hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEP C TREATMENT 4 DUMMIES

For the past few years, standard therapy for hepatitis C has been pegylated interferon plus ribavirin. At first, we had only interferon (IFN) as treatment, and then the "combo treatment"--interferon plus ribavirin--became standard therapy, until pegylated interferon appeared on the scene. Currently, the standard treatment (SOC) for HCV infection is pegylated interferon alpha (either Merck's Peg-Intron or Roche's Pegasys) along with ribavirin (Merck's Rebetrol or Roche's Copegus). This is about to change. It is expected that treatment will include a protease inhibitor.

The protease inhibitors Boceprevir (Merck) and Telaprevir (Vertex) are expected to be approved in the US sometime this year. Hopefully Canada will soon follow suit soon with approval.

The following information is for those of you who are newly diagnosed, those who are to treat), and about 80% or higher for genojust now considering treatment, and those type 2 and 3. who have not responded and are waiting for these new treatments.

Interferons are types of naturallyoccurring proteins produced by our own immune system. They direct our immune system to attack viruses, bacteria, tumours and other foreign substances that may invade the body. Virtually all interferons used in HCV treatment today are obtained from bacteria that have had slight man-made DNA modifications. In general, genetic material from human leucocytes (white blood cells) is spliced into the genetic material of bacteria, and the bacteria are allowed to reproduce and grow. The inserted genetic material causes the bacteria to produce interferon.

Pegylated interferon (PegIFN) is a type of interferon with a large polyethylene glycol molecule attached to it, so that it stays in the body for a longer time, and we can inject it just once a week, rather than 3 times a week, like we did in the past. Side effects are similar to or slightly less unpleasant than those experienced with non-pegylated interferon.

The two available pegylated interferons, Peg-Intron and Pegasys have been compared.

size of the molecule involved, (about 60 kilodalton for Pegasys, 31 kilodalton for Peg-Intron). Pegasys has a longer half-life. Some studies show that SVR rates inhibitors. Where the 40-50% of G1 patients (Sustained Viral Response, or loosely, "cure rates") for Peg-Intron or Pegasys are slightly different, with one being higher than the other, or showing little difference at all.

Ribavirin (RBV) is an antiviral discovered over 30 years ago. No one knows for sure how it works, but when combined with PegIFN, these two drugs have drastically improved the response rates. The dosages of RBV are weight-based, so the more the patient weighs, the higher the dosage of both medications. Generally it seems accepted that SVR rates when combined with either pegylated interferon are about 40-50% for genotype 1 (G1) patients (the most difficult promising treatment since the proverbial

Protease Inhibitors are being added to standard therapy. The protease is a part of the virus that is needed for it to reproduce. Once HCV enters a liver cell, its genes guide the production of proteins that will become the inner core and surface coat of new viral units. First of all, the HCV makes an immature protein-a kind of unfinished sheet of material, which the Hep C protease cuts into the finished proteins, which then become the virus's outer cloak. Scientists

INSIDE THIS ISSUE:

Hep C Treatment 4 Dummies	1
That Fully-Loaded "Cure" Word	3
Affected by Pharmaceutical Shortages?	4
Hep C & Me: That "Cure" Word	5
Hep C on the Internet / HepCBC Marathon	6
Conferences	7
PegCARE/PegAssist/Neupogen/Compensation	
Coming Up	8

The two substances differ basically in the have designed protease inhibitors which stick specifically to HCV protease to stop its scissor-like function.

> There is much hope for these protease achieved an SVR with SOC, new numbers for protease inhibitors show about 75% of treatment naive patients may achieve SVR with upcoming treatment (SOC + telaprevir/ boceprevir). Those who responded to previous therapy but relapsed may have a better than 80% chance of SVR. Those who responded but did not clear have about a 60% chance of SVR. Non-responders and nullresponders have a 30-40% chance of SVR. (These numbers are based mostly on telaprevir data and may vary depending on the study.)

