

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEP C NEWS

ABOUT TIME!!

There is no doubt that tattoos are becoming more popular, but lately the US FDA had to issue a warning because skin infections have been occurring after people have gotten tattooed. The infections have occurred in Iowa, Colorado and New York, among others, and have been associated with nontuberculous mycobacteria. Such infections can be mild, but in some cases, can cause abscesses requiring surgery. Apparently the ink was contaminated when the manufacturer diluted dark ink with water. The tainted ink has been recalled, and some experts have been discussing the need for more regulation for tattoo-related businesses. The tattoo parlours themselves may dilute the ink to produce shading, unaware of the dangers. Only sterile water should be used.

Dr. Drage, assistant professor of dermatology at the Mayo Clinic, says, "There are some people who would say there's no such thing as a safe tattoo currently because of the lack of oversight."

Clients are also at risk for staph infections or even infections from MRSA, a dangerous superbug. Infections can happen if the work surface has been contaminated or the artist doesn't use disposable gloves. Gloves should be changed if the artists touch their face or any other surface that can have germs. And of course, if the needles aren't clean, tattoos can spread HCV or other blood-borne diseases. Many tattoo artists work from their homes, and are never inspected.

Toronto Public Health is developing a system which would require nail salons, piercing studios and tattoo artists to be inspected and licensed and to post the results of the inspection for customers to see. The agents there say that yearly inspections are not sufficient.

Source: www.theglobeandmail.com/life/healthand-fitness/health/experts-want-more-oversight-oftattoo-industry/article4524081/?cmpid=rss1 Sep 6, 2012

(Hep C News continued bottom of page 3)

AYN'S STORY

I was originally diagnosed in 2007. I took Pegasys for 48 weeks and thought I was cured until I went for a test last December and got a positive result. It took until August before I could see a specialist, and until now to get the result of those tests. I am going to the specialist at the clinic tomorrow.

I'm finding the health care in my area leaves a lot to be desired and, as usual, one has to be proactive in one's own health care. I was in need of the Hep A vaccine and was told I'd have to pay \$58.00, but upon further investigation, I was able to get it from public health, for free. There were several places where I inquired (like the methadone clinic.) The people there should have told me to go to public health but instead, everybody said I'd have to pay for it. I'm afraid that I've fallen through the cracks.

My specialist in my hometown told me that I'd never have to get tested for HCV ever again, and that I was cured. It's a good thing I insisted on a test last year, and that is how I discovered the virus has returned. I will find out more tomorrow and will get a copy of the results from those tests. I know that I am genotype 1. I'm not sure what stage I'm in, but when I had my biopsy in 2008 before my Pegasys treat-

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SEQUEL: ROUND TWO!

[Editor: Roseen's first article appeared this year in our April edition.]

Week 8 Happy Dance!!! I was pretty excited to learn that my week 8 blood work stated that the Hep C virus was undetectable. While on treatment previously, with Pegasys, I still had the virus at 12 weeks, so I'm very hopeful with the progress I'm making on Victrelis.

I'm nearing the end of week 12 and I'm counting down—only 36 more weeks to go. It has been a bit of a rough ride lately with the side effects and the doctor has prescribed Eprex for the anemia and that is starting to help. Also, the doctor added Vit B12, Ferrous Gluconate, and Folic Acid into my daily pill regimen to help the Eprex do its job. There is also something to help with diarrhea. Now, if only I could get some relief from dry mouth, feeling nauseated, and some vomiting.

I've had changes in taste and smell so some of my old remedies don't work this time. I find sipping on orange juice helps to stimulate salvia. Chewing gum is no longer an option because it just tastes terrible. I still get some relief from peppermint tea and candied ginger for nausea. I'm looking for an unscented laundry detergent as all scents bother me and don't smell like they used to.

I've read a lot of novels these days and watched TV where I never would before. I have enjoyed Canada's Got Talent and the Big Bang Theory lately. I would never have bothered to watch beyond the news hour very often, but it is pretty much a daily routine. I do miss being active, but know I will be again in about 40 weeks!

I've had to cut back on working and am considering not working at all until I'm finished treatment. The week 8 results are very, very encouraging and make all the side effects worth putting up with. Knowing that the side effects will disappear very quickly when I am finished treatment, also helps me to keep going.

I wish those of you on the Victrelis treatment the very best. I hope your progress is as positive as mine and that you will find this motivates you to keep going to the end.

