

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

## **WORLD HEPATITIS DAY 2010 EVENTS**

Dr Alenezi brought free testing into the community at Vancouver's Testing Fair on May 26, 2010.



From Courtenay, BC: May 18<sup>th</sup> was a busy day for a select group of HCV peer group volunteers. Karen, Greg and Rick (along with AVI [AIDS Vancouver Island] support) hosted a very successful HCV awareness barbeque/chili lunch at Simms Park in Courtenay.

The attendance was spectacular! Well over 100 people came by to have a healthy lunch and chat with the well-prepared and informed peer group about HCV and the issues around living with the dragon. Though the day was cool and blustery, the warmth of the welcome to the event and the hot lunch soon had everyone comfortable and laughing.

Served up with the chili and hot dogs were fresh fruit and veggies along with a healthy dose of HCV facts and issues, both local and global.

Rhonda and Miranda, outreach workers for the homeless from The Wachiay Friendship Center, brought a display of some of the services and equipment they can offer those in need. The tent and sleeping bags drew a lot of attention, as well as the information the workers were able to provide around rent subsidies and availability of accommodations in the valley.

This event was also used to launch a HCV support group that will meet Thursdays from 1:00 to 2:30 at AVI. The hard work and preparation for this event showcases the drive and dedication of this new peer group to improve the HCV awareness and the quality of life in the affected community. Their understanding that shared experience and resources will strengthen the support group

they are leading bodes well for the future of the group.

Once again we find a wonderful example of a few dedicated people finding ways to work together and overcome personal issues to produce something far greater than themselves. It is in this way that the world can be changed for good.

HepCBC took part in the Victoria Day Parade on May 24th in

Victoria, BC



Office Manager Ana Maria Medina and three volunteers manned the booth.

Speakers included Victoria City Council member Philippe Lucas, who contracted

hepatitis C at the age of 12; he shared his concern and fears about how his hepatitis C viruspositive (HCV+) con-



dition will impact his family and loved ones over the short and long term.

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# "N.L." **Died: June 9, 2010**

Our new friend "N.L.", age 51, died at 7 AM today in Royal Jubilee Hospital Hospice from complications of hepatitis C. She first called HepCBC's office asking for support on Monday, May 31st.

Two HCV+ volunteers from HepCBC, along with a couple of her long-term friends, supported and encouraged her over the next few days as she rapidly deteriorated, ended up in hospi-

(Continued on page 5)

#### DONALD THIEL 2010

We received a phone call from Donald's wife, kindly letting us know that he passed away. Donald, of Victoria, BC, was one of our original subscribers and donors—a lifetime member of HepCBC.



# SHERYL BINT **BERESFORD** October 24, 1954-May 22, 2010

Sheryl (Windsor, ON) was a member of the HepCan Yahoo group. She is missed by her family, including her son Jeremy and daughter Melanie, their spouses, and their children Nicole, Matthew, C.J., Aimee, Megan, Joshue and Jaxx. Donations for hepatitis research would be appreciated by her family.

**HEPC.BULL JULY-AUGUST 2010**  **ISSUE NO. 135** 

#### 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 1.I6

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You may also subscribe on line via PayPal at

SUBMISSIONS: The deadline for any contributions to the hepc.bull<sup>©</sup> is the 15<sup>th</sup> 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.

www.hepcbc.ca/orderform.htm

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:**

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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 FAQ Version 8.3 is NOW AVAILABLE, Version 8 is available in FRENCH and Version 7.1 is available in SPANISH. The ENGLISH version includes the latest 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 1997-2010; 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 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.

HepCBC thanks 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, Schering Canada, Shoppers Drug Mart, and the Victoria Conservatory. 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.

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 15<sup>th</sup> 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.

# TIP OF THE MONTH:

It's never too early to make your last Will & Testament

# Got Hep C? Single? Visit:

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

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

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

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

www.dialadietitian.org

Dietitians of Canada: www.dietitians.ca

# MEET NEW FRIENDS!

We need experienced board members to occupy key positions. Also needed: summarizing, telephone buddies, translation English to Spanish. Please contact us at (250) 595-3892 or info@hepcbc.ca

# PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

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# **Hep C Sites** facebook



# **Against Hepatitis C**

http://bit.lv/cvXCGK



http://bit.ly/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 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/

#### GHT YEARS OF INTERFERON PART 2

By David Squires



my story, what I have gone through, and what I face today. I did not clear the virus, but I still have hope that someday this disease will be defeated."