> We have followed the development of this drawing board. It is good to hear it may soon be approved. Will this drug be given to everyone, or only to non-responders? How many of us have not responded to our present standard therapy and need more treatment? Will the drugs be covered by the provinces? That may depend on whether or not our government sees a need for this.

Sources: www.clinicaloptions.com/Hepatitis/ Conference%20Coverage/Berlin%202011/Tracks/ From%20Podium%20to%20Practice/ Capsules/5.aspx http://hepcbc.ca/FAQs/FAQ%20V83%

202009/FAQ%20V8.3.pdf

GLOSSARY:

Allele	One of a pair or series of genes found
	at a given spot on a certain chromo-
	some.
GT	Genotype
Gl	Genotype 1
IFN	Interferon
PegIFN	Pegylated Interferon
RBV	Ribavirin
RGT	Response-Guided Therapy
SOC	Standard of Care (PegIFN + RBV)
SVR	Sustained Viral Response (virus
	undetectable 6 months after treatment)

SUBSCRIPTION/ORDER FORM

Please fill out & include a cheque made out to **HepCBC** - Send to the following address:

HepCBC #306-620 View Street Victoria BC V8W 1J6		
Name:		
Address:		
City: Prov PC		
Home()Work()		
Email:		
□Please email me a PDF copy, free of charge.		
□Membership + Subscription (1 year)\$20.00		
☐Membership Only\$10.00 (Doesn't include the <i>hepc.bull</i>)		
□Subscription Only\$10.00 (Doesn't include membership privileges)		
□Peppermint Patti's FAQ\$12.00		
□Resource CD\$10.00		
□"I enclose a donation of\$		

so that others may receive the bulletin."

TOTAL:

□ "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>

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

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:	Joan King		
	PHONE:	(250) 595-3892		
	FAX: (250) 595-3865			
EMAIL:		info@hepcbc.ca		
	WEBSITE:	www.hepcbc.ca		
	HepCBC			
	306-620 View Street			
	Victoria BC V8W 1.16			

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 FAQ Version 8.3 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 info@hepcbc.ca

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 on this page.

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 HepCBC.

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, A-Channel News, 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.

CUPID'S CORNER

T his 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**, #306-620 View Street, Victoria, **BC V8W 1J6**, (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.



PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

Page 2

HEPC.BULL MAY 2011 ISSUE NO. 144

EASL HIGHLIGHTS

The International Liver Congress 2010 45th Annual Meeting of the EASL

14-18 April 2010 Vienna, Austria www.easl.eu/liver-congress

DEB025

DEB025 (alisporivir) is a cyclophilin inhibitor produced by Novartis. It affects the host proteins that the virus needs to replicate. The product has been shown to be effective against all genotypes. This study treated G1 (genotype 1) treatment-naïve patients, with the product alone or combined with SOC (standard of care, or PegIFN+RBV), for 48 weeks. The main side effect was an increase in bilirubin, and was reversible. The results from week 24 post-treatment showed SVR (sustained viral response) in 76% of the patients in the arm including SOC, vs 55% for SOC alone. The drug is now being used in a Phase III study for G1 untreated patients.

FLUVASTATIN

Fluvastin is a drug that is already approved for lowering cholesterol by inhibiting a liver enzyme, HMG Co-A reductase. The drug is expected to prevent serious fibrosis. This study treated 209 treatment-naïve G1b patients with fluvastatin or placebo plus SOC for 48 weeks. Fluvastatin was given for a total of 72 weeks, no matter the patient's lipid levels. The results showed that SVR was 74.39% in the fluvastatin combo, vs. 58.44% from SOC. And fluvastatin is affordable!

TMC435 ASPIRE STUDY

TMC435, produced by Tibotec and Medivir, is a protease inhibitor, now in Phase III studies. This Phase IIb study examined 462 G1 non-responders (including nullresponders) to SOC. The interim results presented came from tests done at 24 weeks of treatment with different doses of the drug. In the highest dose arm, 91% of patients tested undetectable vs. 82% with SOC alone. TMC435 is being given for 12, 24 or 48 weeks. SOC will continue for 48 weeks.