Roseen in Southern Ontario



HEPC.BULL

NOVEMBER 2012

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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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(Note: The hepc.bull is mailed with no reference to hepatitis on the envelope.)

You may also subscribe or donate on line via PayPal at www.hepcbc.ca/orderform.htm

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

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

SUBMISSIONS: The deadline for any contributions to the hepc.bull is the 15th of each month. Please contact the editors at jking 2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING: The deadline for placing advertisements in the hepc.bull is the 12th of each month. Rates are as follows:

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

HOW TO REACH US:

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



Peppermint Patti's <u>FAQ</u> <u>Version 9.0 is NOW</u> <u>AVAILABLE</u>, Version 8 is available in FRENCH and SPANISH. The ENGLISH

version includes treatment information and research from 2012. Place your orders now. It contains 169 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: *www.hepcbc.ca/orderform.htm*

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 info@hepcbc.ca.

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, The JackFM, Community 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, Cheryl, Anamaria, S. J and L.P.

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, Country Grocer, 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.

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 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 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.

AD 30

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

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

Tell me about yourself—hobbies, website, photo?

J. Lemmon

<u>hcvresearch@rogers.com</u> perienced in medical and legal r

Experienced in medical and legal research Assistance with HCV compensation claims and appeals

High success rate / Low payment rate References are available



TIP OF THE MONTH:

KEEP COPIES OF ALL YOUR TESTS and know what they mean



Allison Crowe's
Annual Christmas
Benefit for HepCBC
Sat., Dec 1, 2012
7:00pm
Fairfield United
Church

In her annual concert benefitting HepCBC and Artemis Place (life skills and academics for at-risk girls), Allison Crowe cooks up an organic blend of rock, jazz, folk, gospel and soul. Favourites It Came Upon a Midnight Clear, In the Bleak Midwinter, What Child Is This, The First Noel, Silent Night, and O Holy Night are performed with rare artistry and passion alongside the modern canon of Leonard Cohen, Joni Mitchell, Lennon & McCartney and original song selections (including the elegiac "Arthur", and the epic, foot-stomping, "Disease").

"Allison Crowe is a stunningly talented performer. Her voice celebrates the music with a bluesy rock-gospel intensity; her controlled vibrato, silken rasp, and powerful projection rivet your attention. This is no casual background music... be prepared to be amazed." ~ <u>ChristmasReviews.com</u>
http://music.allisoncrowe.com/album/tidings

Peace on Earth ~ Goodwill toward All. Featuring: special guests TBA Tickets available online now:

www.allisoncrowe.com/shoptickets.html

(HEP C NEWS—Continued from page 1)

CONVENIENCE

In a recent clinical trial combining ABT-450, ABT-267, and ABT-333 plus RBV (Ribavirin) 76 out of 77 patients had an SVR12 (undetectable virus 12 weeks after completing treatment). More astounding were the 38 out of 41 null-responders testing undetectable 12 weeks post-treatment. (Some data is missing and could change the rates a bit.)

Ideally patients would take just one pill a day, but one pill must be taken twice a day, and the other, once a day. Gilead has a two-pill combo (GS-7977 and GS-5885). Luckily, Hep C patients only take their drugs for a few months, unlike HIV patients, who must take them for the remainder of their lives.

Doctors will likely suggest the most effective drug, as long as it is safe. Convenience will be an important factor when the cure and safety rates are equally good.

Source:

www.fool.com/investing/general/2012/10/15/a-hep-c-hip-check.aspx

(AYN'S STORY—Continued from page 1)

ment, I was in stage 1. I think my liver is inflamed, and whenever I have a glass of wine I get a sore side, so needless to say, I have virtually quit drinking. That being said, it is difficult to go out socially and not drink, so I find myself having "one" glass of wine or a drink every once in a while. I did quit drinking entirely the last time I was in treatment, so I know I can do it, but find myself avoiding social situations for this reason.

I am very troubled by my boyfriend's reaction to my infection. He treats me like a leper since we found out the virus has returned. His family is treating me differently, and just last week he said my Hep C infection was like "the elephant in the room" and that the infection was "my fault" because of the lifestyle choices I made 40 years ago. He blames me and makes me feel as though it is my own fault that I am sick. This man is 69 years of age and from "the old school." He won't touch me sexually, and we have had virtually no contact since last February when I discovered the virus was back. He won't even use the same tube of toothpaste as me, and I feel more and more like a second class citizen every day.

