatitis C Network in Canada, and supporting a resolution to recognize viral hepatitis as a major world health challenge.

I commend all of you, and the organizations that you represent, on your tireless work to make a meaningful difference to those living with, or affected by hepatitis. I'm certain you are here today because you want to make a difference.

Best wishes for a successful forum.

Leona Aglukkaq Minister of Health / Ministre de la Santé Government of Canada / Gouvernement du Canada

Kruhhag

In preparation for our Forum, many groups were invited: Patients and caregivers, medical professionals, pharmaceutical companies, government leaders, PharmaCare officials, and media. Unfortunately PharmaCare was not able to find anyone free to attend, but since their participation is so important, one of their representatives kindly offered to present us with a written response to our questions, which could be read out at the Forum. We still hope one of them can come in person and speak, even if only briefly. The questions below have been presented to the representative. We hope that the official response to the questions below arrives in time, so that our participants will be able to move forward with a more complete and shared understanding of PharmaCare policies.

(1) Below are the current Standard of Care (SOC) hepatitis C treatment criteria (these include contraindications and futility-stopping rules). Do you know who decides this sort of criteria? If it is an agency outside PharmaCare, could you please refer us on to them so we can invite their participation in our forum?

From: <u>https://www.health.gov.bc.ca/exforms/pharmacare/5356fil.pdf</u>

All patients must meet these **Treatment Criteria:**

- •Be confirmed PCR Positive (for HCV) and genotyped.
- Be treatment-naive (for current pegylated interferon/ribavirin only SOC).
- •Have ALT level 1.5X upper limit of normal on 2 consecutive occasions at least 3 months apart.

Contraindications:

- •<18 years of age
- •De-compensated liver disease
- •Pregnancy or lack of appropriate contraception
- •Higher risk of non-compliance
- •Active alcohol abuse
- •Illicit IV drug and/or intra-nasal cocaine use

Futility Stopping Rules (limits of coverage):

Genotypes 1,4,5,6: Initial coverage is

(Continued on page 4)

(BOOMERS—Continued from p. 1) ince's HCV epidemic. As they lay out new treatment protocols, patient-access criteria and PharmaCare coverage eligibility, policy-makers must somehow balance demands for fiscal

how balance demands for fiscal responsibility with the efficient allocation of resources, long-term public health issues, and justice for individuals and their families. Unfortunately, as of today, though invited, no officials from the Ministry of Health or from PharmaCare have agreed to attend. In lieu of his attendance, one PharmaCare official has consented to answer some written questions in advance. (See page 3)

(**OUESTIONS**—Continued from page 3)

14 weeks. To continue past this point, must achieve 2-log drop in viral load at Week 12 lab test. At that point, an additional 34 weeks coverage is allowed. (48 week maximum)

Genotypes 2, 3: All patients get 24 weeks coverage.

- (2) Hepatitis C treatment is moving to a multi-drug 'cocktail' (current SOC + one or more protease inhibitors) using patient-customized 'response-guided therapy'. And these new 'cocktails' were tested using sets of criteria, contraindications, and futility stopping rules quite different from current SOC. Therefore, we anticipate changes in these areas. Who makes these changes and how (what is the process/timeframe/is there opportunity for stakeholder input)?
- (3) You mentioned that PharmaCare follows guidelines set by specialists. However, the Canadian Association for the Study of the Liver (CASL) recommends new Consensus Guidelines for the Management of Chronic Viral Hepatitis every few years, and BC PharmaCare has not yet adopted the 2007 guideline recommendations (Source: http://www.hepatology.ca/cm/FileLib/hepC.pdf)

The 2007 guidelines, based on current research findings, contain numerous recommendations at odds with those used by PharmaCare. For example, the 2007 Guidelines state: "Although patients with advanced liver disease are most in need of therapy, those with early disease are most likely to clear the virus," and "Patients with normal alanine aminotransrerase (ALT) should be considered for treatment; some will have significant histological liver disease." In a couple of weeks or so, CASL's 2011 guidelines will be published. (This is the topic of our forum). What deliberative body decides which, if any, of these specialist guidelines

will be incorporated in BC-- and is its decision-making process transparent?