BI 201335 + BI 207127 IFN-FREE CURE?

Boehringer Ingelheim's protease inhibitor BI 201335 was administered with SOC to 429 GT1 subjects, both treatment-naïve and treatment-experienced, in their SILEN-C1 Phase II trial. Results show an SVR of 71-83% in na-

ïve patients, and 28-41% in previous nonresponders, depending on the treatment arm. The best results were seen in the 240 mg daily dose arm, in those who had an extended rapid viral response (at weeks 4, 8 and 20), showing a 93% SVR with only 24 weeks of SOC. Interestingly, a 3-day lead-in treatment with SOC alone produced higher rates of breakthrough. 4-12% dropped out due to adverse events. The US FDA has granted Fast Track designation to approve the marketing of this drug combined with SOC, and also of the IFN-free combination of this protease inhibitor BI 201335 with BI 207127, their polymerase inhibitor, for G1 patients. Phase II trials of the IFN-free combo, with and without RBV, have begun. Their Phase III trials are starting soon.

CTS-1027 FOR NULL-RESPONDERS

Conatus Pharmaceuticals was founded by a team from Idun in 2005 when it was sold to Pfizer. CTS-1027 is thought to assist the immune system's clearance of the cells infected with the virus. CTS-1027 was given to 67 G1 null-responders (no response at all to previous therapy), the most difficult of all to treat. These patients were tested for the CT and TT allelic variants of the IL28B gene, which predict non-response, and 95% possessed them. Even so, interim results from week 24 showed 34% undetectable at week 24.

VICTRELIS (BOCEPREVIR)

Victrelis is Merck's protease inhibitor. Results from their Phase III studies of the drug combined with SOC in G1 patients, with a 4-week lead-in of SOC alone (high -dose RBV 600-1400 mg/day) were presented. Primary results showed a 59% SVR for the RGT (Response-Guided Therapy) arm and 66% for the 48-week arm, compared to 21% of the control arm subjects. In treatment-naïve patients, adding Victrelis to SOC produced an SVR in 63% in the RGT arm and 66% in the 48week arm, compared to 38% in the control group.

The patients were tested for IL28B, a genetic marker which identifies patients who are unlikely to respond to treatment. The study showed that the chance of a patient responding can be predicted based on the patient's response to the 4 week lead-in period and to the presence of

IL28B (CC, CT or TT). In patients with the CC gene allele, 89% of the treatment-naïve and 82% of the non-responders (NR) had undetectable virus at 8 weeks, and were scheduled for shorter therapy. Among those with the CT or TT gene allele, 52% of naïve and 48% of NR had an ER (early response) and could take shorter therapy. The response to the 4-week lead-in was the stronger predictor of SVR. The discovery of the importance of the IL28B alleles came from the results of the company's HCV SPRINT-2 (naïve patients) and HCV REPOND-2 studies (NR patients).

There were some serious side-effects. EPO (Epoetin) was given to some patients to manage anemia.

QUADRUPLE THERAPY: 100% SVR for NR

Results at 12 weeks after finishing quadruple therapy showed 100% of patients testing undetectable, with no resistant variants emerging in the 21 null-responders who took part in the trial. (19 had unfavourable IL28B genotypes.) The patients received SOC plus BMS-650032 (an HCV NS3 protease inhibitor) and BMS-790052 (an HCV NS5A replication complex inhibitor). This may be the future of HCV therapy, and new hope for nonresponders. Null responders have a 30% response rate to SOC plus telaprevir, so treatment is still needed for the other 70%.

Source: <u>http://www.hcvadvocate.org/news/</u> EASL 2011.html

НОРЕ





MUSIC SUMMIT BACK TO BUSINESS BIZA 2011 MAY 25-27 The Hepatitis C Trust and The International Music Summit (IMS) Ibiza are getting together for the second year running for the GET TESTED! mission and WE NEED

YOU to get involved and urge people to GET TESTED! for Hepatitis C.

