# hepc.bull

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

#### **NEWS**

## RESEARCH

#### **IMPORTANT!!**

BC PharmaCare has started the review of the first HCV protease inhibitor, Victrelis. Part of that process is hearing from British Columbians who have hepatitis C, from caregivers, and from patient advocacy groups. The time period for health care client input will only be three weeks, likely starting on November 7 through to November 28. We hope you will offer your feedback. If you want to be reminded of the review for hepatitis C treatment, you can register for notification of the start of input at this address: www.health.gov.bc.ca/pharmacare/vourvoice

For notification about other drugs: www.health.gov.bc.ca/pharmacare/ yourvoice/subscription.html

#### **ANADYS MERGES** WITH ROCHE

Roche and Anadys Pharmaceuticals just announced their merger agreement for Roche to fully acquire Anadys for approximately USD 230 million. Anadys has developed Setrobuvir (ANA598), a direct-acting nonnucleoside polymerase inhibitor presently being studied in a phase II trial combined with Roche's Pegasys and Copegus.

"Our aim is to offer physicians and hepatitis patients a powerful combination of therapies that bring us closer to a cure, even without the use of interferon," said Jean-Jacques Garaud, of Roche Pharma Research. "With Roche's considerable capabilities and experience in HCV, this acquisition provides the best chance of success for the new potential treatments our team has been dedicated to developing," said Steve Worland, President of Anadys. Roche plans to combine Setrobuvir with other direct acting antivirals in its portfolio, with and without interferon.

Anadys is also developing ANA773, an oral inducer of innate immunity, now in Phase I trials, which may be effective treatment for HCV, other chronic infections, and cancer.

#### **MBL-HCV1 PHASE II**

MassBiologics (University of Massachusetts Medical School) began enrolling patients in a Phase II trial of their monoclonal antibody MBL-HCV1 in December 2010. Their intention is to prevent re-infection in liver transplant patients. They hope to enrol 16 patients in the first part of the study. Unfortunately, liver transplantation does not cure hepatitis C, and the disease progresses more rapidly in the new liver, developing cirrhosis in 5 years in 20% of the recipients. Current treatment is not well-tolerated in transplant patients. In this Phase II study, patients will receive the drug or a placebo 1 to 4 hours before surgery, right before the new liver is transplanted, after surgery, once daily for the first week after the transplant surgery, and once more 14 days after surgery. This is an effort to remove the virus from the patient's bloodstream so it can't annunnunnunnunnunnun infect the new liver.

Source: <u>http://www.eatg.org/eatg/Global-HIV-</u> <u>News/Hepatitis/MBL-HCV1-Phase-2-trial-begins</u> -to-prevent-hepatitis-C-virus-infection-in-liver-transplant-patients 19/01/2011 transplant-patients 19/01/2011

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#### **INSIDE THIS ISSUE:**

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We hope you can attend our annual Benefit Christmas Concert: ALLISON CROWE "TIDINGS" CONCERT with Haley Walker and Billie Woods Benefit for HepCBC and Artemis Place Saturday, December 17, 2011, 8:00 pm Fairfield United Church 1303 Fairfield Road, Victoria, BC Gen. Admission \$20 Students & Seniors \$15 Tickets available from www.allisoncrowe.com/shoptickets.html, Lyle's Music, Larsen Music, & Ivy's Bookshop To hear samples of Allison's music: www.allisoncrowe.com/music.html 

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

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□Peppermint Patti's FAQ\$12.00						
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□"I enclose a donation of\$ so that others may receive the bulletin."						

#### TOTAL:

interest of space.

□"I cannot afford to subscribe at this time, but I would like to receive the bulletin."

"I want to volunteer. Please contact me."

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

(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 <u>www.hepcbc.ca/orderform.htm</u>

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SUBMISSIONS: The deadline for any contributions to the hepc.bull<sup>®</sup> is the  $15^{th}$  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

**ADVERTISING:** The deadline for placing advertisements in the hepc.bull is the 12<sup>th</sup> 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:	Joan King					
PHONE:	(250) 595-3892					
FAX:	(250) 595-3865					
EMAIL:	info@hepcbc.ca					
WEBSITE:	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.