As I said last month, in December 1998, I was dying. I was in jail, literally dying from this disease, and could be heading back to the Big House, so in my mind and with every fibre in my body I cried out, "If there is a God, show me!" There was no burning bush and God didn't talk to me and say everything was going to be alright—no, nothing like that. But what did happen was that I went to a men's recovery centre and I did see God working in my life.

Right off I was getting tested to see where I was at because after months, I was still sick. My stool was never firm-always loose—so my doctor had stool samples taken and all they could say was that it was probably my liver. So again I had a biopsy and it showed 3+ damage and 3+ inflamma-

My hepatologist had said, "We don't usually put people on treatment with as severe liver damage as you have, but if you would like to try, it's up to you. It may or may not help.'

Well I didn't see a whole lot of options, so started my journey with interferon and ribavirin. I was now taking these new age drugs that didn't get you high!

I took treatment for over 13 months, including 6 pills a day. I have to say this because it really gets me. I'd get a vial for so many injections (every 3 days) and always there would be about half a dose left over! Why would they do that? Drug companies! Man, what a waste! It took almost a year on treatment for them to even measure my viral load. I'm assuming they didn't have the technology to go that high. It must have been in the hundreds of millions, or higher!

I was lucky. I guess you can call it that. After 13 months pegylated interferon-Pegintron—was available, so I started on that. It was one shot every week with 6 pills a day. Only after 9 months did my viral load come down to the 600,000. By then it was almost 2 years of non-stop treatment and that new treatment had brutal side effects. I just couldn't take it anymore and I was hearing of a new drug that was having better results with my genotype 1A.

I believe it was in 2002 when I was referred to Stanford in California. I believe it was still in trials but I started on Pegasys (Roche's pegylated IFN) and within a month, I cleared the virus! After 9 months, however, I was again having a hard time. I

From last month: "This is quit treatment, but I truly believed that it would stay cleared. After 2 weeks, my viral load returned and was up in the millions! I felt like a quitter. I really beat myself up, thinking, "If I'd only gone 3 more months on treatment it might have been cleared for life!"

> I took a year off and swore I'd go though whatever it took when I got back on treatment! What I have to say is that in my first treatments I started juicing and eating a lot of veggies, and I had started Yoga and Pilates. I had a pretty vigorous workout program, and no matter how bad I felt I went to the YMCA. I truly believe this is why I'm still alive today. I had the mindset that it was helping me immensely and I was watching my diet and exercise, and I would truly push myself. I had quit smoking, as well (one of the smartest things I'd done in my life), so because of all of this, I was learning a healthier way of life.

> I do have to also say that my treatments didn't just affect me—by no means! They especially affect those you live with.

#### (WORLD HEP DAY 2010—Continued from page 1)

On April 29th, Victoria's Mayor Dean Fortin presented the proclamation declaring

May 19<sup>th</sup> Hepatitis Awareness Day in the city to HepCBC Board and staff members.

\*\*\*\*\*

Surrey's mayor also proclaimed May 19<sup>th</sup> Hepatitis Awareness Day.

HepCBC Fraser Valley and South Fraser Services held a 3-hour luncheon and candlelight vigil at Positive Haven remembering those from our community who have passed away.



Elder Tom Oleman opened the event with his song.

Speaker: Dr. John Farley



Speaker: Fran Falconer



Sam Mohan guided us through the candlelight

FROM PEPPERMINT PATTI'S FAQS VERSION 8.3

#### HOW CAN HCV AFFECT MY EMOTIONAL LIFE?

### HOW IS DEPRESSION **RELATED TO HEPATITIS?**

Many emerging illnesses, before they have gained acceptance by the medical community, have initially been discounted as being hysteria, depression, etc. Before the hepatitis C virus was identified in 1989, many of its symptoms were correlated to depression, and many un-read physicians today still believe that HCV is normally asymptomatic.

Another issue is that HCV patients can get "secondary depression" if their lives have been disrupted because their illness has interfered with their job or their social or family life. This indirect consequence of the illness may be taken by some medical professionals as indicating a cause rather than an effect of the observed symptoms.