<u>www.internationalmusicsummit.com/html/</u> tested.html

HAVE YOU BEEN AFFECTED BY PHARMACEUTICAL SHORTAGES? by Marjorie Harris, HepCURE Patient Advocate

non-profit patient coalition group here in the North Okanagan, 100% of the pharmacies reported pharmaceutical drug shortages across a wide spectrum of drug classes involving numerous therapeutic molecules: blood pressure, blood thinners, psychiatric (antidepressants), surgical anaesthetics, gastrointestinal, sleeping pills (hypnotics), allergy meds, nose sprays, cancer drugs, diuretics, diabetes and antibiotic medications. Some antibiotics reporting shortages were Amoxicillin, Keflex, Cephalexin, Doxycycline, Penicillin, and Tetracycline. These findings correspond with reports of drug shortages across Canada in the national press and by the Canadian Pharmacists Association. At this point in time it is unclear what is causing the shortages that are reportedly the worst in 30 years. North Okanagan pharmacists started noticing an alarming increase in drug shortages over the last fifteen months, with severe shortages causing large numbers of drugs on back-orders over this past fall and winter. One names? pharmacy gave the example of ordering 30,000 3.) Were any patients adversely affected by this therapeutic items and having only 13,000 items | shortage? come in on the order!

So far the pharmacists have largely been able to protect patients from the drug shortages and did not know of any adverse events caused to patients from not being able to access a therapeutic. However, drug shortages have imposed a huge inconvenience for pharmacists who have to find work-arounds to supply the needed medications for patients. Patient needs have been met by substituting pharmaceuticals, shifting between brand name products and generic drugs, or between generic brands. Other times drugs needed to be located elsewhere. In one instance the pharmaceutical had to be

In a recent survey conducted by a national sourced by Interior Health through the hospital pharmacy system, which has a different supplier system than the drugstore chains. Other times different formulations of the same product were used, switching the patient from tablets to a liquid product, requiring a new protocol for dosage frequency and refrigeration. The certified "Compounding Pharmacies" were able to order in raw materials and compound the therapeutic medications on site to fill prescriptions. Pharmacists are concerned that substitution is not always the best medicine for the patient.

Seventy percent of local pharmacies were able to participate in the short four-question survey to help determine if the Okanagan residents were being adversely affected by drug shortages. The four questions were the following:

1.) Have you noticed any drug shortages in the past 6 months?

2.) If so, what drug categories are the drug

4.) Were the medications able to be sourced elsewhere for the patient?

The Best Medicines Coalition, a national coalition of non-profit patient groups, is looking for patient stories as part of their mandate to ensure timely access to 'best medicines.' If you have a personal story or someone you care for has experienced an adverse health event caused by the recent drug shortages and want to share your story on a national level, please send your patient story to me here:

MarjorieHarris@telus.net

Or you can mail it to Box 195, Armstrong BC, VOE 1B0. Thank you!



MAY HEPATITIS MONTH **EVENT**

We are organizing another Hepatitis C Health and Services event similar to the one we did at Centennial Square last year. This year we are excited to be holding this event at Our Place, Suite 3-1500 Ouadra St., Victoria, BC, and hope you will be involved. The tentative date is for Tuesday, May 20th. More info:

Hermione.jefferis@avi.org 250-384-2366



WE LOVE A PARADE!

Balloons, floats, music from marching bands competing with each other for your attention, dancers, baton twirlers, horses, food, costumes, the smell of hot dogs, balmy warm weather, flowers, happy

crowds... Can you think of a better thing to do with your kids this spring than to take them and their friends and your friends and your dog and your parents (you get the idea) to a parade?