## FAQ version 8.3

Peppermint Patti's <u>FAQ Version 8.3</u> is <u>NOW AVAILABLE</u>, Version 8 is available in FRENCH and Version 7.1 is available in SPANISH. The ENGLISH version includes treatment information and research from 2009. Place your orders now. Over 140 pages of information for only \$12 each. Contact HepCBC at (250) 595-3892 or <u>info@hepcbc.ca</u>

#### HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2011, the FAQ V8.3,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 <u>HERE</u>.

**DISCLAIMER:** The hepc.bull<sup>®</sup> 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 the following institutions and individuals for their generosity: The late John Crooks, The Ocean, JackFM, Community Living Victoria, Provincial Employees Community Services Fund, Dr. C. D. Mazoff, Lorie FitzGerald, Chris Foster, Judith Fry, 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, Margison Bros. Printers, Roche Canada, VanCity, Merck Canada, Shoppers Drug Mart, and the Victoria Foundation. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com.

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.

#### **DIAL-A-DIETITIAN**

#### (604) 732-9191 or 1 (800) 667-3438

Dietitians of Canada: <u>www.dietitians.ca</u> *HealthLink: www.dialadietitian.org* 

#### **NEED A BETTER RESUME?**

We need a volunteer Executive Director. Also needed: Board members, summarizing, telephone buddies, translation English to Spanish or French. Please contact us at (250) 595-3892 or <u>info@hepcbc.ca</u>

#### PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

#### Got Hep C? Single? Visit:

http://groups.yahoo.com/group/HepCingles2 http://groups.yahoo.com/group/ <u>NewHepSingles/</u> www.hcvanonymous.com/singles.html www.hepc-match.com/ www.hepcsinglesonline.com/

CHAT: <u>http://forums.delphiforums.com/</u> <u>hepatitiscen1/chat</u>



#### J. Lemmon

hcvresearch@rogers.com Experienced in medical and legal research Assistance with HCV compensation claims and appeals High success rate / Low payment rate References are available



HEPC.BULL

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#### FOODS THAT BITE, FOODS THAT FIGHT: CAFFEINE by Douglas Laird

Recently, data from the Hepatitis C Antiviral Long-Term Treatment against Cirrhosis (HALT-C) project was examined that demonstrates drinking three or more cups of coffee while on treatment, at different time points over the day, may help manage the side effects from interferon and ribavirin. There is also good statistical indication that there is a higher rate of sustained viral response (SVR) for this group of coffee drinkers. Is this a clear signal that coffee, and its psychoactive counterpart, caffeine, is beneficial? What does Health Canada say about caffeine? While it now appears that coffee may help get rid of the hepatitis C virus (HCV), I will demonstrate that caffeine remains problematic, and a potential threat of the spread of HCV due to its effects on the central nervous system (CNS).

There are still some serious questions for management of the top symptoms of HCV—insomnia and fatigue—for the thirty to forty percent of clients who suffer neurocognitive impairment from HCV.



The effects from caffeine are difficult to categorize since they vary from individual to individual. A friend of mine drinks coffee for the energy to fall asleep, while I suffer from increased insomnia that needs to be managed medically if I drink a cup of coffee later than noon. I use melatonin, which has been shown to lower stress, but has warnings for the liver; however it is unlikely to be enough for me to maintain good sleep hygiene and adequate rest. Incidentally, fatigue is persistent after SVR in 20% of cases, demonstrating possible damage to the CNS by HCV.

It is known that each individual is differently susceptible to drug dependence. Caffeine addiction is a physical problem that is very close in nature to cocaine addiction. Starting caffeine use at a young age has more potential to lead to an addiction than using caffeine as an adult. In behavioural psychology, caffeine creates anxiety and stress. A teenager might easily conclude there may be some relief from that stress and anxiety through alternate substances, and this has been demonstrated by much study. Even a well-educated teenager may make unwise choices about drug use, or a home tattoo, or unhealthy sexual behaviour learned off the internet, after a drink or two to calm their nerves. While the strategy of 'drugsnot4me' is the official party line, the measurement of policy successes would certainly arrive at

different places.

