

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

CLINICAL TRIALS

SD-101

Dynavax Technologies has developed SD -101, an oligonucleotide called a TLR-9 ago- 2011 in San Francisco. SCY-635, a cyclonist, which is made to boost the body's immune response to HCV by affecting the Tcell and natural killer cells by way of the tolllike receptor 9 (TLR-9) and encouraging our bodies to make more interferon-alpha.

In this Phase 1b trial, 34 treatment-naïve genotype 1 (GT1) patients were injected once a week for 4 weeks, with doses of SD-101 ranging from 0.1 mg to 5.0 mg or placebo to see how safe and effective the drug is. There were few side effects, usually mild flulike symptoms and irritated injection sites. SD-101 produced a drop in viral load after only one dose of SD-101 given as monotherapy. The fast drop of HCV RNA indicate that more trials should be done.

www.kenes.com/easl2010/posters/ Source Abstract188.htm

MitoO

Antipodean Pharmaceuticals' MitoO is a super antioxidant that binds with coenzyme Q10, causing it to accumulate 700 times more intensely than co-Q10 alone inside the mitochondria. The mitochondria produces energy within the cell, and MitoO, which has a special tendency to gather in the mitochondria, protects the cell from oxidation damage and appears to be more powerful than common antioxidants. Oxidation in liver cells can be very dangerous to those with liver disease so some clinical trials have been done. Researchers in Alabama studied the effect of MitoQ on fatty liver in animals, whose livers were damaged with alcohol for the study. MitoO was able to neutralize free radicals before they could hurt the mitochondria, preventing the effects that cause fatty liver.

Source: www.hepatitis-central.com/mt/ archives/2011/11/ and http:// onlinelibrary.wiley.com/doi/10.1002/hep.24377/ abstract 24 JUN 2011 April 2011 edition of the journal Hepatology

SCY-635

Scynexis presented data at the AASLD phillin inhibitor, lets the immune system detect the virus. It reactivates the body's natural defences so that it can stop the HCV from replicating, raising hopes that it may be a good replacement for the interferons used in SOC (pegIFN/RBV), with fewer side effects. SCY-635 is currently in Phase II studies.

In earlier studies the drug was welltolerated and showed antiviral activity. It interacted well with other approved drugs in vitro, and may be an important addition to any new SOC. It may be less likely to produce resistant strains than the DAAs (directacting antivirals). SCY-635 monotherapy showed increased concentrations of interferons like IFN alpha and lambda-1 in GT1a patients.

Two other studies were also presented. One showed a correlation of SCY-635 levels and the presence of type 1 and type 3 interferons in vitro, and that SCY-635 is as effective as IFN α -2b in clearing the virus and preventing rebound in vitro. The other studied drug interactions between SCY-635 and telaprevir and showed that SCY-635 was less likely to produce adverse drug interactions compared in vitro to other cyclophilin inhibitors.

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HERB MOELLER November 6, 2009

In his lifetime, Herb Moeller endured, suffered, struggled, persevered, overcame and conquered. He took all this life threw at him-the good and the bad—and made a life some of us only dream of. Herb Moeller was a man of pride, strength and unshakeable character. From the simplest place he was Stephie and Linnv's dad and Dianne's husband. He loved with greatness and had high expectations for his rate of return. He got all of his love back from each one of us in overwhelming affection and loyalty.

Herb landed in Canada from Germany in 1967, planning to do amazing things, and he did, but not the way he expected. He had his own Graco Franchise and was one of the top distributors in Canada. His plan was to buy more franchises and build a small business empire. Another plan was about to interrupt his life. On January 12, 1984 Herb was in a workplace explosion at his Burnaby Graco office. He suffered 3rd degree burns to over 75% of his body and 2nd degree burns to 25%. Life was never the same again. Herb spent over 6 weeks in a medically-induced coma and 7 months in the burn unit at VGH. There he underwent numerous plastic surgeries to reconstruct his badly disfigured face and hands which involved many painful skin grafting procedures. When he finally came home to his wife and two young daughters under seven, he did not sit around and wallow in self pity or complain about pain. Instead he used his energy to go to physio, rebuild his life and start the first burn survivor

(*Continued on page 5*)

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

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SUBMISSIONS: The deadline for any contributions to the hepc.bull[©] 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 interest of space.