We have been together for 6 years, and I have tried to educate him about the virus, but he still thinks it's my fault and treats me badly at times. I have tried to distance myself from him, but all my friends are his friends, and I feel even more isolated when we are not together. Don't get me wrong. Even though he seems anal and controlling, there are a lot of good times, and when he is not giving me s*** for having HCV, he can be a lot of fun to be around, and we do share a lot of laughs. I will be able to expand on my story more when I have been to the doctor, and have the test results.

Update: Guess what! I just left the doctor, and he said that all my tests were negative, the ultrasound was normal, and there is no trace of virus. I had another blood test done just to be sure. I'll get the results in two weeks. He said that it was not uncommon to get a "false positive" and blamed the lab. Wish me luck as I wait for the results of today's test! I'm in shock... All the reading... Support grSoups... Stress and anguish... But this is good news.

—Ayn Styles

[Editor's note: We Hep-C'ers usually need both Hep A & B vaccines unless we have already had one or both of those infections.]



SUPPORT GROUP TIPS

I am an HCV+ peer volunteer, and must admit our group is not the greatest at all times (attendance has varied between 2 and 25!), so don't feel so bad about yours if it isn't an instant success. Here are a few humble suggestions. Though I am a retired teacher of adults, I have found there are very few parallels with my previous teaching; expect peer support to be worlds apart from a classroom!

The best advice I ever got about peer support groups was from a friend, Gordon McClure of Kamloops, who died recently. He had taken leadership of the group when its leader, Sharon Grant, died. Even if he was the only person there, he stressed to me it was important not to get discouraged. People notice constancy and commitment over time. His group is still operating as far as I know, even though he's gone. And he took it over immediately after the founder of it died.

One thing I've discovered is that it's good to have guest speakers frequently, even if they're simply HCV+ peers visiting from another town. Actually, we should all try to stop in and visit one another's groups when we can, I think. This involves keeping in close touch about the times and places, what/where/when groups are available. Joan tries to do this via the last page of the *hepc.bull*.

Flexibility is key. Always have a backup plan B, but be ready to tailor the topic of the group to what the immediate needs of the group are, particularly any new members. Bring pamphlets and develop a 'library' of books to be signed out. (Before setting these books out, you need to develop a good method of keeping track of the books and communicate it to all the members.)

Having 2 or 3 trained peer co-facilitators is very important. We all trained via a program developed by Victoria's 24/7 phone support line. (Their line is no longer operating, unfortunately.) One person in charge at a particular group is ok, as long as there are one or two others present to back them up, and to take turns with facilitating the next time.

Keeping in touch between meetings is really important, and something we never seem to do enough of. Enduring ties among peer members, and loyalties to the group are built that way.

Confidentiality is very key. It's good to mention it at the start of each meeting.

GOOD LUCK!!

—An HCV+ peer volunteer.

HEP C CLINIC AT PERCURO



VICTORIA, BC

THANKSGIVING WEEKEND

October 5-7, 2012 – Victoria, BC Report by Anita York

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 selfadministration 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





OUR RE-DESIGNED WEBSITE!! HEPCBC.CA



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

the Marathon Weekend.

FRIDAY 10:45 AM start. Time to load up Stephen's truck with HepCBC booth supplies for the Expo site Conference centre.

SATURDAY 9:00 AM start. All day Saturday we (Theresa, Steve, Caitlin, Cheryl, and I) wore a plenitude of hats. Operating our HepCBC booth, photo shoots, and operating the Good Life Marathon booth. Finishing the day off with a high-carb dinner at Cheryl's house.



Clockwise from upper left: Cheryl, Ethan, Anita, and Theresa

SUNDAY 6:55 AM start. It is still dark, cold, and breezy when Theresa and I arrive at our cheering station along the waterfront. We are definitely shivering as we set up our cheering signs.

Theresa and Anita at Cheering Station



The marathoners are starting to come by. Some are briskly walking, some are lightly jogging, and some are in a full-bore run. There are happy smiling faces, deep concentration faces, and some wearing their just having fun faces as they flow past our Liver Warriors cheering station. There are marathoners in no shirts, 3 piece suits, logo shirts, long pants, short pants, serious runner's outfits and outfits consisting of whatever was close by when they woke up in the wee hours of Sunday.

Here is a quick rundown from my side of SUNDAY 9:00 AM. The sun is warming up our weary bones. The faces are happier now and noticing our cheering signs. It's time to dance to the music, cheer loudly and chat up the weary trekkers as they pass by. Our station's population and noise level increases with Joanne, Karen and her two daughters, John and Jenny, and others.