Come celebrate Victoria Day by joining us alongside the HepCBC float in Victoria. Come join in the fun by helping us decorate it, if you'd like. Your kids can help us distribute candy to the crowds-and they're allowed to keep some for themselves, too. Dress up or down. Bring your Hep C T-shirts, if you have any, balloons, banners and placards. Dance to the music from the bands surrounding you.

Camera shy? No problem! Wear wigs, scarves, dark glasses, make up, or hats. There is something for everyone at the Victoria Day Parade.



The parade takes place in Victoria, BC on May 23rd at 9 AM. It starts at Mayfair Mall and works its way down Douglas Street to downtown in about 3 hours.

For more info: http://www.harbourliving.ca/event/islandfarms-victoria-day-parade2011/2011-05-23/



WORLD HEPATITIS DAY 2011 An Open House Event to aid in the Education Prevention and

tion, Prevention and Awareness of Hepatitis C July 28, 2011 Bear Creek Park 13750 - 88 Avenue, Surrey, BC 6 - 9 pm Speakers: TBA Goodies ~ Prizes ~ Entertainment Contact: Petra Hoffmann petrabilities@aol.com

Looking for Volunteers! Please let me know if interested!

FREE HEPATITIS C/HIV CO-INFECTION WORKSHOP

Wednesday, May 25th Victoria, BC

Dr. Mark Hull presenting. Light lunch provided, followed by panel on local perspective with Dr. Chris Fraser

For details and to pre-register, please contact Hermione 250-384-2366 <u>Hermione.jefferis@avi.org</u>

Presented by AIDS Vancouver Island and Merck.

Everyone welcome

HEP C AND ME: THE INCREDIBLE JOURNEY!

by Petra Hoffmann



That Fully Loaded "Cure" Word

Well, ladies and gents, another month has whizzed right by, and it is once again time to sit down and write a new article. The only thing

that keeps popping into my mind in this regard is a series of events that have taken place over the last couple of weeks regarding this intense word, "CURE." I had no idea whatsoever that it would ruffle oh so many feathers. Let me tell you as best I can what happened, and in effect what made me even more aware.

It all began with a Front Page article in the Vancouver Sun on March 31, 2011! I was so excited to see that hepatitis C had finally hit the papers, never mind the top of the front page! That seemed like progress to me. The article was headed "Drug Combo Boosts Hepatitis C Cure." I loved the fact that, although it mentioned that British Columbia's illness rates are the highest in Canada due to intravenous drug use, it ended by saying this, and I quote: "The virus can be spread via injection drug use, tattoos or body piercing, acupuncture using unsterile equipment, sharing razor blades and toothbrushes and needle-stick injuries in hospitals. We've got bankers, lawyers, doctors - all sorts of walks of life." As you may or may not know, it is my mission to interview and present to the general public, that they, too, might be afflicted, and that just because they have not stuck a needle into their own veins, it is not impossible that they, too, may very well also have this pandemic disease. So the way the article ended made me grateful.

Now, this is where things got a bit shaky. I am all over social media sites, as they are my main venue to create awareness. I saw a thread put out on Facebook by "Hepatitis C Research," that also touched on the great results being reached with the new treatments undergoing study. They say that the treatment times are being cut in half, and even non-responders are seeing as high as 80% results.

Well, needless to say, when I wrote the word "cured" in my quest to share the Vancouver Sun's article, I caused a public outcry. No sooner had I hit the "enter" button, than very upset "Heppers," spoke up rapidly, and it was then that I realized again how truly lucky I was to have been treated. I received messages from both the US and

the UK. They cried out in regards to the fact that if the medical profession is saying that there is a "cure," then why are the life insurance agencies turning people down, even when they come out "cured"? Another outcry was the fact that in the UK (not sure about the States and Canada, etc.), people do not state on the death certificates that the cause of death has anything to do with Hep C. I could not well swallow the new information that I was given that day. Apparently in the UK, a coroner will not have anything to do with a "Hep C" corpse. I was told they get "suited up" if they do, and the body must be disposed of in a special plastic bag, with black and yellow biohazard tape or a tag stating "Infectious Disease", whether the deceased had been successfully treated or not. For more information, please see: http:// www.hepctrust.org.uk/

Living+with+Hepatitis+C/Other+issues

They also have to pay a lot of extra money to have a coroner handle and dispose of such a body! Every day I am learning all these new things, most of which I wish I never knew. Well, it certainly has put a damper on the word "cured," for me. There is obviously so much to do, and so much to change, and we all know that takes way too much time. Meanwhile I cannot shake the word "pandemic", as stated by all authorities now. The best news ended up being that I made 4 or 5 new friends that day!