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

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LETTERS TO THE EDITOR:

The *hepc.bull* welcomes and encourages letters to the editor. When writing to us, please let us know if you *do not* want your letter and/or name to appear in the bulletin.

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[®] 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.

JANUARY 2012

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

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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>

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Got Hep C? Single? Visit:

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

NEW YEAR'S RESOLUTION:

ADD A SALAD TO YOUR DIET EACH DAY

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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



MY EXPERIENCE WITH HEPATITIS C AND TREATMENT

On August 1^{st} of 2007, I was informed that I it was deeper and darker. had hepatitis C, and that I must have contracted it some 30+ years ago during my youth when I experimented with intravenous drug use. Knowing nothing about hepatitis C and thinking I had just been given a death sentence, I told my doctor that I thought that I was one of the lucky ones who survived those davs but I guess I didn't. It just took longer. On the morning of August 1st, 2007, I was a 50 year old, happily married man with 3 great adult children. I had a great job and was working towards early retirement. On the evening of August 1st, 2007, I still had all these things, but I was thinking all my future plans evaporated.

A billion things went through my head that day. My family physician gave me a few details about hepatitis C and said he would try getting me in to see a liver specialist next year. I went home very uninformed and very confused. I spent the next few days reading anything I could find on the subject on the internet and most of it went from bad to extremely bad. I felt very alone and unsure of what to do next. During my internet search I found the HepCBC bulletin. There I found an email address for Tanya Frizzle, who said she would discuss issues with other hepatitis C sufferers. She had gone through a couple of bouts of therapy and had lots of experience on the subject of hepatitis C. I can't thank her enough for her words of encouragement and just for being there to answer my questions and listen to my whining. I really do believe I may have done something stupid if it weren't for her.

I had gone through 4 of the 5 stages of grief -disbelief, anger, bargaining-and was fully into depression by October of 2007 when I was admitted into the program at the University of Alberta Support Clinic. There I met a fine group of nurses and my liver specialist. On my first visit, I was told everything about hepatitis C by one of the nurses and then met my doctor who arranged for a liver biopsy. They sounded fairly positive and mentioned that I would probably have the option of taking treatment or not. I left feeling better about my future for the first time in a long time, that is, until I went back for the results of my liver biopsy in December. My specialist informed that my liver biopsy score was a 3 to a 4 on the scale with 4 being the worst or cirrhosis of the liver. She recommended I start treatment although chances of success were less then 50%. She also mentioned that I might have to get on a transplant list. To do either of these I would have to stop drinking totally. Well hello stage 4 again, only this time

I stopped drinking on New Year's Eve and started pegetron treatment in May of 2008. I had to inject myself once a week and take 6 ribavirin capsules daily. My first injection was assisted by a treatment nurse and she had to force my hand to steady out. That first night was pretty bad: fever, chills and all the good stuff. The whole time I just kept thinking, "I hope this is worth it and the treatment works." I felt pretty crappy most of the week until Friday when I injected myself again. The second week was not so bad as the first, but still in the top ten. This cycle repeated itself each week. By week six it was fairly routine that my weekend was shot. Monday I went back to work when I rather would have stayed home, and progressively felt better until Friday. Funny how most people look forward to Friday, and I was beginning to dread it. I never informed anyone at my workplace that I had hepatitis C and hoped that the treatment would cure me. I don't believe there is a very good understanding of this virus in the general public and there is a good chance I would have been shunned in my work environment. On week 4 I started taking antidepressants to help with the depression. I continued to get my weekly tests and waited for that 12th week test.

On my 13th week I met with the liver specialist, who informed me the virus was still there, however there had been a dramatic drop in the virus count, and she said if I continued the treatment there might be a chance I could beat it, but it was up to me. She said there was less than a 40% chance, but a chance. I was losing weight, my skin was drying up to the point where my hands and feet were developing cracks, my hair was turning grey and thinning, and I constantly felt weak and tired to varving degrees. This was a difficult decision, however, since there was a glimmer of hope, and I decided to continue. I kept the week-long cycle of Friday to Friday for another 12 weeks. I took my week 24 test, and on week 25 the treatment nurse phoned me to say I could stop taking the drugs. The treatment had failed. I can't really tell you whether this was a more shocking bit of news then when I was informed that I had hepatitis C. I do know that I couldn't think of anything for 2 days. I was in almost a vegetable state. I had just spent the worst 6 months of my life for nothing. I had lost 17 pounds, you could see my scalp through my grey hair

and was greased up like a pig for a barbeque to help with dryness.