An article in *Hepatology*, June 2000, p. 1207-1211, Vol. 31, No. 6, "Hepatitis C, Interferon Alfa, and Depression," the authors note that "two separate lines of evidence support an association between HCV and depression. First, patients with psychiatric disorders have a higher prevalence of HCV infection. Second, patients with that are most important to you. chronic hepatitis C may have a higher prevalence of psychiatric disorders including depression."

#### **DEALING WITH A** CHRONIC DISEASE

Many people never fully appreciate their health until they suddenly have to face the fact that they now have an illness that is not going away. This new state of affairs can make you feel angry and depressed, and it's hard to get beyond the question "Why me?"

People commonly work through what Dr. Elisabeth Kubler-Ross has identified as the five stages of adjustment as they learn to accept a chronic illness. There are feelings of denial, anger, depression, bargaining and acceptance. All of these feelings are natural, and there is no fixed time schedule for your passage through the stages. Many times the stages overlap.

#### **ACCEPTING**

Realize that you have to experience the pain in order to work through it. Don't try to hide the physical and emotional hurt. Experience the pain and then let it go. Don't be afraid to express the hurt you feel.

Learn to laugh; try to see humour in your situation, and to enjoy the simple pleasures of life.

Keep the lines of communication open. It helps to know that someone understands how you're feeling and can help bear the load.

Don't neglect your personal "self-time." Being alone can provide a personal perspective from which calm, wise judgments, opportunities for personal growth, and a new optimism about life can emerge.

Don't hesitate to seek counseling for your special situation.

Some problems are too big to work through on your own.

Take responsibility for yourself and realize that you DO play a role in your illness.

#### **FATIGUE**

Fatigue is a common symptom of hepatitis, and it can become worse while you are taking treatment. Here are some things you can do to help yourself feel better:

- 1. Get plenty of rest. Sleep more at night and take naps during the day if you can. Try to schedule regular rest periods each day.
- 2. Limit your activities: Do only the things
- 3. Delegate tasks. Don't be afraid to get help when you need it. Ask family and friends to pitch in with things like child care, shopping, housework, or driving.
- 4. Eat well, and be sure to include plenty of healthful foods.
- 5. When sitting or lying down, get up slowly. This will help prevent dizziness.
- 6. Don't stand when you can sit.
- 7. Plan your activities and assemble everything before you start.
- 8. Reschedule daily tasks so you do some only 3 or 4 times a week and have time to rest each day.
- 9. Use a cart, wagon or basket to carry things from one part of the house to the other to eliminate retracing your steps.
- 10. Sit on a stool in the bathroom while shaving or applying makeup. Prop elbows up on counter if you can.
- 11. Use warm, not hot water for baths or showers. Hot water increases muscle fatigue.
- 12. If your fatigue is severe, think about asking your doctor for a handicap sticker for your car. 13. Shop when you are at your peak energy.
- 14. When shopping alone, ask a grocery clerk to carry out groceries.
- 15. If you arrive home from grocery shopping tired, put away only the perishables. A family member or friend can do the rest.
- 16. Shop by phone whenever possible.
- 17. Avoid peak shopping/traffic hours.

#### **IRRITABILITY**

Anger is a known side effect of liver disease. And just being sick and tired and achy just about all the time does not help. What helps is slowing down. But most of us can't. If we do we won't be able to eat and pay the rent.

People with symptomatic HCV should be on disability pensions. They should have home care, and day care provided for their children. They should have help cleaning their homes and doing the shopping and cooking.

When you are tired and achy and nauseous and dizzy, getting caught up in the day-to-day aspects of life becomes increasingly difficult. Often you feel like you have cement in your blood. You feel so heavy.

So when you feel overwhelmed by the welfare system, or a doctor, or a bank clerk or whomever, it's no wonder you just might explode.

The best thing is having a friend who understands. Joining a local support group really helps, too.

### **TABBOULEH**

#### **Ingredients:**

3/4 C. dry bulgur wheat per person, cooked in 1 cup water per person.

