

hepc . bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HCV IN THE NEWS

INCIVEK WARNING

Due to several deaths, Vertex has issued a warning about skin reactions associated with its protease inhibitor telaprevir (Incivek), now approved in Canada. I know you think no one dies from skin rashes, but in this case, the skin problems are just a symptom of systemic problems and possibly of organ failure, which is preventable if the medications are stopped in time. Most patients who develop rashes are fine, but must report them to their doctor just in case. Those who died continued to take the drug even after it was determined that their reaction was serious, with rashes that kept getting worse or were accompanied by other side effects. Patients should not stop taking their drugs, however, without the doctor's orders. Problems with rashes in clinical trials affected only 1% of patients, and all recovered. The US FDA says that treatment must be stopped as soon as possible in patients with rashes that get progressively worse, or that are accompanied by systemic symptoms. Doctors should (1) explain dangerous symptoms to their patients, and in case of serious reactions, (2) stop all medications, including pegIFN and RBV (P/R), and (3) see that the patient gets urgent medical care.

Sources: Dec. 19, 2012

www.medpagetoday.com/InfectiousDisease/Hepatitis/36528
www.fda.gov/Safety/MedWatch/SafetyInformation/SafetyAlertsforHumanMedicalProducts/ucm332860.htm

HCV & IVDUs

Experiments were done among IVDUs (Intravenous Drug Users), to find out how many of them may have been infected with Hep C through the improper use of filters, the water used to dilute the drugs and/or the containers for the water. The experiments tried to copy practices used in real life, using the equipment normally used by IVDUs. The life span of the Hep C virus was tested by putting some virus in bottled water. To test for possi-

(Continued on page 3)

LARRY HAGMAN

Larry Hagman, perhaps best known for his role as J.R. Ewing of the TV series "Dallas", died November 23 at age 81. His death was caused by complications from throat cancer, although he suffered from Hep C and liver cancer, too. He advocated for organ transplantation, anti-smoking and solar energy. He received a liver transplant in 1995.



Sources: <http://ca.news.yahoo.com/larry-hagman-dead-81-portrayed-notorious-tv-villain-044041015.html>
<http://ca.news.yahoo.com/video/dallas-star-larry-hagman-dies-144614183.html>
<http://theclicker.today.com/news/2012/11/24/15413880-larry-hagman-was-a-character-on-screen-and-off>

MICHAEL'S STORY

Editor: Michael is a long-time member of HepCBC. The CanHepC list and the HepCan list. He and I have been emailing frequently since 2004. He has volunteered for HepCBC and has provided caring support and information to many fellow Hep C sufferers in our community, both by email and in person. Perhaps you have spoken to him on the phone. I just spent some time chatting with him. This is what I learned:

Michael was born in Oxford, England in 1941, and moved to Canada in 1965, along with his wife and baby daughter, because his wife's sister lived here and loved it. They first settled in Prince George.

In 1986, Michael was hospitalized for a hip replacement. The surgeon at the time advised him, because of test results, to never donate blood. Later, he had emergency surgery to remove his gall bladder, and suffered what he believes to have been peritonitis. Michael was employed by BC Tel for 32 years. He has since retired.

Their daughter, now grown, is the mother of two boys. Michael and his wife also had a son, whom they lost in a car accident. Their son left behind a son and daughter.

When he was well, Michael and the family enjoyed boating, water skiing and camping. Unfortunately, Michael is now suffering with end-stage liver disease, and is interferon-intolerant. He has been through at least 3 attempts at treatment, all unsuccessful: Interferon alone, IFN/RBV and Pegasys/RBV. He hasn't given up. He is investigating the possibility of one of the new clinical trials, but is not interested in a transplant because of his age. He is receiving home nursing support, and takes lactulose to ward off brain fog. He reports having trouble writing/typing. He has been in hospital several times this year.

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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!! FAQ version 9.0



Peppermint Patti's **FAQ**
Version 9.0 is NOW
AVAILABLE. Version 8 is
available in FRENCH and
SPANISH. The ENGLISH
version includes treatment information
and research from 2012. Place your
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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 pam-
phlets. The Resource CD costs \$10 includ-
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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 info@hepcbc.ca.

THANKS!!

HepCBC thanks the following
institutions and individuals for their
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Community Living Victoria, Victoria
Positive Living Centre, Provincial
Employees Community Services Fund, the
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Lorie FitzGerald, Judith Fry, Allison Crowe,
and the newsletter team: Beverly Atlas,
Diana Ludgate, Alp, Cheryl, Anamaria, S. J.
and L.P.