At my appointment with the liver specialist after treatment I was told to see my family doctor every 6 months to complete a blood test and to have an ultrasound done once a year. We made an appointment for 18 months ahead to see how I was doing. I sort of felt like I was getting dumped, but really they could do nothing more for me.

Within 4 weeks of stopping treatment I was almost back to the physical shape I was in before the treatment but I had lingering effects for at least 6 months afterward. By the time my 18 month revisit with the specialist came around, I was fully back in shape and actually felt pretty good. My liver enzymes were in control and my ultrasound was OK. But I still had a very high virus count and a badly damaged liver. She asked me if I would like to enter a trial treatment program. I agreed even though I knew what to expect.

After meeting with the treatment nurse and undergoing some initial testing I started my second round of treatment in September 2010. This included the interferon injections once a week, 1200 mg of ribavirin each day and a dose of the study drug in pill form in the morning and evening. This was a blind study so I may have been taking a high dose of drug, a small dose of drug or a placebo. I still do not know which I was taking. I have since found out the study drug was boceprevir.

The initial weeks were just like the first time around: physically bad to very bad. However, there was a difference with this treatment. I suffered from severe depression and confusion. The confusion was a problem with my job. My job requires me to make decisions that impact the safety of other people. I made it through the initial 4 weeks but it got to the point where I couldn't make simple decisions and my mind was wandering constantly. These symptoms required me to inform my employer and go on short-term disability. I knew this treatment was affecting my job and my home life, but I kept going. I found an excellent website where I found other people who were going through the same things I was. The website is hcvsupport.org and I would recommend that anyone with hepatitis C check it out.

I thought I was winning. My December blood test showed that I had gone from an initial virus count of over 7,000,000 to 642, but my January blood test result was one I would rather forget. The Monday after taking the test my treatment nurse emailed me and said the virus was undetectable. For one (Continued on page 5)

Source: www.scynexis.com/scy-635-restoresthe-bodys-innate-immune-response-to-hcv/ No vember 7, 2011

PF-03491390

PF-03491390, a caspase inhibitor, lowers AST/ALT. Liver damage is indicated by abnormally high AST and ALT enzymes, and more programmed cell death and activated caspases are noted as well. This trial in 204 HCV patients tested them in 4 arms: 1) placebo, 2) 5 mg, 3) 25 mg, or 4) 50 mg, taken orally twice daily for a maximum of 12 weeks. AST/ALT tests were performed each week, and good drops in AST/ALT levels occurred from the start in those taking the drug. AST/ALT levels returned to pretreatment levels when the drug was stopped. Increased doses did not help. The most common side effects were fatigue and headaches.

Source: 29 April 2010 in Aliment Pharmacol Ther, 31(9): 969-78.

<u>http://</u> chronicfatiguesyndrome.researchtoday.net/ archive/6/4/1621.htm

DACLATASVIR / TMC435 / pegIFN / RBV

Bristol Myers-Squibb and Tibotec have agreed to work together to investigate the benefits of combining the NS5A inhibitor daclatasvir (BMS-790052) with the NS3 protease inhibitor, TMC435 in a Phase II trial expected to start in the first part of 2012. Researchers will be looking for SVR at 12 and 24 weeks post treatment in GT1 patients. There will be 3 once-a-day treatment arms: 1) daclatasvir/TMC435/pegIFN/ RBV; 2) daclatasvir/TMC435/RBV; or 3) only daclatasvir/TMC435. Their goal is to find an all-oral treatment for hepatitis C.