1/4 C. dry garbanzos per person soaked overnight, then cooked (or canned) Tomatoes, 1 per person

Add to taste:

Celerv

Avocados

Green onions

Parslev

Optional: mint, cinnamon, currants, nuts, curry

#### **Dressing:**

Olive oil

Lemon juice

Soy sauce

Garlic

Pepper

#### **Preparation:**

Chop vegetables and mix with cooked garbanzos and bulgur. Add spices, optional items, etc.

**Dressing:** Mix equal amounts of olive oil and lemon juice, then add soy sauce to taste, so that you make 1/4 to 1/3 C. of dressing per person. Serve cool or cold, as a salad.

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#### ("N.L."-Continued from page 1)

tal, and then less than 24 hours ago, was transferred to hospice. Her family (an adult son, 5 sisters, a brother, and their mother) flew out from Alberta on Monday, June 7th. This has been a tough time for everyone.

For me, there were many lessons learned in this short time: about the extreme appearance, feelings, mindset, and behaviour of people with end-stage liver disease, the heartbreaking stages of liver failure -- and most riveting to me personally, how these patients and their families are perceived and treated by the various layers of our medical system. The cleaning and disposal of the body for hepatitis C patients is a little unique, for the safety of those who handle the body.

The first and foremost thing we can all do immediately to protect ourselves and our families is to get all our affairs in order, everything up-to-date, with every i dotted and t crossed(!), to make it easy for all our possible caregivers to know our final wishes, and legal for them to make sure they are

followed. Second thing: Keep your family informed of any changes to your health, and when the time comes that you think your liver may be failing. don't be afraid to contact your



family and tell them your situation honestly! Don't put it off; you may be alive but unresponsive by the time they come. These are hard lessons, and I'm so sorry about this particular sweet lady's death. The hardest part was seeing all her sisters that looked like healthier versions of her, and then seeing photos of her as a bright, delightful little girl. Anyway, let's all be careful and look after one

Because of stigma against those with hepatitis C and out of concern that additional pain could result for the patient's family, we chose to conceal both the patient's and the volunteers' names. Also, note that this patient, like so many other women with hepatitis C, had RH-negative blood, and received a RhoGAM (a blood product) injection during a 1982 pregnancy. RhoGAM is not considered a risk factor in Canada, but perhaps this should be studied further. Take care, all.

Big hugs,

Cheryl cherylreitz.hepcbc@gmail.com



# **HEP C AND ME: THE INCREDIBLE JOURNEY!**

by Petra Hoffmann



Isn't it strange how life just plays itself? We first met 12 years ago. It is a story unto itself as to how he found me these medications. again, 2 years ago in June. I had received my hepatitis C diagnosis just 2 months earlier, in April. I am now

just over a month away from finishing the http://www.youtube.com/petrabilities Pegasys treatment, and I have been severely sick. Time and life being as it may, Eli, my true love, received his own diagnosis today. What the doctors had first thought was apparently a gastric ulcer when he ended up in the hospital a couple of weeks ago, turned out to be Non-Hodgkin's Lymphoma, a blood cancer. Great. It had felt weird enough that we had ended up going in for our blood work together, but now we were going to be on chemo together as well.

Although I realize in my head that this is not about me now, and that I should be strong for him, I cannot contain my own emotions as I sit here, sick, today. The meds are very difficult to work with, and yet it is strange how some days they make things seem easier, simpler. I am finding it a complete impossibility not to feel sorry for myself and think of my own plight. Here I am, just over a month away from having an entirely new life, one that I have envisioned nearly every day lately.

I have seen cancer before, and the fact that Eli is going to have to take this poison too, just eats me up inside. I am feeling helpless, useless, clueless, scared, angry, disgusted, hateful, cheated, selfish, but mostly guilty for feeling all these things, and being so self absorbed.

I feel especially guilty for not being able to take care of him, and that I do not even care whether I get buried alive in dirty dishes and all these damned empty water bottles! I am battling self loathing. arrangements for a good friend to come over and bring me some wine, which I know I am not supposed to have, and which I am so selfishly going to drink in

#### ADVERSE EVENTS

Report problems with medical prodand serious adverse events.

www.accessdata.fda.gov/scripts/medwatch/ medwatch-online.htm

front of Eli. Poor, sleeping, Eli, how innocent and sweet he lays there. This is now his story.