Karen & daughter cheered us all on!



Some of our signs made people laugh:

THE END IS NEAR I THOUGHT YOU SAID 'TELETHON' RUN LIKE YOU STOLE SOMETHING

SUNDAY 11:30 AM. It's time to hike back to the Expo site and dismantle our booth. Hats off to everyone, the Marathoners, the people front and behind the scenes and everyone involved in making this a great success for HepCBC and the Liver Warriors in the Good Life Victoria Marathon 2012. See you next vear!

Cheryl & Rosemary passed FINISH line!







HepCBC LIVER WARRIOR NEWS

Good Life Victoria Marathon October 5-7, 2012 – Victoria, BC Report from C. Reitz

HOW MANY JOINED, AND WHY?

Twenty-three people signed up to run (or walk) the October 7, 2012 GoodLife Fitness Victoria Marathon with the HepCBC Liver Warrior Team in its first year as a Charity Pledge Program member, and every person successfully completed his/her chosen race! The team's three goals were to fight stigma against those with hepatitis C, to publicize the benefits of exercise such as walking for those with liver disease, and to raise funds to help HepCBC continue its vital education, prevention, and support programs. In 2011, the first HepCBC Liver Warriors team had only 2 members and didn't raise any money. What a difference a year makes!



Steve at Info Booth ...

...and on the Half-Marathon route, October 7, 2012



WHAT DID THE LIVER WARRIORS DO?

The Liver Warriors team and volunteers managed to place 19th in the Half Marathon, man a hepatitis C information booth at the marathon's EXPO for 3 days (reaching many of the 11,500 marathon participants), and raised almost \$7800 to help HepCBC. Merck Pharmaceuticals helped sponsor the event, but the Warriors themselves raised a significant portion of the total by inspiring their friends and relatives to donate generously to their cause. Besides participating on the team itself, another dozen or so Liver Warrior volunteers manned the EXPO booth, screamed wildly in our enthusiastic Charity Cheering Station along the ocean side of Dallas Road, and billeted out-of-town volunteers and runners.

One cheering volunteer, Pilar Rodriquez-Gomez, gave a spirited interview to CHEK News. Muchas Gracias, Pilar and everyone else!

WHAT SORTS OF PEOPLE JOINED THE TEAM?

Focused on fighting their common enemy, hepatitis C, the Liver Warriors came to Victoria from BC, Florida, and Oregon; among them were those both with and without HCV; men and women from their early twenties through mid-sixties; university students, several nurses, social workers, and teachers, an accountant, a 3D digital animator, a civil servant, and a small business owner. The Warriors included a large group wanting to support Daisy, who received a liver transplant 18 years ago and is now facing a health crisis. This group included two of Daisy's daughters, a mother-daughter pair, cousins, and other long-time friends and relatives who love Daisy. Another Liver Warrior, Steve Farmer, in his mid-fifties, a liver transplant recipient, and several-time contestant in the All-Canada Transplant Games, completed the half marathon in 2 hours, 56 minutes! A husband-wife team was celebrating the husband's recent successful cure through the newly-approved "triple therapy" HCV regime.



Clockwise from upper left: Rosemary, Steve, Wally & Haixia

Here are a few other 2012 Liver Warriors:

SOLITARY RUNNER OF FULL MARATHON:

Sarah Sullivan, the only 2012 team member to run the full (42 k) marathon, is a Registered Social Worker and Manager of the Courtenay and Campbell River offices of AIDS Vancouver Island. She has been running for five years and when she heard that HepCBC was sponsoring a fundraising team for the Victoria Marathon, she jumped on board. Sarah says goals are a great training motivator for her! Plus, the cause is near and dear to her heart as she works with many folks living with Hep C, and one of her best friends is a Hep C and two-time liver transplant survivor. Thanks, Sarah, for all your positive energy! Hopefully three

(or more) new Liver Warriors will join you in the full marathon in 2013! (At least four people must be registered in a particular category to be a competitive team as the best 4 times are used to compute team standings).



Sarah Sullivan, HepCBC Liver Warriors Team's 2012 Marathon Runner!