Please patronize the following businesses
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Canada, Vertex, Gilead, Janssen, VanCity,
Shoppers Drug Mart, Market on Yates,
Country Grocer, and Safeway.

Special thanks to Thrifty Foods for
putting our donation tins at their tills and to
Sooke Shoppers Drug Mart, for donating
the water for sale at the Christmas concert
and for having donated the water for our
CASL Forum.

HAPPY NEW YEAR

CUPID'S CORNER

This column is a response to requests for a
personal classified section in our news bul-
letin. 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 dona-
tion, if you can afford it. Send a cheque payable
to HepCBC, and mail to HepCBC, Attn. Joan,
2642 Quadra Street, PO Box 46009, Victoria,
BC V8T 5G7 (250) 595-3892. Give us your
name, telephone number, and address.

To respond to an ad: Place your written re-
sponse in a separate, sealed envelope with noth-
ing 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.*

AD 30

Youthful, early 50's single Caucasian
male. 5'11", 200 lb non-smoker, out-
doors, nature walks, camera, musical, sci-
ence educ. Half life on hold since diag-
nosed. Time to break-out.

Searching intelligent, young at heart
woman to share some time, hobbies, activi-
ties, friendship leading to...? Maybe just
friends, maybe a family. Life rarely turns
out as you wish or imagine.

Tell me about yourself—hobbies, web-
site, photo?

Got Hep C? Single? Visit:

<http://forums.delphiforums.com/hepatiscen1/chat>
<http://groups.yahoo.com/group/HepCingles2>
www.hcvanonymous.com/singles.html
www.hepc-match.com/

NOTE: Before paying for full service HepC
Match, be aware that the site is not kept up-to-
date. We have been advised that there are
members there who are no longer active, and
at least one who is no longer alive, and his
listing remains, even though the owners have
been notified.

TIP OF THE MONTH

**Taking protease inhibitors?
Set the alarm on your phone.
Keep the time you take your
pills the same each day.
It's important!**

ble infection from contaminated containers, the researchers used infected water and emptied and refilled the containers. Risk of infection from filters was tested by drawing the virus through a filter after the incubation period, to make sure it was infective.

They found that HCV can live up to 3 weeks in bottled water, and the virus remains infective even after washing containers that held contaminated water. HCV could also be transmitted from the filters, since some of the virus remained.

Source: Nov. 5, 2012

www.phac-aspc.gc.ca/ccdrw-rmtch/2012/ccdrw-rmtcs4412-eng.php#a

MK-5172 (AASLD 2012)

Merck presented results from its not-yet-completed Phase II trial of MK-5172, a protease inhibitor, being tested in treatment-naïve GT1 patients. Researchers tested 136 patients (called the "Vanguard Cohort") by dividing them into 4 arms, and giving them MK-5172 treatment, each arm with a different amount. All 4 arms received pegylated interferon plus ribavirin (P/R), as well. The results from the arms were compared to a control arm, where the patients took 4 weeks of P/R alone, then added boceprevir (an already-approved protease inhibitor.) Responses were compared at week 12 and 16. 82.8 to 93% of MK-5172 patients tested undetectable compared to 74.2% of those in the control group—a significant improvement. The "Vanguard Cohort" patients taking 100 mg/day of MK-5172 had an SVR12 of 96%, compared to 54% of those in the control arm.

Dr. Alnoor Ramji, a study investigator at University of British Columbia, said, "At present, we will continue to treat persons with genotype 1 hepatitis C with standard of care triple therapy given the already high eradication rates we can achieve. Future therapies, such as MK-5172, may offer higher eradication rates, be better tolerated and have easier dosing schedules, however, it will be sometime before they will be available in Canada."

Side effects such as elevated liver enzymes and elevated bilirubin normalized either during or after stopping treatment. New trials will be done without interferon or by combining the drug with MK-8742 (NS5A inhibitor).

More info: <http://clinicaltrials.gov> Identifiers, NCT01717326 and NCT01716156.