I prefer the days where I feel nothing on

I know that we will get through this, and that everything is for a reason, and that it will make us stronger. I know....

Please feel free to follow my journey on and visit http://www.petrabilities.com/ for more information.



# **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<sup>th</sup> 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

If you are receiving this news-The worst part is that I have already made letter by snail mail but have a computer and/or 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

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#### **BLUBERRIES FIGHT FIBROSIS**

According to the results of a study published in the World Journal of Gastroenterology on June 7, 2010, a research team from not they were able to put more money into Guiyang Medical College gave blueberries to lab animals with liver fibrosis (scarring), which was induced for the purposes of this research. Blueberries were able to reduce 2002. He received tainted blood in 1985, a liver enzymes and hyaluronic acid, inhibiting inflammation of the liver and lipid (fat) peroxidation. More studies are needed. Blueberries are also beneficial for the cells of the retinas and the brain, and they have an effect on tumour cells. Until now there were few studies of the effects of blueberries on liver diseases.

www.wjgnet.com/1007-9327/full/v16/ Source: i21/2657.htm

#### ZALBIN (Albuferon)

Human Genome Sciences and its partner Novartis received discouraging comments from the US FDA in response to their application to approve Zalbin, which is interferon fused with human albumen so that it can be injected once every 2 weeks. Human albumen is a blood protein that stays in the circulatory system for about 19 days.

The company believes that approval is not likely, although the FDA has not submitted a final decision. The company withdrew its application for approval of the product in Europe last April. It is now reviewing the possibility of a dosing schedule of once every 4 weeks, since there were good results from the Phase 2b trial using that schedule.

Editor: Personally, I consider this sad news. The product, which I would expect to be safer, has been used here in Canada in clinical trials. I know a few people who have responded to the treatment, but here is the comment of one of those people. Judge for vourself:

"When I did [the trial] there were 4 computer generated choices and I got 1200 mcg of Albuferon every two weeks for 44 weeks in 2005/2006 and it was all I could do to get that far...Then I was 'under the influence' and didn't know if I should stop. I couldn't think, then didn't care, and because of the sides they took me off it. I always believed they could have stopped me sooner and maybe I would not have so many problems now. I still have recurrences of some sides, and some things that were made worse by the treatment are still getting worse. It did deactivate the virus and nearly me, too. I would never do it again."—B

Source: www.ibtimes.com/ articles/28415/20100614/humangenome-sciences-fda-bla-zalbinjoulferon-novartis-hepatitis-c.htm

#### WILL WE BE PAID?

When asked on May 31 of this year, Health Canada didn't respond to whether or the class action settlement for those outside the 1986-1990 "window".

Bob Green died from Hep C back in month before his kidney transplant. His family was told that most of the money for those eligible for compensation cannot be paid because the funds have been spent.

The government had \$1 billion to pay the victim's claims. The money was divided into two parts: a general fund and a pool of money for those most likely to need coverage for lost income and help for their dependants.

Approximately \$250 million is still left in the general fund, but it isn't known whether or not the money from the second pool will be available to pay claimants if the general fund isn't enough.

Health Canada did state that it's the lawyers' job to ask the court to approve a transfer of funds, and that while they are sympathetic, they have not been notified of any such request.

Source: www.thespec.com/article/779445 June 01. 2010

## **BREAKING NEWS: GREGG ALLMAN**

Rock 'n' roll Hall of Famer Gregg Allman (Allman Brothers Band) underwent successful liver transplant surgery in late June at the Mayo Clinic in Jacksonville, Fla. He was up on his feet by the evening. His manager Michael Lehman told reporters, "He's psyched to put this time of his life behind him and have a chance again to feel really healthy and good, and hopefully live for many more years to come," Lehman said.

The musician received Hep C treatment in 2007, but the damage couldn't be reversed. He was on the transplant list longer than the average patient, and finally got The Call late Tuesday afternoon. He was expected to be in the hospital for about a week. He will be staying near Jacksonville for about 3 weeks, and expects to be back touring in November. He hopes to be able to walk his daughter down the aisle at her wedding on July 26.

"Every day is a gift, and I can't wait to get back on the road making music with my friends," he was quoted as saying.