- (4) Other current and upcoming tests and drugs may optimize treatment success and cost-effectiveness. For example: new genetic testing (IL28B) can help predict those patients who will succeed with current SOC without addition of the more expensive protease inhibitors; less-invasive and lessexpensive biopsy tools are already available but not widely-used; monitoring for resistance and auto-immunity may be more critical with the additional drugs; covering treatment that combats the cocktails' new side-effects may prevent patient drop-out. What set of criteria are used to determine which additional tests and treatments such as these (which would, ideally, accompany the new SOC) get covered by PharmaCare?
- (5) As new drugs are added to the HCV treatment cocktail, and the various treatments and protocols become more customized to each patient's needs, we may end up with a very confusing set of situations in which a patient may meet PharmaCare's criteria to have the SOC part of his/her treatment covered, but not the protease-inhibitor part, or vice versa. How do medical staff counsel a patient and ensure treatment will not stop in the middle of such a situation?
- (6) BC patients with some diseases such as HIV/AIDS and cancers do not have to provide PharmaCare with proof of considerable damage to their bodies (such as 1.5X highnormal ALT) before they can have their treatment costs covered. In light of the 2007 CASL recommendation that patients with early HCV (and the least liver damage) are the most likely to clear the virus, what is PharmaCare's rationale for this delay?

(EXTRA CREDIT) One related but very 'speculative' question I ask you as a medical expert, not as a PharmaCare executive: Alberta has a Centre of Excellence for Viral Hepatitis Research. Do you foresee a Centre for Excellence for Hepatitis C in BC any time soon?

LONG WAIT TO SEE A SPECIALIST?

ASK TO BE PUT ON THE CANCELATION LIST.



RESEARCH NEWS

ERYTHROPOIETIN FOR ANEMIA

Does erythropoietin (EPO) improve SVR (sustained virological response) in patients taking Hep C treatment? An article from the February 2012 issue of the Journal of Viral Hepatitis says yes. The authors pooled results from available clinical trials. Among 257 patients with treatment-caused anemia, those receiving EPO had SVRs of 88% compared to 67% of patients who had to have their dose of ribavirin (RBV) reduced. There were no adverse events in these patients. Unfortunately EPO isn't covered in many provinces in Canada, or may need special permission.

Source:

www.natap.org/2012/HCV/020612 03.htm

PPI-668

On January 9, 2012, Presidio announced the end-of-treatment Phase Ia results for PPI-668, its 2nd generation HCV NS5A inhibitor, which studied the effects of a range of doses in 32 healthy volunteers in New Zealand. All doses were well-tolerated up to 5 days and showed that the drug remains in the body long enough to allow once-a-day dosing. The company will be initiating a Phase Ib trial now. The company has discovered some polymerase inhibitors that could be combined with PPI-668.

Source: www.hivandhepatitis.com/hepatitis-c/ hepatitis-c-topics/hcv-treatment/3428-achillionpresidio-and-inhibitex-announced-hcv-drugpipeline-developments

IDX719

Idenix has begun a Phase I study of IDX710, an NS5A inhibitor, effective against multiple genotypes. The first part of the study will test the drug in healthy volunteers, and the second part will be a 3-day trial in treatment-naïve genotype 1 patients. They have two polymerase inhibitors, IDX19368 and IDX19370, which they will test soon.

Source: www.hivandhepatitis.com/hepatitis-c/ hepatitis-c-topics/hcv-treatment/3428-achillionpresidio-and-inhibitex-announced-hcv-drugpipeline-developments

IDX184 HOLD REMOVED

In September 2010 Idenix's product IDX184, a nucleotide prodrug of 2'-methyl guanosine, was put on hold because of 3 cases of elevated liver enzymes during a trial combining that drug and IDX320. An investigation concluded that IDX320 probably

(Continued on page 5)





River Rock Show Theatre 8811 River Rd Richmond, BC

> Tickets are \$50.00 With Dinner \$125.00 *DANCING*

ATLANTIC CROSSING & TRULY TINA



RAFFLE TICKETS and much more...