Until October 2011 Canada was proudly one of the last bastions amongst nations regulating caffeine content. However, against Health Canada's own recommendations, the current government has extended the use of unhealthful caffeine levels in a range of drinks that were limited before the present government's time. The problem is that caffeine consumption will require constant vigilance and perpetual determination by parents who want to protect their children from long-term caffeine addiction. The youth most vulnerable to IV drug abuse are those affected by the generational cycle of addiction-prone biology and behaviours, where the parents may not be vigilant. Somewhere in between would be a healthy model of parenting; firm and respectful.

Why have caffeinated drinks been deregulated? The justification to lift a trade ban against Scottish drinks was so the products could be imported fairly into our markets. Ironically, in some regions of Scotland, the average life expectancy is only 57 years of age. I suspect these Scots consume a lot of caffeine along with a high-fat, high-salt and high-sugar diet that is universally accessible to impoverished people. What else can you do on a low budget? 30 new HCV cases are reported every week in Scotland.

Certainly some sources of caffeine, such as yerba mate, are directly harmful to the liver and should be avoided. You would only know that this was proven fact with access to higher education.

It was no surprise, really, that our new government was a bit lacking in knowledge of public health when they originally came to power as relative neophytes. They really didn't get the idea of social determinants of health and the subsequent prevention policies required. Impoverished groups of the population have poorer health. The large sums of money spent to fight an extended legal battle against Insite (the drug injection site in Vancouver) in my opinion would have been better spent in hepatitis C education and prevention, which is seriously underfunded. I hardly expect any government to understand the complexities of the science of caffeine, or how it could relate to the spread of HCV, but I do believe that they should fund more research and development by quadrupling the HCV budget.

In the mid-seventies it was discovered

that there was a metabolic process that occurred in people genetically predisposed to the DSM-IV condition of alcoholism. The theory suggested that any central nervous system stimulant or depressant can be converted to an addictive substance that reacts on the body like opium. My long-time belief, demonstrated through anecdotal experience with tricyclic antidepressants, hints that you don't have to drink alcohol to make an alcoholic illness progress. This metabolic process of chemical conversion is something that becomes a permanent pathway in those genetically predisposed, gaining increased efficiency with practice. Many alcoholics say that during abstinence their disease can also get worse. The potential consequence, if caffeine could possibly contribute to this biochemical conversion during formative years, is frightening. It remains uncertain to me that caffeine contributes directly to the health of the liver and could raise SVR rates by drinking three cups, without the known negative effects of caffeine. However biochemistry is a complex topic. It would be good to know for sure.

This should suggest we examine the data and the biological processes involved, and if warranted, argue to reverse the deregulation of caffeine. The research literature needs to be re-examined in this light to be clear about the substances in question, and about the specific issues of genetics and biochemistry. Specifically, we need to find out why hepatitis C can lead to peripheral neuropathy and if caffeine could be part of that process. Then we can make better mistakes tomorrow.

My second suggestion is that we send the bureaucrats behind caffeine deregulation to

Afghanistan to monitor the health policies of the Taliban as our contribution to the coalition against terrorism. Subsequently, when we have to officially apologize to the Afghan Pashtuns for the unruly enthusiasm of these Tim Horton-toting dip-



lomats, they just might see, learn, and demonstrate that Section 7 of the Canadian Constitution (Human Rights) is the most effective protection against economic injustice in the world.

Sources: www.gastrojournal.org/article/S0016-5085%2811%2900273-3/fulltext www.biologyonline.org/articles/actions caffeine brain special/ comparisons known addictive compounds.html www.nurseslearning.com/courses/corexcel/cxnrp -1600/Chap3/course/chap1/P2.html

## **OUEST: CROSS-BORDER** TESTING **PART II**

(If you recall from last month's edition, our hero was trying to cross the US border to obtain an IL28b test, not yet available in *Canada, and was stopped at the border....)* 

The agents entered as well and told me to sit anywhere on the bench. The room seemed to be a small jail block. There were lockups that circled the room on 3 sides. The bench I was told to sit on seemed to be made of cement. It was unmoveable. EVERY-THING in the room seemed to be made of cement blocks. Everything was the same off white semi-gloss. Along the bottom of the bench seat were sturdy metal rings all along the length, no doubt for people to be shackled to while being held in this room. Several of the "lockup" doors were open. Inside they looked a lot like a jail cell or secure holding cell you see on TV or in the movies. But this was not a movie. My hopes went down several notches. I sat on the cement bench. There were 2 cameras on the cement "desk", both pointed in my direction. One of the agents stood behind the desk. One of the agents stood at the doorway. He still had his sunglasses on. There may have been some type of LCD computer screen set up on it facing him. I don't quite remember exactly.