Source:

www.merck.ca/newsroom/ca_en/research-and-development-news/MK-5172_AASLD_FINAL_ENGLISH_Nov_10_2012.pdf

PROMACTA (ELTROMBOPAG) FOR LOW PLATELETS

Thanks to trials enrolling 1521 patients with low (under 75,000) platelets, Glaxo-SmithKline's Promacta (eltrombopag/Revolade) has been approved by the US FDA for treatment of low platelets, but **only** if that condition prevents optimal HCV treatment. Caution must be used, since the drug damages the liver. Two Phase III trials showed the drug to be safe enough to approve with pegylated interferon + ribavirin (P/R) treatment, but it has not yet been approved for treatment with DAA's (Direct-Acting Antivirals) such as the protease inhibitors. Many precautions should be taken, such as avoiding taking DAA's within 4 hours of antacids or milk products, and should not be prescribed for patients with heart conditions or cirrhosis without careful monitoring. This approval will help about 3.5% of patients previously unable to take treatment.

Source: www.gsk.com/media/press-releases/2012/FDA-approves-new-indication-for-PROMACTA-eltrombopag.html

WHO TO TREAT FIRST?

With approval of protease inhibitors, so many people want to start treatment, that waiting lists have developed. A limited number of people can be started on treatment each week. At the recent meeting in Boston, the AASLD (American Association for the Study of Liver Diseases) discussed who should be treated first.

AASLD gave highest priority to younger patients with advanced liver disease due to its significant impact in preventing future illness and hospitalisation. In contrast, even though European guidelines recommend treating all patients with fibrosis stages F3 and F4, and EASL (European Assoc. for the Study of Liver Disease) recommends treatment in those with F2, as well. The following order will be discussed more later, but for now, US recommendations are as follows:

- (1) Stage F4 (Cirrhosis)
 - [a] younger age
 - [b] prior relapser
 - [c] treatment naïve or previous partial responder
 - [d] IL-28B genotype CC
 - [e] others
- (2) Fibrosis stage F3
 - [a] younger age

[b] others, and

(3) Fibrosis stage F0–F2.

The authors say that their modelling exercise provides a needs-based prioritization score of patients that they call "clinically intuitive", which will "maximize the value of DAAs to society".

Source: www.aidsmap.com/Which-patients-should-be-prioritised-for-new-hepatitis-C-treatments/page/2553698/

ANEMIA STRATEGIES

Many patients suffer anemia with P/R treatment, and some must discontinue or modify their dose of ribavirin (RBV), possibly making treatment less effective. At the 2012 AASLD Meeting in Boston, Merck announced retrospective results from a Phase III study that compared how two anemia management strategies, RBV dose reduction and the use of erythropoietin (EPO), affected SVR rates in GT1 treatment-naïve patients treated with P/R and boceprevir (Victrelis). 687 patients were enrolled. All had baseline hemoglobin levels between 12 g/dL and 15g/DL, and fibrosis grades 1-4. 500 of them became anemic (≤ 10 g/dL).

In those treated with RBV dose reduction, SVR rates were generally similar in spite of the timing of the first reduction, the lowest dose (taken for at least 14 days), or the number of steps of dose reduction, but SVR rates were lower in those receiving less than 50% of their total assigned dose of RBV. SVR rates were higher in those who had already tested undetectable HCV RNA by the time they began their anemia management, in spite of the strategy chosen.

The results confirm that for patients treated with P/R/boceprevir therapy who develop anemia, RBV dose reduction is a better choice than EPO, according to study investigator Dr. Samuel Lee, University of Calgary.

Source: Nov. 12, 2012

www.businesswire.com/news/home/20120419005286/en/MSD-Reports-Phase-III-Study-Results-Evaluating

SR9238 AND FATTY LIVER

Researchers from The Scripps Research Institute have come up with a compound called SR9238 that reverses the effects of fatty liver disease. The compound suppresses production of fat in the liver, stopping and even reversing the collection of fat accumulation in trials with mice. It also lowers cholesterol levels, reduced a cholesterol-producing enzyme by 80%, and lowered liv-

(Continued on page 5)

ROB'S STORY

The year: 1969. I was hospitalized with non-A/non-B hepatitis. I spent one or two weeks in isolation—I can't remember. What I do remember is that the doctors said I was so lucky to be alive, and down the road, they warned me that alcohol intake could jeopardize me in the future.

Fast forward: 1985. My doctor asked me to "come clean" about my alcohol addiction. This doctor was "old school", and he said my blood work showed cirrhosis. I assured him my alcohol usage was in check. I maybe went through a 6-pack once a month. He told me reassuringly that he'd seen this many times before, and I didn't have to be afraid of the stigma of being an alcoholic. Sadly he had a triple heart bypass and had to relinquish his career.