We will be honouring Dr. Eric Yoshida

Proceeds going to The Happy Liver Society



(RESEARCH NEWS—Continued from page 4)

caused the abnormalities. 31 patients were allowed to continue. Early this year, the FDA removed the hold order. Idenix will now start treating 30 more patients in the 12-week phase IIb study of IDX184 combined with PegIFN/RBV.

Source: http://ir.idenix.com/releases.cfm

GS-7977 (formerly **PSI-7977**)

Gilead acquired Pharmasset as of January 2012. Early data from the Phase II "Electron" trial raised hopes that a combination of GS-7977 plus RBV could cure genotype 1 patients. 35 patients (25 treatment-naïve and 10

null-responders) were treated with the 2 drugs, and 100% of them tested undetectable at 4 weeks of treatment. Unfortunately, further testing showed less favourable results. In February, Gilead told the press that 6 of the 10 GT1 null-responders relapsed by 4 weeks after the 12-week treatment. 2 of the patients have just tested undetectable at 2 weeks post-treatment. Researchers now believe that the drug will have to be combined with other direct-acting oral antivirals.

Source: www.thestreet.com/story/11399517/1/gilead-woes-with-new-hep-c-data-boxing-out-poor-2012-guidance.html

HEP C CLINIC AT PERCURO VICTORIA, BC



Did you know that the Hepatology Clinic at PerCuro provides comprehensive HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region?

Specialized nurses assist with the procurement of financial coverage for treatment, ensure lab tests are scheduled appropriately, provide instruction in the self-administration of injectable medication, assist with the management of side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding your HCV status, treatment and any other issues of concern.

This type of professional support is imperative now that standard or care therapy often involves three medications.

PerCuro also offers access to cutting edge clinical trials for both naïve and treatment-experienced patients.

Every attempt is made to meet the individual needs of all patients. There is no cost involved.

Nursing Support improves outcomes. Contact 250-382-6270

NORMAL LFTs

"Significant liver disease may be present ... irrespective of viral load, genotype and alanine transaminase levels."

www.ncbi.nlm.nih.gov/pubmed/11677973

"In patients with chronic hepatitis C with normal transaminases level interferon therapy improves structure of hepatic tissue." <u>www.ncbi.nlm.nih.gov/pubmed/12498116</u>

"Almost 85% of the patients with HCV and persistently normal liver enzymes have got abnormal liver histology."

http://www.saudijgastro.com/article.asp?

issn=1319-3767;year=2002;volume=8;issue=1;spage=9;ep age=13;aulast=Akbar

"The available literature suggests that PNAL [persistently normal ALT levels] are characterized by a higher prevalence of female sex." "Between 14 and 24% of persons with persistently normal values have more-than-portal fibrosis on liver biopsy. These persons may have progressive liver disease over time despite persistence of normal ALT values." www.medscape.com/viewarticle/709156 2

"It is not easy to explain the reason for the phenomena that patients present with severe liver damage though the ALT levels are normal or nearly normal." http://labmed.ascpjournals.org/content/40/3/167.full

Hep C Sites on facebook.

Hep C, the Silent Killer

http://www.facebook.com/pages/Victoria-BC/HepCBC/274985724940





FIGHT Against Hepatitis C

Open Group — fightagainsthepatitisc@groups.facebook.com



Transplant Support Group of British Columbia

You can join the Facebook group by putting "Transplant Support Group of British Co-

lumbia" in your browser or by using this URL: http://www.facebook.com/group.php? gid=311699175404&ref=share

HCVEDGE Get the edge on managing your Hepatitis C



- Why choose HCV-Edge?
- access to a broad array of reliable background information on Hepatitis C
- electronic reminders for pill taking and office visits, wherever you are
 detailed information on response rates, potential side effects and duration
- of your antiviral therapy gets you familiar with the latest antiviral therapies..., and more.