Now on a better note, we are holding the 2nd Annual World Hepatitis Day here in Vancouver/Surrey on July 28th, 2011. We have booked a gorgeous Pavilion in Bear Creek Park (the biggest and best out here!) My life has become very busy trying to get back on my feet, and I am seeking volunteers to help me with phone calls, flyer handouts, and everything that requires doing to host such an event. If you are in the area, and can find it in your hearts to help us out, please contact me directly at <u>petrabilities@aol.com</u>. I thank you in advance!

Good luck, and health to you all, and again, until next month, Petra

Please come and follow my journey on: http://www.youtube.com/petrabilities and visit http://www.petrabilities.com



Hep C Sites on facebook.

FIGHT **Against Hepatitis C**

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



http://bit.lv/9Nvlw3

Transplant **Support Group of British Columbia**

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

witter

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



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/

Page 6

HEPCBC LIVER WARRIORS HALF-MARATHON WALKING TEAM

On Sunday, October 9, 2011 in Victoria, BC, join the HepCBC "Liver Warriors" and participate in the Victoria Marathon. We will walk 21.1 km in 6 hours (or less) to publicize the benefits of exercise such as walking, particularly to those with liver disease.

If you are interested in training with this team or participating in this walk, go to www.runvictoriamarathon.com/events/

register.php. Be sure to select "Half-Marathon" and "Open" and "Hep C BC Liver Warriors" as your team. You must pay a \$64.86 registration fee with a credit card. You don't have to pledge anything else-only that you'll WALK with a SMILE!



Phone Cheryl at 250-360-4068 if you need help with registration or require lodging in Victoria.

If you want to join the full (42.2 km) running marathon, please phone Rachel at 250-853-3424.

See you there!

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

COMPETITION

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

MAY 2011

ISSUE NO. 144

HEPC.BULL

PHYSICIANS FOR PATIENTS



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

http://hepatitisc.physiciansforpatients.com/

If you are receiving this newsletter by snail mail but have internet access, please consider switching to our pdf version. All you need is Adobe Acrobat Reader, free at this site: www.adobe.com/products/acrobat/ readstep2.html

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

The Combo Survival Guide from A to Z

http://www.hepcsurvivalguide.org/ *comboguide.htm*

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



Are you Infected? It's a Simple Blood Test. Call HepCBC re info or support 595-3892

Stats from Public Health Agency of Canada Hepatitis C

www.hepcbc.ca

CONFERENCES 2011

1st World Congress on Controversies in the Management of Viral Hepatitis (C-Hep) May 19-22, 2011 Barcelona, Spain http://comtecmed.com/chep/2011/

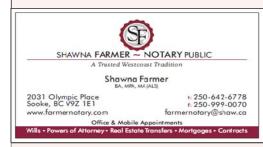
6th International Workshop on Hepatitis C, Resistance and New Compounds. June 22-23, 2011 Boston MA, USA http://www.virology-education.com/

HCV 2011 18th International Symposium on Hepatitis C Virus and Related Viruses September 8-12, 2011 Sheraton Seattle Hotel & Towers Seattle, WA Registration: Opens 1 February, 2011 www.hcv2011.org/

HEPATITIS C TELECONFERENCES

Join us every Tuesday 7-9 PM CST. Listen to speakers discuss various hepatitis C related topics, followed by a Q&A session, and time to "chat." The teleconference is free and confidential.