Source:: http://www.greggallman.com and http:// www.allmanbrothersband.com

# CONFERENCES 2010

#### XIII International Symposium on **Treatment of Viral Hepatitis**

1st Meeting on the Management of Liver Cirrhosis of the Brazilian Society of Hepatology 14 - 17 July, 2010

Bahia Othon Palace Hotel (Simultaneous translation into English)

Tel: (55) (71) 2104-3477 Fax: (55) (71) 2104-3434

E-mail: eventus@eventussystem.com.br www.hepatologiadomilenio.com.br.

#### **Australasian Viral Hepatitis Conference 2010**

6 - 8 September 2010 Sebel Albert Park Melbourne, Victoria, Australia Tel: +61 2 8204 0770 Fax: +61 2 9212 4670 Email: info@hepatitis.org.au

#### **Hepatitis 2010 Viral Hepatitis World Congress**

13-14 September 2010 St Hilda's College, Oxford, UK Hepatitis2010/Home.htm Registration deadline: 5 August 2010 Contact: Dr M Sohail Tel: +44 (0)1865 275743 Email: HepatitisOxford@gmail.com www.libpubmedia.co.uk/Conferences/ \*\*\*\*\*\*\*\*\*\*

#### The Liver Meeting 2010

AASLD's 61st Annual Meeting 29 October -2 November 2010 John B. Hynes Convention Center Boston, Massachusetts Registration: Mid-July www.aasld.org/thelivermeeting/

## **Interdisciplinary Viral Hepatitis Education Workshop**

BC Hepatitis Services September 23 & 24, 2010 Holiday Inn Vancouver Center 711 West Broadway, Vancouver, BC

For health and social service providers, who want to increase their knowledge about viral hepatitis and improve prevention and care services.

Please register ASAP Contact Carolyn Timms carolyn.timms@bccdc.ca (604) 707-2423 1(866) 660-1676.

Forms: http://www.bccdc.ca/NR/rdonlyres/ C68426AA-AABA-44E2-A99E-D195BF9AE6EF/0/2010IVHEWRegistrationFilla bleForm.pdf

# THE ACQUISITION OF **ERYTHROPOIETIN**

#### CORRECTION:

In the previous June article named "The Acquisition of Erythropoietin," I, the writer A. York, would like to re-submit Step 9 to read as: "Submission of this form would then complete my acquisition".

Note: As fellow HepCer's, I am sure we all are aware of daily, weekly, monthly and yearly changes within our body chemistry and diagnosis. I am most definitely one of these. Subsequently our medications may have to be adjusted to meet these changes accordingly.

I thank you, and apologize for any misunderstandings my previous submission may have created.

Sincerely, A. York

# J. Lemmon **Contact:**

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

# INTERFERON UPDATE

On September 1, 2009 the U.S. Food and Drug Administration (FDA) announced that label warnings for interferon alpha products were updated to reflect some newly recognized safety issues, namely stroke, retinal detachment, peripheral neuropathy, and pulmonary hypertension.

# **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. \$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-

#### 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. 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 any financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or co-payments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients homes or to the clinics.

# **NEUPOGEN** VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependant on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge. Please note that Amgen will only provide Neupogen to patients on a compassionate basis as long as it is prescribed and dosed in accordance with the approved product monograph. This service is accessed through the Victory Program: 1-888-706-4717.

# **COMPENSATION**

#### **LAW FIRMS**

#### 1986-1990

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

Fax: 1-604-609-6688

#### Pre-1986/ Post-1990

Klein Lyons Vancouver, BC 1-604-874-7171. 1-800-468-4466, Fax 1-604-874-7180 www.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 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 PegAssist Reimbursement 1-888-332-5663 (local 3467) or 604-707-3467

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

http://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: <a href="http://www.reko.ca/html/">http://www.reko.ca/html/</a> <u>hepc\_settleagreement.pdf</u>

# COMING UP IN BC/ YUKON:

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

**AIDS Vancouver Island** The following groups provide HCV info, harm reduction, support, education and more:

• Campbell River: Drop in, 1371 C - Cedar St. Contact 250-830-0787 leanne.cunningham@avi.org

• Comox Valley Hep C Support group-Drop in, needle exchange. 355 6<sup>th</sup> St. Courtenay. Contact Sarah 250-338-7400 sarah.sullivan@avi.org