I then started to see a younger doctor, who for 3 months wanted to treat me for clinical depression. I kept saying no; everybody has sad days, and that I'd get over it.

When asked if I ever contemplated suicide, I said, "Sure. Doesn't everyone?"

However, he kept poking around with this question, "Have you ever fantasized as to how to do it?"

I said yes, and then I told him--in detail--what I had planned. I think hearing the details shocked both of us.

Upon receiving the blood test results, he called me at home. "Can you come into the office?"

I said, "Sure. No problem."

He sat me down and said I had Hep C. I felt two emotions: 1) Relief, knowing that there was actually something wrong with me, and 2) Worry. What do we do? Is it treatable? Could I keep working? As a trucker in the fuel business, I worked long hours, which caused me to ask for amphetamines earlier in my visits.

I was then sent to see the liver specialist, who told me I needed the meds to treat Hep C. He told me the cost was about \$10,000 dollars.

I said, "Thank you for all you've done."

He asked, "When do you want to start?"

I told him I wouldn't start. When asked why, I told him I couldn't afford it. He asked what I was going to do. My answer was, "I'll work until I die." He responded by saying, "I'll see you later."

Six years later, I knew I had to go back. He welcomed me and said, "I told you I'd see you later." So I went on the meds, and experienced ALL the negative symptoms of the meds and wound up in the hospital for a week. They took me off the meds because

they were killing me. Even now, I have skin rashes that my doctors say will never go away. The rashes still continue to grow, and their medical name is "morphea utopica sclerosis." I know that it is just one of the negative symptoms I've encountered from the meds, but I'm still here, where a lot of my friends are not, which begs the question--do we have statistics on suicide deaths due to taking the medication? I had three friends who took their own lives, following suicidal ideation, a symptom of the meds. We don't say suicide. We say, "They went to sleep." Their drug of choice was morphine, an overdose which in "normal" people will cause death.

At present, I'm too sick for new trials, and at present, I'm too sick to work. I feel stuck in between: no regression, and no healing. I'm genotype 1a, a non-responder, but totally thankful I'm still here. Please use this in your bulletin.

--R.J. Bowie 416-283-1785

HEP C AROUND THE WORLD

HCV: #1 VIRAL KILLER IN AUSTRALIA

Hepatitis C is now a bigger killer than HIV/AIDS in Australia. Sharing needles is the most common route of infection now. Approximately 304,000 have tested positive for the antibodies there, and over 250,000 of those are chronic. 3% of the indigenous population (Aboriginals and Torres Strait Islanders) are infected and need treatment.

Teresa Gambaro, deputy chairperson of the parliamentary group for HIV and blood-borne viruses, and author of the article summarized here, made a private member's motion in the House of Representatives to list Boceprevir and Telaprevir in Australia's Pharmaceutical Benefits Scheme, which would double patients' chances of clearing the virus. She states that Hep C costs the government around \$252 million a year, and should escalate to \$1.5 billion in the next few years. Compare that to the savings: Each 1000 people treated means 107 fewer liver cancer patients to treat, 7 fewer transplant surgeries and the cost of anti-rejection drugs, and 245 fewer deaths.

Source: Dec. 28, 2012
theaustralian.com.au/national-affairs/opinion/we-need-to-give-hope-on-hep-c/story-e6frgd0x-1226544300080

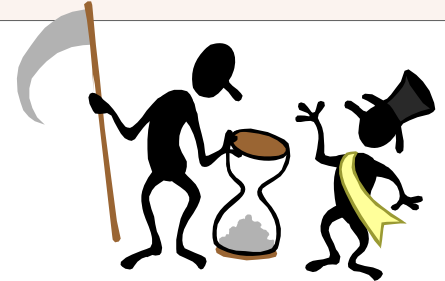

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HEP C COVER-UP IN CHINA

An outbreak of hepatitis C is, according to residents, being covered up by authorities in Fengyang County, Anhui Province in China. Over 100 people have ended up in hospital in several villages there, and all information about the epidemic is being blocked. The source of infection is believed to be a needle shared in a clinic, where at first the doctors thought it was an outbreak of Hep A.