More info: http://www.hepcmo.org



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

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% reimburse-The income maximum ment. 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

Pre-1986/ Post-1990

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



Klein Lyons Vancouver, BC 1-604-874-7171. 1-800-468-4466, Fax 1-604-874-7180 www.kleinlvons.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) Irene.dines@Blood.ca

RCMP Blood Probe Task Force TIPS Hotline 1-888-530-1111 or 1-905-953-7388 Mon-Fri 7 AM-10 PM EST 345 Harry Walker Parkway, South Newmarket, ON L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/ COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296 Health Canada Compensation Line: 1-888-780-1111 Red Cross Compensation pre-86/post-90 Registration: 1-888-840-5764 HepatitisC@kpmg.ca Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764 www.phac-aspc.gc.ca/hepc/comp-indem_e.html

CLAIMS ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

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

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

HEPC.BULL

MAY 2011 ISSUE NO. 144 Page 7

SUPPORT BC/YUKON:

Armstrong HepCURE Contact 1-888-437-2873 Phone support.

AIDS Vancouver Island The following groups all provide HCV 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 Drop in 9-12 M-Th, harm reduction M-Fri, counseling, advocacy 355 6th 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 each 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 at 604-435-3717 batlas@telus.net

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

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: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947

Cook St. Drop-in/Office/Library, 306-620 View St. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-3891 •Fraser Valley Peer Support: 3rd Wed month-

ly 7PM, N. Surrey Rec Centre Meeting room 10275-135th St Info: 604-576-2022, petrabilities@aol.com

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.as<u>kwellness.ca</u>

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 2nd Thurs. monthly, 7 PM (Location to be arranged.) Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Peer Support Group 1st & 3rd Thurs. monthly 4-5 PM, AVI Health Centre, #216-55 Victoria Rd, Nanaimo. Contact Fran 250-740-6942

hepctxpeersupport@hotmail.com

Page 8

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

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

New Westminster "HepC" Support Group each Fri 10 AM May 13th till August 26th. 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.

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

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

Prince George Hep C Support Group 2nd 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

Oueen 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 Hep C group 2nd & 4th Thurs monthly 1 PM. 10697 135A St. Contact Monika 604-589-9004.

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

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

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

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

Victoria CoolAid Peer Support each Wed 10-11:30 AM, 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Carolyn cshowler@coolaid.org

YouthCO AIDS Society 900 Helmcken St. 1st floor, Vancouver 604-688-1441 or 1-877-YOUTHCO <u>www.youthco.org</u> Support pro-<u>www.publichealthgreybruce.on.ca/</u> gram manager: Sasha sashab@youthco.org

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

OTHER **PROVINCES:**

ONTARIO:

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

Sandi's Crusade Against Hepatitis C/ **Durham Hepatitis C Support Group** Contact Sandi: smking@rogers.com www.creativeintensity.com/smking/

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

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange. 269 Main St. W, Suite 201, North Bay. Contact 705-497-3560, 1-800-387-3701 or 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 hars@kingston.net, www.hars.ca

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, NEW: Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Kitchener, Contact Bob 519-886-Mavis 519-743-1922 or 5706 waterlooregionhepcsupport@gmail.com

London Hepatitis Peer Support Group 1st Tues monthly 7PM, 186 King St, London. For those infected as well as affected by Hep C. Con-

NElliott@aidslondon.com, 519-434 -1601 ext. 260, 1-866-920-1601, aidslondon.com

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

Bennett Peel Region (Brampton, Mississauga, 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 First Mon. monthly

Oct. through June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. More info: www.liver.ca. Contact Billie 416-491-3353, bpotkonjak@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 Educa-tion 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:

Edmonton Contact Jackie Neufeld 780-939-3379.

Wood Buffalo HIV & AIDS Society #002-9908 Franklin Ave, Fort McMurray, 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 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca

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

HEPC.BULL **MAY 2011** **ISSUE NO. 144**