He asked me, "What type of hepatitis do vou have—A. B...?"

"C" I said. I was wondering if they were recording this, if I would be grilled with questions and if they used the cameras to detect if I was being honest. "They use infra -red to tell if you are lying, maybe they have microphones and can detect a lie by the timbre of your voice," I thought as I remembered all those anti-terrorist mini-series I had watched on TV. It looked like a place they brought criminals and terrorists to and locked them up while they decided what to do with them. My hopes continued to drop. I had no idea why I was in here or what past transgression may have come up on their computers about me that made them think I should be in here. My heart felt like it was in my mouth.

"How long have you had it?"

"1979, diagnosed in 1990"

"ARE YOU CONTAGIOUS?" the agent asked. He made it sound extremely important. Like I could make people sick. Like I was a danger. I was taken aback. I have never been asked if I was contagious. I did not know how to answer. I had a virus, I guess that makes it a communicable disease,

but you could live with the disease for decades and not transmit it to a soul. I knew the illness could be spread only if the blood of a pool, take taxis, go to parties. someone infected got into the blood of again," I thought. "They are going to think I am a drug addict. They are going to search me and my car, I am going to have a hard time here." I did not know what to say.

"How is the disease spread?"

"Body fluids," I responded. It was not 100% correct, but it was what came to my mouth. My brain was a bit overwhelmed with the situation and was having trouble forming words from the explosion of all. thoughts that were going on in my head. It was extremely intimidating sitting in there, to say the least.

"Tell us about hepatitis C. Assume we don't know about it."

"It is a liver disease. It is spread through blood" I said. I hated what I said. It is more than just a liver disease.

"What do they say you should do? How should you be careful with this disease?"

I felt stunned. My mind would not work. I was not used to being questioned in this manner, in this type of situation. I tried to form words to explain but nothing was coming. They must have sensed this. The tone seemed to change. But only a little.

"You might be out of here a little faster than waiting in that line. You've seen the line, haven't you?"

"Yeah", I agreed with a bit of a laugh. But it was kinda like out of the frying pan and last time?" into the fire. I was now in a terrorist interrogation room, or so it seemed to me at the time.

"So tell us. What have they told you that you have to do with this disease?"

The fact was that nobody really told me that I had to do anything or had to be careful of anything. Nor has anyone told me how to conduct myself with this disease. I have led a mostly normal life--as normal as is possible living with a chronic illness. In fact I have managed to do a lot of things some 'normal' people have not or could not.

I have read all about the disease and know how it is transmitted. Long ago through the internet and through support groups, things one had to be careful of or consider were it. listed or talked about. But that was a bit different from being told to do something. I of things someone has *told* me to do.

Get exercise. Eat a healthful diet. See a hepatologist. Try to live a normal life. Expect to be treated as a normal person. You don't have to be too worried of getting mar-

ried or passing it on to your wife or kids or co -workers. You can eat in restaurants, swim in

Some things to be careful of: You should someone who was not. "Here it comes not drink alcohol. Do not share razors, toothpicks, toothbrushes, manicure equipment. If you are getting a tattoo, tell the tattooist. If you are having dental work, tell the dentist. Surgery? Tell the doctor. Do not share hypodermic needles. Anything that comes into contact with infected blood can infect someone if it comes into contact with an open wound or is inserted into the blood stream of an uninfected person. And so forth ... I knew it

> None of it would come out of my mouth. It was too complicated for me to put into words. I was "on the spot" and the surroundings and the situation made it difficult to formulate a proper response. It was extremely uncomfortable and difficult talking about this very personal condition under the circumstances.

> "My blood," I replied. "I have to be careful with my blood".

> It did not seem to be what they wanted to hear. It seemed they were waiting for more. But that was about all I could get out. I was asked where this clinic was. I gave the booth agent the paper from my pocket that had the two addresses I was going to on it.

He looked it over and returned it to me.

The booth agent asked me if I had been in the U.S. before. I replied that I had.

"You've been here before? When was the

"About a year ago, summer."

"What was the purpose of your trip?"

"Hang gliding, at Black Mountain."