Source: 12/02/2011 www.businesswire.com/ news/home/20111202005035/en/Bristol-Myers-Squibb-Enters-Clinical-Collaboration-Agreement -Tibotec

PSI-938 ON HOLD

During regular monitoring of patients receiving 300 mg daily of PSI-938 on a clinical trial, it was discovered that they had elevated liver enzymes. There were no irregular another arm of the same trial. Gilead Sciences has just recently acquired Pharmasset, the developer of these drug, and is handling the clinical trials. They have stopped all of the arms of its Phase IIb trials that use PSI-938. Other drugs have recently been put on hold, such as HCV-796 in 2008, produced by ViroPharma and Wyeth. The same happened

es, and with Idenix's IDX320. Elevated liver enzymes are fairly common with many drugs, but in hepatitis patients, they can be a serious cause for alarm. Investors are worried that Inhibitex's INX-189, somewhat similar to PSI-938, could cause the same sort of problems, but no liver damage has been seen yet, and some experts have pointed out that there are important differences from Alberta and an outdoor enthusiast, she between the two. We shall see...

Source

www.natap.org/2011/HCV/121711_01.htm

ABT-450 + ABT-333 or ABT-072

Abbott announced data from its clinical trial suggesting patients could achieve an SVR without IFN and with shorter treatment time, hopefully in 90% of subjects. 44 treatment-naïve subjects were enrolled and given ABT-450r (ABT-450 boosted with ritonavir) plus either ABT-333 or ABT-072 and RBV (ribavirin) during 12 weeks. All patients still being treated at 12 weeks had an EVR, and of the 10 patients who have been tested 24 weeks after finishing the 12week trial, 9 achieved an SVR. The FDA has granted fast track status to the regimen. It is expected to be available to the public by 2015. The company is developing a 4-inone pill including ABT-450r 2 polymerase inhibitors, and RBV.

Sources: www.pharmpro.com/News/2011/10/ Business-Abbott-Announces-Positive-Data-from-Mid-Stage-t 24 Oct 2011 and www.nature.com/nm/journal/v17/n12/full/

MEET CHRIS!

Chris has been one of our most faithful volunteers. She has now retired from her work with us, and is, unfortunately for us, moving on to other ventures. Originally

was with HepCBC for over 15 years! Recommended highly to us by Volunteer Victoria, Chris was a real treasure, because unlike so many of us, she has energy to do things. That is why it is so good to get our families and friends involved in volunteering for our cause.

Chris was the person in charge of updating and guarding our database so that everyone's information was kept confidential and your data doesn't get passed on to mailing lists and nasty things like that. (Don't worry: That privacy will still be assured.) She was also at one time our excellent volunteer coordinator, a job which she now does professionally. Chris was also a member of the board for a period of time.

After a time away from BC-but not away from us-she moved back to her adopted home, residing in beautiful Sidney, BC. She continued to help us via email even when she was living out of town.

Thank you so much, Chris, for your wonderful dedication to our organization and to our community's cause. We will miss you, and hope you return some day.

I H CONVERN RE DAM MY E DINY NE ROD RUDAY E

Proudly presented by HepCBC Discussion of the CASL Consensus Guidelines 2012 Begbie Hall, Royal Jubilee Hospital 2101 Richmond Avenue, Victoria, BC March 2, 2012 9:00 AM-3:30 PM

The purpose of the forum is to explore the benefits of the newly approved protease inhibitors, and to raise awareness about the 2012 Management of Chronic Viral Hepatitis: Consensus Guidelines, a compilation developed by CASL, the Canadian Association for the Study of Liver Disease, of scientifically proven assessments of best practices.

Speakers:

Rob Myers, MD, FRCPC, Professor, Liver Unit, Gastrointestinal Research Group, University of Calgary. AHFMR Clinical Investigator, Director of Calgary's Viral Hepatitis Clinic.

results in patients receiving PSI-7977 in Mel Krajden, MD, FRCPC, Director of BC Hepatitis Services, BCCDC, professor of pathology and laboratory medicine at UBC, adjunct scientist with Canadian Blood Services.

> John Farley MD, Internal Medicine and Infectious Diseases; Infectious Diseases Consultant for the Pacific Region for Correctional Services Canada.

