# hepc.bull

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

TIDBITS FROM EASL 2013 - 48th ANNUAL MEETING OF THE EUROPEAN ASSOCIATION FOR THE STUDY OF THE LIVER

#### 24-28 April 2013 Amsterdam, Netherlands

#### BMS052 + GS-7977 = 95-100% SVR for NR

This first summary is based on a report by Jules Levin, who points out that this trial is important because it is the first to treat those who are non-responders to boceprevir or telaprevir. The trial tested the NS5A inhibitor, Bristol-Myers' BMS052 or daclatasvir plus the polymerase inhibitor that Gilead bought from Pharmasset—GS7977 or sofosbuvir. The SVR rate was 100%, and this, in the hardest of the hardest group to treat!! [Editor: This is a great example of how two companies could work together for the benefit of the community!]

The trial examined 41 GT1 patients. All took BMS052+GS7977 once daily, 20 without RBV and 21 with RBV, for 24 weeks. One patient missed his week 12 post-treatment blood test, but appeared at week 24 posttreatment, testing undetectable, but officially they had to call it only a 95% SVR. 80% of those treated had at least stage 2 fibrosis, and some may have even been cirrhotic, according to unofficial reports, making the results even more amazing-- exactly what those who failed boceprevir or telaprevir + pegIFN/RBV need to hear.

The worry is that if a patient develops a mutation resistant to a protease inhibitor, then retreating with a protease inhibitor may not work. Some researchers say that the mutations disappear after 1 to 3 years, and then the patient can be re-treated. There is a lot of debate about this important issue. If the mutations *don't* disappear after 2 years or so, we *(Continued on page 5)* 



#### GLORIA GARRAWAY ADAMS November 8, 1950 - April 18, 2013

Born in Cumberland, BC., Gloria was living in Comox, BC. You can still find her on Facebook: gloria.adams.7315

Gloria was a bookkeeper, a Hep C advocate, a widow, pre-deceased by her husband Dave Adams, and the mother of Shon Garraway.

Gloria educated herself about Hep C. She attended conferences. She supported other

(Continued on page 6)

# **INSIDE THIS ISSUE:**

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# WORLD HEPATITIS DAY

World Hepatitis Day is a global event that takes place annually on **July 28th** to bring attention to chronic viral hepatitis worldwide, and stands in solidarity with persons who have hepatitis B or C. Every year, events are organized around the world to help bring attention to hepatitis.

The Canadian Society for International Health (CSIH) is a non-profit, non-governmental organization based in Ottawa, and through funding from the Public Health Agency of Canada, is responsible (for the 5<sup>th</sup> consecutive year) for chairing the National World Hepatitis Day Planning Committee. Members of the committee include individuals and organizations from across Canada. Through monthly teleconferences, we discuss ideas for events, media outreach, and promotional materials. Anyone interested in planning an event is eligible to receive free promotional materials. Contact Alison at *amarshall@csih.org* for access to the Event Proposal, which is due by April 30<sup>th</sup>.

CSIH also organizes an annual **World Hepatitis Day National Art Contest** for youth (ages 13-29) to further increase awareness. This year, youth artwork categories include written submissions, such as poems and short stories, and video entries, in addition to posters. Winners of the youth contest will be awarded a \$200 Apple<sup>TM</sup> gift card!

For access to poster contest guidelines and more information regarding World Hepatitis Day in Canada, please visit our website:

www.whdcanada.org. Also, follow us on Twitter at globalhepcnet.

We look forward to your par-

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□Peppermint Patti's FAQ\$15.00			
□Resource CD\$10.00			
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#### TOTAL: \$\_\_\_\_\_

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

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

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

You may also subscribe or donate on line via PayPal at <u>www.hepcbc.ca/orderform.htm</u> Download the hepc.bull free at

http://hepcbc.ca/hepc-bull-monthly-newsletter/

SUBMISSIONS: The deadline for any contributions to the hepc.bull<sup> $\otimes$ </sup> is the 15<sup>th</sup> of each month. Please contact the editors at SUBMISSIONS: The 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  $12^{th}$  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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HepCBC		
2642 Quadra Street, PO Box 46009		

# Victoria, BC V8T 5G7

#### **LETTERS TO THE EDITOR:**

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

# NEW!! FAQ version 9.0

9 0

in

version includes treatment information

and research from 2012. Place your

orders now. It contains 169 pages of

information for only \$15 each. Contact

HepCBC at (250) 595-3892 or

HepCBC Resource CD

hepc.bull from 1997-2012, the FAQ V9.0.

the slide presentations developed by Alan

Franciscus, and all of HepCBC's pam-

phlets. The Resource CD costs \$10 includ-

ing S&H. Please send cheque or money

order to the address on the subscription/

order form: www.hepcbc.ca/orderform.htm

DISCLAIMER: The hepc.bull<sup>®</sup> cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you

receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily

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REPRINTS

copy and on CD ROM. For a list of articles and

Past articles are available at a low cost in hard

and individuals

and the newsletter team: Beverly Atlas,

Diana Ludgate, Alp, Cheryl, Anamaria, S. J.