What can HCV-Edge do for me? Find out by checking out our walk-thru demo >



I have been working on my peer support Wendy's Wellness Website and wanted to offer everyone a safe place to get together.

This is the link to my post, offering a secure place to blog about Hep C health. I hope to connect with anyone interested in sharing how we cope and manage our health challenges.

Please pass this along to anyone out there who would like a safe place to blog.

http://wendyswellness.ca/

PHYSICIANS FOR PATIENTS



An online physician-mediated support group for patients, families, and friends of those with hepatitis C.

http://hepatitisc.physiciansforpatients.com/

If you are receiving this newsletter by snail mail but have internet access, please consider switching to our pdf version. All you need is Adobe Acrobat Reader, free at this site:

www.adobe.com/products/acrobat/readstep2.html

Just send your email address to <u>info@hepcbc.ca</u> and say, "Send me the email version, please," and you, too, can enjoy this newsletter in glorious colour, free of charge.

twitter



Hey there! hepcbc is using Twitter.

Twitter is a free service that lets you keep in touch with people through the exchange of quick, frequent answers to one simple question: What's happening? Join today to start receiving hepcbc's tweets.

http://twitter.com/hepcbc

ADVERSE EVENTS

Report problems with medical products, product use errors, quality problems and serious adverse events.

www.accessdata.fda.gov/scripts/medwatch/ medwatch-online.htm

COMPETITION!

epCBC needs writers for the hepc.bull, and will pay \$50.00 for a featured article. The article should be original, 500 to 800 words, and be about hepatitis C. It may be, for example, about the author's experience with hepatitis C, a study (with references) on some aspect of Hep C, or a call for action. Submissions must be in by the 15th of next month, stating interest in receiving the bonus. If there is more than one submission chosen, the editors reserve the right to print both, or leave one for a future edition.

info@hepcbc.ca

There is NO vaccine for hepatitis C!

Hepatitis C is spread by blood-to-blood contact. 251,000 Canadians are infected with hepatitis C, and because there are often no symptoms, 95,000 of them don't know it *



Are you Infected? It's a Simple Blood Test.



Call HepCBC 595-3892 www.hepcbc.ca

*Stats from Public Health Agency of Canada Hepatitis C



www.facebook.com/?ref=home#!/pages/ Hepatitis-C-Trust/107063971566?v=info



GLOBAL HEPATITIS C NETWORK IN CANADA



www.globalhepc.net



"At any age, staying strong and flexible helps you do the things you enjoy, and perform day-to-day activities with great ease."

Here, you can find a link to the Move for Life DVD, good eating tips and a series of short "walkabouts," "energy bursts," and lots of great health tips:

www.actnowbc.ca/move_for_life_dvd

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CONFERENCES

The International Liver Congress 2012 The 47th Annual Meeting of EASL 18-22 April 2012 Barcelona, Spain

http://www.easl.eu/ the-international-livercongress/general-information

The Viral Hepatitis Congress 7-9 September 2012 Johann Wolfgang Goethe-Universität Frankfurt, Germany http://www.theconferencewebsite.com/ conference-info/Viral-Hepatitis-Congress-2012

8th Australasian Viral Hepatitis Conference 10-12 September 2012 SkyCity Convention Centre Auckland, New Zealand http://www.hepatitis.org.au/

EASL Special Conference Clinical Drug Development for Hepatitis C 14-16 September 2012 Prague, Czech Republic http://www.easl.eu/_events/easl-specialconference/easl-special-conference-clinicaldrug-development-for-hepatitis-c

2nd World Congress on Controversies in the Management of Viral Hepatitis (C-Hep) 18-20 October 2012 Berlin, Germany http://www.comtecmed.com/chep/2012/

AASLD - The Liver Meeting 2012 9-11 November 2012 Boston, Massachusetts www.aasld.org/lm2012/program/Pages/ default.aspx