Chris Fraser, MD, Medical Director and Principal Investigator, Cool Aid Community Health Centre, UBC Faculty of Medicine

with Roche's danoprevir with the high dos- **REGISTER NOW:** info@hepcbc.ca 1-250-595-3892 ATTENDANCE IS FREE

HEPC.BULL **JANUARY 2012 ISSUE NO. 151**

(**MY EXPERIENCE**—*Continued from page 3*)

morning I was very happy and looked forward to the future. Monday afternoon the treatment nurse phoned and said she had sent the wrong results and mine were not in yet. But I was still hopeful. Tuesday morning she phoned again, told me that the virus count was back over 20,000 and to stop taking the study drug as I would build up a resistance to it. Talk about your emotional roller coaster. I was very discouraged and considered stopping the treatment, however if I stopped before the 24 week mark, I would not be eligible for future studies and there was still a slim chance that the standard treatment would work. I thought that a slim chance was better than zero chance, so I continued on to the 24 week mark. An added bonus to this treatment was that I cannot take any of the protease inhibitors for future treatment as I showed that I was resistant to the drug.

At the 24-week mark I stopped taking all the treatment drugs and tried to wean myself off the antidepressants. I found that I could not stop taking them without putting myself in a very bad mental state. I started taking the antidepressants again and my family doctor added another drug to supplement them another bonus from my second round.

It has been approximately 6 months since I stopped treatment, and again I feel good. But my virus count is back up to 6,200,000 and I know I only have a small amount of healthy liver to work with. I try to keep upbeat, exercise and eat healthy. I take it day by day and appreciate the time I remain healthy. Even though I suffered considerably through treatment, if I was asked to try another treatment I would jump at the chance.

In closing I would just like to mention that treatment is different for everyone. Some people have only minor side effects and some people have no side effects at all. I would encourage anyone who has a chance at taking treatment to take it. Although I was not successful with the protease inhibitors, the majority of people who take this treatment do beat this virus and achieve SVR. I wish good luck to anyone who starts or is in treatment.

-gotoguy



(**HERB MOELLER**—*Continued from page 1*) support group in BC.

Eventually Herb started to recover from his burns, but his energy level was very low. At that time people were just beginning to hear about blood tainted with HIV and Hep C. No one really knew what Hep C was yet except that it wasn't good. Herb was diagnosed with Hep C in 1989. He received the "gift of life" from 120 blood transfusions during the time he was in the hospital.

He immediately began researching the disease, treatment and how he could get involved. Well, involved he got! He started the BC chapter of the Hep C support group and sat on the volunteer board of directors to the Vancouver Richmond Health Board. By sitting on the board, he was trying to affect change in a medical system that was cutting corners and letting innocent people fall by the wayside. Herb also went to Toronto and sat on the board of directors for the dissolution of the Red Cross and the creation of the Canadian Blood Services. This was monumental to him, as it meant he could now have a say and a voice for how blood products are now tested and collected, stopping the improper handling and testing of blood products that harmed so many.

Once Justice Krever released his findings on the contaminated blood scandal, Herb, along with Klein Lyons, had all he needed to join forces and begin the process of initiating the cross-Canada class action lawsuit for tainted blood recipient victims. Through this process thousands of people who were infected with Hep C were finally compensated but more importantly, validated.

Behind all of Herb's volunteerism was a man who lived many lifetimes in one. In search of alternate treatment, he spent time in Peru and canoeing the Amazon river. To begin to write here the extent of all he accomplished is not possible. I can tell you that he was a force of nature who would never put off what he could do today until tomorrow. "Can't" was a word that did not exist in his life. "How?" replaced it in so many moments when he could have given up.

Herb was instrumental in helping Rick Hanson create the Rick Hanson foundation and Rick asked Herb to work with him. Herb was too ill by this time, so he had to decline with regret.

He was in stable health and was looking forward to a trip to New Zealand with his wife Dianne and to a family holiday with his daughters and their husbands in Hawaii. He suddenly fell ill with complications from Hep C and ended up in the hospital on Sep-

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

tember 28th of last year. He was not on the transplant list until after he ended up in VGH, and after 5 1/2 gruelling weeks he passed away on November 6th, with his wife Dianne sleeping beside him.