More: Dec. 25, 2012

www.theepochtimes.com/n2/china-news/hepatitis-outbreak-covered-up-by-chinese-authorities-328523.html

HCV SUSPECTED IN DIALYSIS UNIT IN INDIA

A hospital in Yeshwanthpur, Bangalore, India, is being investigated because a dialysis patient there claims he was infected with hepatitis C during treatment. He was admitted to the hospital in February, suffering kidney problems, and blood samples were sent for testing. Those samples were HCV free. After a few months of dialysis, blood tests in August showed he was HCV+, and the tests were confirmed. The patient now needs money to pay for dialysis and Hep C treatment. His mother died after finding out about his infection.

Source: www.dnaindia.com/india/report_patient-gets-hepatitis-c-virus-during-dialysis_1750063



IF IT ITCHES...

by Joan King

REPRINT from *hepc.bull* November 2002

Itching: An unpleasant cutaneous sensation that provokes the desire to rub or scratch the skin to obtain relief.

“Doctor, the worst part of this hepatitis thing is the itching.”

I have heard this from so many people! It’s not the swelling from end-stage liver disease, or the liver pain, or the brain fog that bothers them so much. It’s the darn itching. And you don’t have to have end-stage disease or be jaundiced (yellow) to suffer from it, either.

Itching in hepatitis patients occurs because the liver can’t remove toxic substances and bile, so they build up in the skin. Doctors would do well to have any of their patients tested for hepatitis C if they are complaining of itching. On the other hand, not all itching may be due to a malfunctioning liver, and even patients with Hep C should go to their doctor to make sure nothing else is going on.

What the heck can you do to make it stop? The first thing to do is to stop putting toxins into your body, and get rid of the ones that are there by drinking plenty of water. We have to remember that anything we put into our bodies or onto our skin has to be filtered out by the liver. By trying to remedy the itching by taking medicines or lathering on cream, we may be harming our livers more, causing still more itching, and creating a vicious circle. Even products from the health food stores with all-natural ingredients may contain herbs like comfrey (allantoin), which are toxic for our sensitive livers. Read the labels! Double check on the Internet.

Having said that, here are some things you can try, depending on how desperate you are:

Internal:

- Treatment may get rid of the symptoms by getting rid of their cause.
- Bile acid sequestrants: Cholestyramine
- Antihistamines: Hydroxyzine, Benadryl, Atarax, Chlor-Trimeton
- Ursodeoxycholic Acid
- Rifampicin
- Opioid Receptor Antagonists - Naltrexone orally. (High doses of this drug are toxic to the liver.)
- Colchicine (Has been known to reduce itching, and has been used for Hep B and alcoholic cirrhosis.)
- Bio-Antax (an antioxidant compound) plus Coenzyme Q10 may relieve itching and fatigue.

- Neurontin
- Diphenhydramine

External:

Keep your skin moisturized. Check the ingredients of anything you put on your skin.

- Phototherapy
- Acupuncture
- Udder cream
- Bath additives:
 - Oats: (Put 2 cups of oats into one leg of a nylon stocking and close with a knot. Use like a tea bag, then discard. Soak for 10-15 minutes. Pat dry.)
 - Cornstarch

Tips: Keep your fingernails short. Wear all cotton clothes. Stop shaving for a while. Try cold compresses or ice. Eat organic foods. Open the windows at home. Stop smoking. Don’t drink alcohol. Reduce stress. Be careful with laundry detergents. Avoid skin products containing alcohol that can be drying. And if it itches, don’t scratch it.

Sources:

- <http://jpcpr.eu/abstracted.php?level=5&ICID=978358>
- www.prnewswire.com/news-releases/studies-demonstrate-positive-data-in-treatment-of-hepatitis-c-75109927.html
- www.remedyspot.com/showthread.php/865231-Skin-Care-Products-and-Liver-Disease-Read-the-Label-Before-You-Us



YOGA AT AVI, VICTORIA

Ahhh! A laid back, gentle class for people who have chronic health conditions. Every Tuesday, 10:30 am at Bayanihan Hall, 1709 Blanshard St., Victoria, BC.

Julia Breese is returning to teach us. (<http://garudayoga.ca/>) Wheelchair accessible. Free. More info: 250-384-2366 ext 2270



COME VISIT OUR RE-DESIGNED WEBSITE!!
HEPCBC.CA

(MICHAEL’S STORY—Continued from page 1)

Once, the doctor told him he wasn’t going home. Fortunately, the doctor was wrong. He has recently had a fall in the bathroom, and since then, uses a walker or cane.

We have seen many similar stories, but hopefully with the new medications, we will soon see more people, maybe Michael, living full, healthy lives, unburdened by hepatitis C.