HEP C TELECONFERENCES

Tuesdays 7- 9 PM CST. Speakers. Q&A session. Chat. Free and confidential. More info: http://www.hepcmo.org

INCIVEK

CARE PROGRAM: 1-877-574-4298

EPREX ASSISTANCE **PROGRAM**

Janssen-Ortho Inc., Canada has a program that may provide assistance in obtaining epoetin. It is the Eprex Assistance Program (EPO) 1-877-793-7739

For more info, provincial coverage and forms: http://profiles.drugcoverage.ca/en/ default.asp?DrugID=25

PEGCARE

PegCARE is a reimbursement program to help people who have been prescribed Pegetron and need assistance with any copayment they might have, whether through their provincial coverage (i.e., Pharmacare) deductible or their 3rd-party health insurance. It is pro-rated, so the less the family income is, the more help they get. If someone's net family income is less than \$30,000, they will get 100% reimbursement. The income maximum is \$100,000. Patients must be signed up for Fair Pharmacare to qualify, and they need to provide a copy of last year's T4 form.

A 24/7 Nursing Hotline and bilingual assistance is available, at no charge. Other services are access to live translation services (150 languages) and injection assistance from registered nurses. Ask your doctor or nurse to enroll you in PegCARE. It's an easy single-page form to fill out, which they will provide. PegCARE: 1-866-872-

PEGASSIST

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM - 6 PM EST) by calling: 1-877-PEGASYS or 1-877 -734-2797. Patients can also obtain a program enrollment form from their nurse/ physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting RCMP Blood Probe Task Force TIPS Hotline treatment, i.e., deductibles and/or copayments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

NEUPOGEN VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependant on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge. Please note that Amgen will only provide Neupogen to patients on a compassionate basis as long as it is prescribed and dosed in accordance with the approved product monograph. This service is accessed through the Victory Program: 1-888-706-4717.

COMPENSATION

LAW FIRMS

1986-1990

Bruce Lemer/Grant Kovacs Norell Vancouver, BC Phone: 1-604-609-6699 Fax: 1-604-609-6688

Pre-1986/Post-1990

Klein Lyons Vancouver, BC 1-604-874-7171. 1-800-468-4466, Fax 1-604-874-7180 www.kleinlyons.com/class/settled/hepc/

Lauzon Belanger S.E.N.C. (Quebec) Toronto, ON

Phone 416-362-1989; Fax 416-362-6204 www.lauzonbelanger.qc.ca/cms/index.php?page=108

Roy Elliott Kim O'Connor LLP.

hepc@reko.ca www.reko.ca/html/hepatitisc.html

Kolthammer Batchelor & Laidlaw LLP #208, 11062 - 156 Street, Edmonton, AB T5P-4M8 Tel: 780-489-5003 Fax: 780-486-2107

kkoltham@telusplanet.net

William Dermody/Dempster, Dermody, Riley & Buntain Hamilton, ON L8N 3Z1 1-905-572-6688

LOOKBACK/TRACEBACK

Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056

Lookback Programs, Canada: 1-800-668-2866

Canadian Blood Services, Vancouver, BC 1-888-332-5663 (local 3467) or 604-707-3467

Lookback Programs, BC: 1-888-770-4800

Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362

Manitoba Traceback: 1-866-357-0196

Canadian Blood Services, Ontario 1-800-701-7803 ext 4480 (Irene) Irene.dines@Blood.ca

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

Class Action Suit Hotline: 1-800-229-5323 ext. 8296 Health Canada Compensation Line: 1-888-780-1111 Red Cross Compensation pre-86/post-90 Registra-

tion: 1-888-840-5764 HepatitisC@kpmg.ca Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764 www.phac-aspc.gc.ca/hepc/comp-indem_e.html

CLAIMS ADMINISTRATOR

1986-1990

Administrator 1-877- 434-0944 www.hepc8690.com info@hepc8690.com www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf

Pre-86/Post-90

Administrator 1-866-334-3361 preposthepc@crawco.ca www.pre86post90settlement.ca

Settlement Agreement: http://www.reko.ca/html/ hepc_settleagreement.pdf

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SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more:

• Campbell River: Drop in, needle exchange, advocacy. 1371 C - Cedar St. Contact leanne.cunningham@avi.org 250-830-0787

• Comox Valley Harm reduction, counselling, advocacy. 355 6th St. Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400
Nanaimo Meetings 4th Tues monthly, 1"15

pm 201-55 Victoria Rd, Contact Anita 250-753-2437

anital.rosewall@avi.org for details.

• Port Hardy (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shorncliffe Rd. Contact Tom, 250-949-0432 tom.fenton@avi.org.

• Victoria Access Health Centre, drop in, disability applications, peer training. Support group Tues 12:30 PM, 713 Johnson St., 3rd floor, 250 -384-2366 Hermione.jefferis@avi.org

Boundary HCV Support and Education Contact Ken 250-442-1280 ksthomson@direct.ca

Burnaby HCV Support Contact Beverly 604-435-3717 <u>batlas@telus.net</u>

Castlegar Contact Robin 250-365-6137 eor@shaw.ca

Comox Valley NILS Treatment/Pre & Post-treatment Support Group 2nd & 4th Wed., 615-10th St, Courtenay. Lunch. Contact Cheryl Cheryl.taylor@viha.ca 250-331-8524.

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231 dggrimstad@shaw.ca

Cowichan Valley HCV Support Contact Leah 250-748-3432 *r-l-attig@shaw.ca*

HepCBC info@hepcbc.ca, www.hepcbc.ca •Victoria Peer Support: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-3891

•Fraser Valley Support/Info: 604-576-2022

Kamloops ASK Wellness Centre. Chronic illness health navigation/support. <u>fo@askwellness.ca</u> 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing and counseling 250-315-0098. www.askwellness.ca

Kamloops Hep C support group, 2nd and 4th Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support and meeting info. Contact Elaine 250-768-3573. eriseley@shaw.ca, Lisa 1-866-637-5144 ljmortell@shaw.ca

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Support AVI Health Centre, #216-55 Victoria Rd. Contact Fran 250-740-6942. hepctxpeersupport@hotmail.com

Nelson Hepatitis C Support Group 1st Thurs. every 2nd month, afternoons. ANKORS, 101 Baker St. Library M-Th 9-4:30. Contact Alex or Karen 1-800-421-2437, 250-505-5506,

information@ankors.bc.ca alex@ankors.bc.ca www.ankors.bc.ca/

New Westminster "HepC" Support Group each Fri 10 AM. Nurse. Acupuncture. Refreshments. Contact: Michelle 604-526-2522., mail@purposesociety.org

North Island Liver Service Info, support, treatment. Doctor or self-referral. 1-877-215-7005 250-850-2605.

Courteney: 2nd Fri monthly 1PM, Dropin, Comox Valley Nursing Čentre (nurse)

Campbell River: 2nd Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

Powell River Hepatology Service Powell River Community Health, 3rd Floor-5000 Ave. Contact Melinda Jovce Melinda.herceg@vch.ca 604-485-3310

Prince George Hep C Support Group 2^{nd} Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 421. Contact Ilse 250 -565-7387

ilse.kuepper@northernhealth.ca

Prince Rupert Hep C Support Contact: Dolly 250-627-7942

hepcprincerupert@citytel.net

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-1-888-557-2487, 2487, http:// health.groups.yahoo.com/group/Network-BC/ wendy@wendyswellness.ca www.wendyswellness.ca

Slocan Valley Support Group Contact Ken 250-355-2732, ken.forsythe@gmail.com

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources, contact Catriona 604-886-5613 catriona.hardwick@vch.ca or Brent, 604-740-9042 <u>brent.fitzsimmons@vch.ca</u>

Surrey Positive Haven Info, harm reduc tion, support, drop in, clinic. 10697 135A St. Contact Monika 604-589-9004.