The agent from the booth said something to the agent at the door and left the room. The other agent remained near the door. I noticed that sometime during the "interrogation" he had removed his sunglasses. He looked a bit less intimidating. He mentioned that having Hep C must be unfortunate. I replied "Hepatitis, cancer, hit by a bus... Everybody gets something to worry about. Everybody has their problems." He agreed.

Silence.

He asked what I do for a living. I told him the family owned a building. I helped manage

"A super? A super-super?" he asked.

"No, I work over the internet. There is a considered it more common sense than a list building manager running the building. I tell him what to do. He gets it done." He nodded his understanding.

Silence.

"It seems pretty serious in here," I said to (Continued on page 5)

#### (**QUEST**—*Continued from page 4*)

him, looking around at the cameras, the cells, the metal rings for handcuffs along the bench.

"Yes, it probably IS intimidating if you have never been in here before," he agreed. "You have nothing to worry about... He isn't going to find anything in your car, is he?"

I shook my head, "No".

I felt what might be a very, very slight smile form on my face. Not quite a smile, more of a relief really. Then I thought I had better not smile too much or he might think I was cocky and that I might be thinking that they would never find what I had hidden and that I was smug I would never be caught. Of course, there was nothing 'illegal' in the car I was aware of, and if there was something it would probably be something like a can of bear spray (I frequent the mountains) or a bottle of juice or bag of nuts or such.

Eventually the booth agent came back. I was told I could be on my way. I was taken to a door. I was told to take the road around to such and such and show the orange paper to the guy at the thing. I have now forgotten what he said exactly. It seemed simple enough. I thanked them and left.

I found my car where I left it. The keys were on the roof. The first problem I had was how to get out of the parking lot. I knew where I came in, but that was one way in. They sure do not make it easy for the uninitiated. First I have to follow yellow arrows that stop a bit before a parking area with no obvious sign of how to proceed. Then I have to figure out how to get out of a parking lot with no clear exit signs. I did not want to do something wrong and end up in more hot water. I took a guess. I found a marked roadway a parking row away. I followed it. It lead to a fork. By now I had totally forgotten the instructions I was given to navigate out. As I approached the fork another agent had just finished letting a car through the left fork and was putting road cones across it. I did not know if the cones were meant for me or not. The sign above the fork did not help me. I stopped.

"Where should I go?" I asked. He told me to read the sign. The look on my face as I read it again probably told him I needed more help. None of the options listed made any sense to me.

"The sign says Port Exit to the right. Follow it." I did so. I got to the guy at the thing. It was another customs agent. He was standing outside a small shed at mechanical arm barrier which blocked me from proceeding. I stopped just before I got to him. I had the orange paper in my hand. The window was down. He did not move. He was standing

about where my headlights were, maybe a bit closer. He motioned that I should drive closer. I had to bring the car window to him. I advanced until he was next to the window and stopped. I gave him the paper. He told me to advance to the closed gate. I did so and stopped. The gate went up. I joined the "regular" traffic that was leaving the customs booths. "Finally, I'm out!" I thought. I proceeded onwards towards my next stop. For about 10 minutes a white car seemed to be following me. I was going slower than the other traffic which was all passing me and it remained at about the same distance behind me which I thought a bit strange. "Must be following me to find out if I am really going to the clinic," I thought. An exit or two along the highway later and I did not see it anymore.

The rest of the trip was uneventful. At the walk in clinic I told them why I was there (blood test requisition for IL28B test). I had an hour wait at the clinic before I saw a doctor. The doctor was unaware of the test. He asked if it was a HCV genotyping test. I told him what it was for. He said he did not see why he could not give me a requisition. I paid about \$100 US for the service and was on my way to the clinic/lab for the blood draw. The receptionist there was very friendly. We had some interesting small talk. I paid about \$350 US for the test, had a blood draw, arranged for a copy of the results to be mailed to me and was soon on my way home. As I drove the events of the last 2 hours played through my mind without the stress I felt during the actual events. It came to mind that while I felt isolated and under the gun in that room at customs, that perhaps all they were interested in was whether I was a risk to the safety of the public. Maybe all they wanted to hear me say was that I had to be careful with my blood, and give them a small list of the usual things-razor blades, tattoos, body piercing, needles... If I were not in that room and the surroundings were less intimidating I could have been more informative. I stopped off and spent a little over \$65 on some U.S. gasoline. I filled my tank and the two cans in the trunk.