“This disease is not for sissies. ‘Bye for now.’ --Michael

(TREATMENT NEWS—Continued from page 3)

er enzymes.

The scientists noticed that some natural proteins stimulated the production of fat in the liver, and searched for a compound to block that process. After just a month of treatment, the animals were able to reverse their accumulation of fat, even when fed a high-fat diet for 44 weeks prior to treatment. They had no side effects.

Fatty liver can be caused by alcohol abuse, type 2 diabetes, obesity, and Hep C. It can lead to cirrhosis and liver cancer.

Source:

www.sciencedaily.com/releases/2012/12/121219152703.htm

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 the patient’s HCV status, treatment and any other issues of concern.

This type of professional support is imperative now that standard of 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

Hep C Sites on facebook.



Hep C, the Silent Killer

facebook.com/pages/Victoria-BC/HepCBC/274985724940



Transplant Support Group of British Columbia

You can join the Facebook group by putting "Transplant Support Group of British Columbia" in your browser or by using this URL:
www.facebook.com/group.php?gid=311699175404&ref=share



FIGHT Against Hepatitis C

Open Group — fightagainsthepatitisc@groups.facebook.com



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/>

HCVEDGE Get the edge on managing your Hepatitis C



Hepatitis C management made easy.

HCV-Edge is a tool that assists you by managing your Hepatitis C treatments. Find out what HCV-Edge can do for you.
[Learn More >](#)

Why choose HCV-Edge?

- access to a broad array of reliable background information on Hepatitis C
- electronic reminders for pill taking and office visits, whenever 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 done >

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 info@hepcbc.ca and say, "Send me the email version, please," and you, too, can enjoy this newsletter in glorious colour, free of charge.



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!

HepCBC 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



Hepatitis C Research and News

hepatitiscresearchandnewsupdates.blogspot.ca/

<http://www.patient-experience.com/index.php/hepatitis-c-a-blog-about-the-signs-and-symptoms-of-hep-c/>



Hepatitis C – a blog about the signs and symptoms of Hep C » The Patient Experience
www.patient-experience.com

Welcome to our latest informational blog about Hepatitis C (or Hep C as it is often called).

Pacific Hepatitis C Network

www.pacifichepc.org



www.hcvadvocate.org



PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

COLUMBIA GASTROENTEROLOGY New Westminster, B.C. 604-525-0155

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.seniorsbc.ca/features/move_for_life_dvd.html

CONFERENCES

The 6th Paris Hepatitis Conference (PHC)
14-15 January 2013
Palais des Congrès de Paris
Paris, France
www.colloquium.eu/site/-/Homepage,2334-

Canadian Digestive Diseases Week (CDDW)
and Annual Canadian Association for the
Study of the Liver (CASL) Winter Meeting
1-4 March 2013 Laurel Point, Victoria, BC
www.cag-acg.org/annual-conference-cddw

23rd Conference APASL (Asia Pacific Assoc.
for the Study of the Liver)
7-10 March 2013 Singapore
www.apaslconference.org/

21st Annual Conference of Indian National
Association for Study of the Liver
22-24 March 2013
HICC, Near Hitec City, Hyderabad, India
[www.inasl.org.in/indexhome.php?
do=menu2&lmid=17](http://www.inasl.org.in/indexhome.php?do=menu2&lmid=17)

International Liver Congress 2013 - 48th
Annual Meeting of the European Association
for the Study of the Liver (EASL)
April 24-28, 2013
Amsterdam, the Netherlands
www.easl.eu/liver-congress

2013 8th International Workshop on
Hepatitis C Resistance & New Compounds
June 27-28, 2013
Cambridge, MA
[www.virtualmedicalcentre.com/
conferences/2013-8th-international-
workshop-on-hepatitis-c/2540](http://www.virtualmedicalcentre.com/conferences/2013-8th-international-workshop-on-hepatitis-c/2540)

National hepatitis Health
Promotion Conference 2013
14-15 November 2013
Sydney, Australia
[www.hepatitisaustralia.com/events/hepatitis-
health-promotion-conference](http://www.hepatitisaustralia.com/events/hepatitis-health-promotion-conference)

INCIVEK CARE

Vertex's Incivek Care Patient Assistance Program supports patients with the reimbursement process for Incivek (telaprevir) treatment (Incivek, pegIFN, ribavirin). It will give you an efficient assessment of your options and eligibility. You may qualify to receive co-payment and other financial assistance to supplement your private and provincial drug program coverage. The program also provides dispensing and home delivery options, and expert treatment advice. Call the Support Line at 1-877-574-4298. (Select option 2 for English, then 2 for Incivek Care.)