MOTHER-SON PAIR WALKS & RUNS:

Cheryl walked the 21 k for a second year in a row (4 hours, 40 minutes). She is 64, has cirrhosis, and is currently in Week 16 of a 24-week clinical trial (non-interferon, nonribavirin). Her son, age 40, ran 21 k in 2 hours, 11 minutes. They're both pretty pleased Cheryl felt well enough to do this on treatment. She says distance walking, a gentle form of aerobic exercise, is a big part of her regular personal health regimen because it seems to help her liver digest fats, remove toxins, and regulate her blood sugar levels. Plus, the regular exercise strengthens her entire circulatory system so the HCV treatment drugs can travel easily throughout her body. She plans to continue distance walking regularly every month over the coming year so these positive effects won't wear off, and "special training" for the 2013 marathon won't be necessary.

Also, to keep her joints flexible, and help prevent the wasting of muscle and bone that so often strikes HCV+ men and women, Cheryl will continue regular weight-bearing exercise through everyday tasks such as carrying grocery bags home (without hunching over!), digging and stooping in the garden, grinding whole grains by hand, and kneading bread. Finally, she says that exercise of any sort helps to raise her spirits and 'de-fog' her brain.

Cheryl and Ethan before race





Rosemary and Cheryl run by Cheering Station

lep C Sites

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 Colum-

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



Why choose HCV-Edge?



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

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

Just send vour 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 ques 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/medwatchonline.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, *stat*ing 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-blogabout-the-signs-and-symptoms-of-hep-c/



Hepatitis C – a blog about the signs and symptoms of Hep C » The Patient Experience

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

Pacific • Hepatitis 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

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

The 22nd World Congress of the International Association of Surgeons, Gastroenterologists and Oncologists (IASGO 2012)

5-8 December 2012 Bangkok, Thailand www.apaslconference.org/

Asian Pacific Digestive Week 2012 Congress 8 December 2012 Bangkok, Thailand www.apdw2012.org

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 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



INCIVEK CARE

Vertex's IncivekCare 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 CARETM

 $\begin{array}{l} \text{MerckCare}^{\text{TM}} \text{ is a program to help people} \\ \text{who have been prescribed PEGETRON}^{\text{TM}} \\ \text{VICTRELIS}^{\text{TM}} \text{ or VICTRELIS TRIPLE}^{\text{TM}}. \end{array}$ The program provides:

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

MerckCareTM provides all of these services free of charge. To enroll in MerckCareTM, 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 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 Administrator 1-877- 434-0944 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 Administrator 1-866-334-3361 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

www.hepc8690.com info@hepc8690.com www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf

Pre-86/Post-90

preposthepc@crawco.ca www.pre86post90settlement.ca

Settlement Agreement:

http://www.pre86post90settlement.ca/PDFs/SA/ hepc_settleagreement.pdf

Armstrong HepCURE Phone support 1-888-437-

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 Counseling, advocacy. 201-55 Victoria Rd Contact Anita for details. 250-753-2437 anital.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.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 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. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz rmilne@coolaid.org

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231

dggrimstad@shaw.ca

Cowichan Valley HCV Support Contact Leah 250 -748-3432 <u>r-l-attig@shaw.ca</u>

- **HepCBC** <u>info@hepcbc.ca</u>, <u>www.hepcbc.ca</u> •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 Chemi 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 Contact Fran 250-740-6942. hepctxpeersupport@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.

•Courtency: 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 (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 Ave. Contact Melinda Jovce Melinda.herceg@vch.ca 604-485-3310

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

Oueen Charlotte Islands/Haida Gwaii & Northem 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 Group T&W 12-3, Fri. 9-12. Call for appts M-F 10-6. 205 monthly, 6 PM, 79 McMillan -568 Seymour St, Vancouver 604-688-1441, 1- St. www.ochc.ca Contact 1-855-855-YOUTHCO Stewart stewartc@youthco.org, 808-6242 Briony

brionym@youthco.org www.youthco.org

Whitehorse, Yukon-Blood Ties Four Directions

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

ONTARIO:

Barrie Hepatitis Support Contact Jeanie for info/appointment jeanievilleneuve@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

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 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.hivaidsconnection.com

Oshawa Community Health Centre Hepatitis C Team 115 Grassmere Ave. Social worker, outreach worker, coordinator, nurse. Hep C Support meetings—1st Wed

Owen Sound Info, support. Contact Debby Minielly <u>dminiel-</u>

ly@publichealthgreybruce.on.ca 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257,

www.publichealthgreybruce.on.c

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

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

OUEBEC:

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 <u>bettyc2@hivnetwork.ca</u>

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