As I approached the Canadian customs a sign warned of 15 minute wait times. "I shouldn't have any problem getting back into Canada," I thought. And a little voice in my head said, "Unless they have a problem with me filling 2 cans and my car with gasoline...."



#### HEP C CLINIC AT PERCURO VICTORIA, BC

Did you know that PerCuro provides education regarding disease/treatment, close monitoring and nursing support to individuals in the Greater Victoria/South Vancouver Island area who have been considered for Hep C treatment. Attendance in clinic is completely voluntary and tailored to fit individual needs from telephone visits periodically to routinely scheduled clinic appointments. The nurses assist in procuring financial coverage for treatment, ensure lab/imaging tests are scheduled appropriately. provide instruction in selfadministration of injectable medication, assist in the management of side effects and liaise with your physician regarding your status and any issues of concern. This type of professional support is imperative now that standard of care therapy often involves three medications. There is no cost involved.

Nursing support improves outcomes. Contact: 250-382-6270



(NEWS — Continued from page 1) Source: <u>www.roche.com/media/media\_releases/</u> <u>med-cor-2011-10-17.htm</u> Oct 17, 2011

#### MIRIAM STUDY: HCV IS STD IN HIV+ GAYS

HIV-positive people don't know they may be at risk for Hep C, which is being transmitted sexually among gay males infected with HIV. Many believe that HIV+ patients should be screened to catch the infection early, when treatment is more effective. Researchers began a pilot program, the Miriam Study, screening HIV+ patients at their normal quarterly appointments with a risk questionnaire and ALT test. More than half of the males said they did not believe that unprotected anal sex could transmit HCV. The questionnaire also had questions about other risk factors. In these 58 study participants, any rise in ALT even within normal limits prompted testing for HCV. The participants were given riskreduction education at each visit.

Source: www.golocalprov.com/health/miriamattacks-silent-epidemic-in-hiv-patients/ October 21, 2011



#### 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







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/

## **THEY DID IT!!**

All three members of the first annual HepCBC Liver Warriors Walking Team finished the 21.1 km "Half Marathon" course in Victoria October 9th, 2011! We had three goals:

- to publicize the benefits of exercise particularly walking - to those with liver disease.
- to become healthier ourselves, and
- to have fun together!

The Liver Warrior team succeeded on all three counts, and hopes some more members will join us next year. If you don't live in Victoria, consider forming a HepCBC Liver Warriors team for your local walking events.

Two of the team members have been living with hepatitis C for many years, and all are between their mid-fifties and mid-sixties. We all decided we want to better our time next year, so we plan to do more practice walks together. More on this next issue...



http://runvictoriamarathon.com/events/ halfmarathon.php

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

#### **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  $15^{th}$  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

## PHYSICIANS FOR PATIENTS



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

http://hepatitisc.physiciansforpatients.com/



"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

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.



Are you in British Columbia? Are you 16 years old or older? Do you have a BC Care Card? If so, you can now get your lab test results online at a secure internet site at www.mvehealth.ca

You must have had a lab test within the last 10 days at a LifeLabs or BC Biomedical laboratory centre in order to register. Have your Care Card number ready. You must use the mailing address that your lab has. Tel. 1-888-522-7758

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**NOVEMBER 2011** 



#### CONFERENCES

AASLD 2011 The Liver Meeting November 4 -8, 2011 Moscone West Convention Center San Francisco, CA www.aasld.org/lm/Pages/default.aspx

**CASL Consensus Conference** on Viral Hepatitis November 18 - 20, 2011 Toronto, Ontario www.hepatology.ca/cm/

**United European Gastroenterology Week UEGW 2011** November 15, 2011

Somerset, United Kingdom http://uegw11.uegf.org/aboutuegw2011.html

#### HEP C TELECONFERENCES

Join us every Tuesday 7-9 PM CST. Speakers. O&A session. Chat. Free and confidential. More info: *http://www.hepcmo.org* 

#### (**RESEARCH**—Continued from page 1)

**BMS-791325** 

Bristol-Myers-Squibb has announced an all-oral, non-interferon study of its NS5B protease inhibitor BMS-791325, which is scheduled to start in November 2011 and end in December 2013. It will combine BMS-650032, BMS-790052, and BMS-791325 in genotype 1 treatment-naïve subjects.