• Nanaimo Contact Anita 250-753-2437 anita.rosewall@avi.org

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

• Victoria Access Health Centre, drop in, disability applications. 713 Johnson St., 3 r d floor, 250-384-2366 Hermione.jefferis@avi.org

**Boundary HCV Support and Education** Contact Ken 250-442-1280 <u>ksthom-</u> <u>son@direct.ca</u>

**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 info@hepcbc.ca, www.hepcbc.ca
•Victoria Peer Support: 4<sup>th</sup> 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: 3<sup>rd</sup> Wed monthly 7PM, N. Surrey Rec Centre Meeting room 10275-135th St Info: 604-576-2022, petrabilities@aol.com.

•Surrey Positive Haven Hep C group 2<sup>nd</sup> & 4<sup>th</sup> Thurs monthly 1 PM. 10697 135A St. Contact Sam 604-589-8678.

Kamloops ASK Wellness Centre. Chronic illness health navigation/support. <u>info@askwellness.ca</u> 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing and counseling 250-315-0098. <u>www.askwellness.ca</u>

**Kamloops** Hep C support group, 2<sup>nd</sup> and 4<sup>th</sup> Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Sep-May, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 250-768-3573, <a href="mailto:eriseley@shaw.ca">eriseley@shaw.ca</a>, Lisa 1-866-637-5144. <a href="mailto:limortell@shaw.ca">limortell@shaw.ca</a>

Mid Island Hepatitis C Society 2<sup>nd</sup> Thurs. monthly, 7 PM (Location to be arranged.) Contact *midislandhepc@hotmail.com* 

#216-55 Victoria Rd, Nanaimo. Contact Fran 250-740-6942. <u>hepctxpeersupport@hotmail.com</u>

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/

**North Island Liver Service** Viral Hepatitis Information, support, treatment, Fanny Bay North to Pt Hardy, Vancouver Island. 1-877-215-7005

**Pender Harbour** Contact Myrtle 604-883-0010 myrwin@dccnet.com

**Powell River Hepatology Service** Powell River Community Health, 3<sup>rd</sup> Floor–5000 Joyce Ave. Contact Melinda 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 & Northem BC support. Contact Wendy 250-557-2487, 1-888-557-2487, wendy@wendyswellness.ca http://health.groups.yahoo.com/group/Network-BC/

**Slocan Valley Support Group** Contact Ken 250-355-2732, <u>ken.forsythe@gmail.com</u>

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources, contact Catriona 604-886-5613 <u>ca-triona.hardwick@vch.ca</u> or Brent, 604-740-9042 <u>brent.fitzsimmons@vch.ca</u>

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 <u>sd.gk@shaw.ca</u>

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

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, 1<sup>st</sup> floor, Vancouver 604-688-1441 or 1-877-YOUTHCO <a href="https://www.youthco.org">www.youthco.org</a> Support program manager: Sasha Bennett <a href="mailto:sa-shab@youthco.org">sa-shab@youthco.org</a>

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 <u>blood-ties@klondiker.com</u>

# Summer Vacation.

# 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/ http://health.groups.yahoo.com/group/ CANHepC/

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

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, ON. Contact Andrea Monkman 519-967-0490 or

<u>hepcnetwork@gmail.com.</u> <u>http://hepcnetwork.net</u>

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 hars@kingston.net, www.hars.ca

Kitchener Area Chapter 3<sup>rd</sup> Wed. monthly, 7:30 PM, Waterloo Mennonite Brethren Church, 245 Lexington Rd. Waterloo. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

Niagara Falls Hep C Support Group Contact Rhonda 905-295-4260, kehl@talkwireless.ca

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

**Peel Region** (Brampton, Mississauga, Caledon) Contact 905-799-7700 healthlinepeel@peelregion.ca

**St. Catharines** Contact Joe 905-682-6194 <u>jcolangelo3@cogeco.ca</u>

**Sudbury Circle C Support Group** 1<sup>st</sup> 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 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

#### **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 ww.wbhas.ca

Manitoba Hepatitis C Support
Community Inc. Each 2<sup>nd</sup> & last
Tues. monthly, 7 PM, 595 Broadway Ave. Everyone welcome.
Contact Kirk 204-7728925 info@mbhepc.org www.mb
hepc.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!