He will be remembered as a man who never thought anything was impossible and who never gave up hope for himself or others, as a husband who loved his wife and best friend Dianne from the minute he met her, travelled with her to many exciting places, cherished her undying love and support, and as the greatest Dad who taught his girls to be honest, stand tall with integrity and to never give up on themselves, and most importantly as a man who gave his friends and family more love and support than any one person can ever be expected to give.

Karen Stacey Founder happyliversociety.org karen@happyliversociety.org www.canadahelps.com #720-999 West Broadway

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Hep C, the Silent Killer

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





FIGHT Against Hepatitis C

Open Group — fightagainsthepatitisc@groups.facebook.com



Transplant **Support Group of British Columbia**

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

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

HCVEDGE Get the edge on managing your He





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/

1986-1990 VICTIMS

The Joint Committee of the 1986-1990 Hepatitis C Settlement Agreement would like to meet with people who are class members in this settlement to discuss what is working well in the settlement, and what could be improved now that the settlement is undergoing a review for financial sufficiency which takes place every three years under the terms of the agreement.

If you are a member of the 1986-1990 Hepatitis C Settlement Agreement, please contact me if you are willing to be part of such a meeting. If you know any members, please pass this message on to them.

The best way to contact me is by email at smatthews@cfmlawyers.ca. can also be contacted by telephone at 1800-689-2322.

Thank you very much for your help.

Sharon D. Matthews, Partner CAMP FIORANTE MATTHEWS 400 - 856 Homer Street Vancouver. BC V6B 2W5 D. 604-331-9522 T. 604-689-7555

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witter

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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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CONFERENCES

The International Liver Congress 2012 The 47th Annual Meeting of EASL 18-22 April 2012 Barcelona, Spain http://www.easl.eu/ the-international-livercongress/general-information

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

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

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

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

AASLD - The Liver Meeting 2012 9-11 November 2012 Boston, Massachusetts http://www.aasld.org/conferences/meetings/ Pages/default.aspx

HEP C TELECONFERENCES

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

EPREX ASSISTANCE PROGRAM

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

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

PEGCARE

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

A 24/7 Nursing Hotline and bilingual assistance is available, at no charge. Other services are access to live translation services (150 languages) and injection assistance from registered nurses. Ask your doctor or nurse to enroll you in PegCARE. It's an easy single-page form to fill out, which they will provide. PegCARE: 1-866-872-5773

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) 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

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

sarah.sullivan@avi.org 250-338-7400 • Nanaimo Meetings 4t^h Tues monthly, 1"15 pm 201-55 Victoria Rd, Contact Anita 250-753-2437

anital.rosewall@avi.org for details.

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

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

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

Burnaby HCV Support Contact Beverly 604-435-3717 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 info@hepcbc.ca, www.hepcbc.ca •Victoria Peer Support: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9AM-10PM. 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 counselling 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 Contact midislandhepc@hotmail.com

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

hepctxpeersupport@hotmail.com

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

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

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

Courteney: 2nd Fri monthly 1PM, Dropin, Comox Valley Nursing Centre (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 Info, harm reduction, support, drop in, clinic. 10697 135A 3698. 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 Contact Bob 519-886-5706, Mavis 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 920-1601, hivaidsconnection.com 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, <u>ly@publichealthgreybruce.on.ca</u> 1after). Contact Carolyn cshowler@coolaid.org

YouthCO HIV + Hep C Society of BC. Drop -in T&W 12-3, Fri. 9-12. Call to sched ule appts M-F 10-6. 205-568 Seymour St, ga, Caledon) 905-799-7700 Vancouver 604-688-1441, 1-855-YOUTHCO Support Staff: Stewart stewartc@youthco.org, Briony nym@youthco.org www.youthco.org

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

OTHER **PROVINCES:**

ONTARIO:

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

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

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

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

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room, 659 King St. East (Enter off King St) Kitchener. 519-743-1922 or waterlooregionhepcsupport@gmail.com

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

Owen Sound Info, support. Contact Debby Minielly dminiel-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257. www.publichealthgreybruce.on.ca/

healthlinepeel@peelregion.ca

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

bpotkonjak@liver.cawww.liver.ca

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

Unified Networkers of Drug **Users Nationally** undun@sympatico.ca

York Region Hepatitis C Education Group 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 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!

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