MERCK CARE™

MerckCare™ is a program to help people who have been prescribed PEGETRON™, VICTRELIS™ or VICTRELIS TRIPLE™. The program provides:

- assistance with and/or insurance claims.
- financial assistance for co-pay/ deductible for people who qualify.
- 24/7 nursing support by phone.
- multilingual assistance.
- home delivery of medication.

MerckCare™ provides all of these services free of charge. To enroll in MerckCare™, you can call 1-866-872-5773 or your doctor or nurse can submit an enrollment form for you. Reimbursement Specialists are available from 8:00 a.m. to 8:00 p.m. EST Monday to Friday, excluding statutory holidays.

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 treatment, i.e., deductibles and/or co-payments. 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 Elliot
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

Other:

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

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

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 Registration: 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:
[www.pre86post90settlement.ca/PDFs/SA/
hepc_settleagreement.pdf](http://www.pre86post90settlement.ca/PDFs/SA/hepc_settleagreement.pdf)



SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-2873

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, counseling, advocacy. 355 6th St., Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400

• **Nanaimo** Counseling, advocacy. 201-55 Victoria Rd. Contact Anita for details. 250-753-2437 anial.rosewall@avi.org

• **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.jeffers@avi.org

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

Burnaby HCV Support Contact Beverly 604-435-3717 batlas@telus.net

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

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

CoolAid Community Health Centre, Victoria. Meetings each Wed 10 AM and (NEW) Thu 1 PM. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz rmilne@coolaid.org for info on treatment and/or group.

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

Cowichan Valley HCV Support Contact Leah 250-748-3432 r-lattig@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. info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & 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 Cheri 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 mid-islandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Support Contact Fran 250-740-6942. hepcpxpeersupport@hotmail.com

Nelson Info & support for prevention, testing, treatment and living well with hepatitis C. Contact Laura 1-800-421-2437, 250-505-5506, ankorshepc@ankors.bc.ca

New Westminster Stride "HepC" Support Group each Fri 10 AM *except* 4th Fri. of the month. Nurse Practitioner, refreshments. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

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

• **Courtenay:** 2nd Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)
• **Campbell River:** 2nd Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

Penticton & District Community Resources Society, Harm Reduction Program. 330 Ellis Street, Penticton. Contact: 250-488-1376 or 250-492-5814

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

Positive Living Fraser Valley (Abbotsford) Hep C support Drop-in centre: Unit #1 2712 Clearbrook Rd., M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or hepcsupport@plfv.org

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

Prince George Hep C Support Contact Ilse ilse.kuepper@northernhealth.ca

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-2487, 1-888-557-2487, <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 brent.fitzsimmons@vch.ca

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 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 Peter, pvanbo@gmail.com Tel. 250-309-1358.

YouthCO HIV/Hep C Society of BC. Drop-in T&W 12-3, Fri. 9-12. Call for appts M-F 10-6 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart stew-arc@youthco.org, Briony brionym@youthco.org www.youthco.org

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 bloodties@klondiker.com

OTHER PROVINCES

ONTARIO:

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

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 hepccommcoord@gmail.com, 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 hepcnetwork@gmail.com. <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 waterlooregionhepcsupport@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, www.hivaidconnection.com

Niagara Region Hepatitis C Care Clinic Education, Counseling and Support - Individual / Group, Treatment, Community Outreach, harm reduction. Contact 905-378-4647 ext 32554 HCCC@niagarahealth.on.ca www.niagarahealth.on.ca/services/hepatitis-c-care

Oshawa Community Health Centre Hepatitis C Team Drop-in, lunch provided each Thurs. 12-1 PM, 79 McMillan St. www.ochc.ca Contact 1-855-808-6242

Owen Sound Info, support. Contact Debby Minielli dminielly@publichealthgreybruce.on.ca 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, www.publichealthgreybruce.on.ca/

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

healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

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.ca

www.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 905-940-1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

QUEBEC:

Quebec 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:

Manitoba Hepatitis C phone and email support and outreach. Info Line: 1-204-779-6464 or contact Kirk at info@mbhepc.org. Direct line: 1-204-389-5814

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

To list Canadian groups here, please send details to info@hepcbc.ca by the 15th of the month. It's free!