VANDU The Vancouver Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061

vandu@vandu.org www.vandu.org

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

Vancouver Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211. or call 604-522-1714 (Shelley), 604-454-1347 (Terry), to talk or meet for coffee.

Vernon telephone buddy, M-F 10-6 Contact tact Debby Minielly dminiel-Peter, pvanbo@gmail.com Tel. 250-309-1358.

Victoria CoolAid Peer Support each Wed 800-263-3456 Ext. 1257, 519-376-10-11:30 AM, 713 Johnson St. Support for 9420, Ext. 1257, all stages of treatment (deciding, during, www.publichealthgreybruce.on.ca/ after). Contact Carolyn cshowler@coolaid.org

YouthCO HIV + Hep C Society of BC. Drop-in T&W 12-3, Fri. 9-12. Call to schedule appts M-F 10-6. 205-568 Seymour St, Vancouver 604 St. Catharines Contact Joe 905-688-1441, 1-855-YOUTHCO Support Staff 682-6194 Stewart stewartc@youthco.org, Briony brionym@youthco.org www.youthco.org

Whitehorse, Yukon-Blood Ties Four Directions

Contact 867-633-2437 Toll free: 1-877- 333-2437 bloodties@klondiker.com

OTHER PROVINCES

ONTARIO:

Barrie Hepatitis Support Contact Jeanie for info/appointment jeanievilleneuve@hotmail.com

Sandi's Crusade Against Hepatitis C/ **Durham Hepatitis C Support Group**

Contact Sandi: smking@rogers.com www.creativeintensity.com/ smking/

Hamilton Hepatitis C Support **Group** 1st Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St, Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 mkowalski@hucchc.com

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange. 269 Main St. W, Suite 201, North Bay. Contact 705-497-3560. 1-800-387-3701 or <u>hepccommcoord@gmail.com</u>, www.aidsnorthbay.com

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, Teen Health Centre -Street Health Program Office, 711 Pelissier St., Suite 4, Windsor. Contact Andrea Monkman 519-967 -0490 or <u>hepcnetwork@gmail.com.</u> http://hepcnetwork.net

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 www.hars.ca hars@kingston.net

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room, 659 King St. East (Enter off King St) Kitchener. Contact Bob 519-886-5706, Mavis 519-743-1922 or <u>waterloore</u>gionhepcsupport@gmail.com

London Hepatitis Hep C Support 186 King St, London. For those infected as well as affected by Hep C. Contact: 519-434-1601, 1-866-920-1601, hivaidsconnection.com

Owen Sound Info, support. Conly@publichealthgreybruce.on.ca 1-

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700

jcolangelo3@cogeco.ca

Sudbury Circle C Support Group 1st Tues. monthly. Contact Ernie 705-522-5156,

hepc.support@persona.ca

or Monique 705-691-4507.

Toronto CLF 1st Mon. monthly Oct.—June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932

bpotkonjak@liver.cawww.liver.ca

Thunder Bay Hep C support. Contact Sarah Tycholiz 807-345-1516 (or for 807 area only 1-800-488-5840)

Unified Networkers of Drug **Users Nationally**

undun@sympatico.ca

York Region Hepatitis C Education Group 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

OUEBEC:

Ouebec City Region Contact Renée Daurio 418-836-2307 reneedaurio@hotmail.com

ATLANTIC PROVINCES:

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767 info@hepatitisoutreach.com

www.hepatitisoutreach.com

PRAIRIE PROVINCES:

Edmonton Contact Jackie Neufeld 780-939-3379.

Manitoba Hepatitis C Support Community Inc. 1st Tues. monthly, 7 PM, 595 Broadway Ave. Everyone welcome. Contact Kirk 204-772-8925 info@mbhepc.org www.mbhepc.org

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



If you have a Canadian HCV support group to list here, please send details to info@hepcbc.ca by the 15th of the month. It's free!