The company has other trials with BMS-791325 as well, such as a Phase I trial in healthy Japanese subjects (not HCV+). They are not yet recruiting. That trial will start in February 2013 and is planned to be completed by June 2013.

Sources: http://clinicaltrials.gov/ct2/show/ NCT01455090?term=BMS-791325&rank=2 http://clinicaltrials.gov/show/NCT00947245 http://ctr.bms.com/OneBmsCtd/ InitTrialDetailAction.do?pnum=AI443-011

#### 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 http://profiles.drugcoverage.ca/en/ forms: *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: 1-866-872-5773

#### 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 Lookback Programs, Canada: 1-800-668-2866 start, stay on, and complete their treatment successfully. PegAssist Reimbursement 1-888-332-5663 (local 3467) or 604-707-3467 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 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 Lvons 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

Canadian Blood Services, Vancouver, BC

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

Hema-Ouebec 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) <u>Irene.dines@Blood.</u>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: http://www.reko.ca/html/ hepc\_settleagreement.pdf

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#### **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 6<sup>th</sup> St. Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400 • Nanaimo Hep C Meetings twice monthly: Contact Anita 250-753-2437

anita.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 batlas@telus.net

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** <u>info@hepcbc.ca</u>, <u>www.hepcbc.ca</u> •Victoria Peer Support: 4<sup>th</sup> 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 and counseling 250-315-0098. www.askwellness.ca

Kamloops Hep C support group,  $2^{nd}$  and  $4^{th}$  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 2<sup>nd</sup> Thurs. monthly, 7 PM (Location to be arranged.) Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Support Group 1<sup>st</sup> & 3<sup>rd</sup> Thurs. monthly 4-5 PM, AVI Health Centre, #216-55 Victoria Rd. Contact Fran 250-740-6942. hepctxpeersupport@hotmail.com

Nelson Hepatitis C Support Group 1st Thurs. every 2<sup>nd</sup> 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 May 13<sup>th</sup> till August 26<sup>th</sup>. 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**: 2<sup>nd</sup> Fri monthly 1PM, Drop-

in, Comox Valley Nursing Centre (nurse) **Campbell River:** 2<sup>nd</sup> Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

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

Prince George Hep C Support Group 2<sup>nd</sup> 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 250-557-2487, 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

Surrey Positive Haven Info, harm reduction, support, drop in, clinic. 10697 135A hars@kingston.net, www.hars.ca 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 5706, Mavis 519-743-1922 or 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 Peter, pvanbo@gmail.com Tel. 250-309-1358

Victoria CoolAid Peer Support each Wed 10-11:30 AM, 713 Johnson St. Support for tact Debby Minielly <u>dminiel-</u> all stages of treatment (deciding, during, ly@publichealthgreybruce.on.ca 1after). Contact Carolyn cshowler@coolaid.org

YouthCO HIV + Hep C Community Outreach Drop-in T&W 12-3, Fri. 9-12. Call to sched Peel Region (Brampton, Mississauule appts M-F 10-6. 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Support Staff: Lulu *lulug@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

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#### 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 1<sup>st</sup> 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 613-545-1-800-565-2209 3698

Kitchener Area Support 3<sup>rd</sup> Wed. monthly, 7:30 PM, NEW: Ray of Hope Community Room, 659 King St. East ( Enter off King St. ) Kitchener. Contact Bob 519-886waterlooregionhepcsupport@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. Con-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, www.publichealthgreybruce.on.ca/

ga, Caledon) 905-799-7700

healthlinepeel@peelregion.ca St. Catharines Contact Joe 905-682-6194

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 1<sup>st</sup> 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** 

undu<u>n@sympatico.ca</u>

York Region Hepatitis C Education Group 3<sup>rd</sup> 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

#### **OUEBE**C:

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:

Edmonton Contact Jackie Neufeld 780-939-3379.

Wood Buffalo HIV & AIDS Society #002-9908 Franklin Ave, Fort McMurrav, AB Contact 780-743-9200 wbhas@telus.net www.wbhas.ca

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 1<sup>st</sup> & 3<sup>rd</sup> 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 15<sup>th</sup> of the month. It's free!

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