Canada, Vertex, Gilead, Janssen, VanCity,

Shoppers Drug Mart, Market on Yates,

Special thanks to Thrifty Foods for putting our donation tins at their tills and to

Sooke Shoppers Drug Mart, for donating

the water for sale at the Christmas concert

and for having donated the water for our CASL Forum. Thanks, Allison Crowe and

Billie Wood for giving your 110% at the

Christmas concert. What a great way to start

the most beautiful time of the year. Thanks

also to Adrian for his continuous support.

helped

Bookkeeping, Merck Canada,

Country Grocer, and Safeway.

Please patronize the following businesses

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The CD contains back issues of the

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<sup>w</sup>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, 2642 Quadra Street, PO Box 46009, Victoria, BC V8T 5G7 (250) 595-3892. Give us your name, telephone number, and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

Disclaimer: The hepc.bull and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.

# AD 31

Old-fashioned lady, 71 yrs old, European background, seeks solvent, faithful, ageappropriate gentleman in Victoria, BC, for companionship: movies, walks, cooking. Let's grow old together happily.

# Got Hep C? Single? Visit:

http://forums.delphiforums.com/hepatitiscen1/chat http://groups.yahoo.com/group/HepCingles2 www.hcvanonymous.com/singles.html www.hepc-match.com/

for their NOTE: Before paying for full service HepC Crooks, Match, be aware that the site is not kept up-to Victoria date. We have been advised that there are mem-Provincial bers there who are no longer active, and at least Employees Community Services Fund, the one who is no longer alive, and his listing re-Victoria Foundation, Dr. C. D. Mazoff, mains, even though the owners have been noti-Lorie FitzGerald, Judith Fry, Allison Crowe, fied.



**TIP OF THE MONTH** 

**PRESCRIPTIONS?** 



YOU DON'T NEED TO **BE A MEMBER. TELL PEOPLE AT THE DOOR** YOU'RE GOING TO THE PHARMACY.

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# WORLD HEPATITIS DAY CARNIVAL 2013

Open House to promote the Education, Prevention and Awareness of Hepatitis C

July 26, 2013 12 Noon Positive Haven 10997-135A St Surrey, BC





# ANNUAL GENERAL MEETING

Tuesday September 10, 2013 6:30 PM

1947 Cook Street, Victoria, BC (Victoria Health Unit, Activity Room)

Schedule:

6:30-7:30pm Welcome and Main Speaker 7:30-8:30pm Annual General Meeting

#### AGENDA:

• Approve minutes of AGM 2012

• Set number of directors (We are looking for new directors)

- Election of those directors
- President's Report
- Coordinator and Staff Report
- Financial Report

#### Main Speaker & Topic: T.B.A.

Refreshments provided. Public welcome. No charge. Must be a member to vote. Hope to see you there.

A member is entitled to one vote at a meeting of members, and must become a member at least 30 days prior

# CALENDAR

## SAVE THESE IMPORTANT DATES!!

#### MAY 15, 2013:

-- FIRST REGISTRATION DEADLINE FOR Oct. 13, 2013 GOODLIFE FITNESS VIC-TORIA (BC) MARATHON (8k run, marathon —full or half, walk or run). After May 15th, entry fees increase. To register, go to <u>www.runvictoriamarathon.com/events/</u> <u>register.php</u> Be sure to select HEPCBC LIVER WARRIORS as your team on the dropdown list. FREE MARATHON T-shirts (from 2011/2012) go to anyone who sets up a Personal Pledge Page for our team! We also welcome volunteers for the cheering station, pledge-collectors, and other supporters!

-- For more information, go to <u>www.hepcbc.ca/marathons-walks/</u> or contact:

marathon.hepcbc@gmail.com.



-- HepCBC's participation in the marathon's Charity Pledge Program is one of our major HCV anti-stigma, awareness, and fundraising activities. Over 12,000 people attend this Boston Marathon qualifying event. See you there!

#### JULY, 2013:

-- WORLD HEPATITIS DAY (hepatitis B and C) is officially Sunday, July 28th, but most commemorations will be on the previous Thursday or Friday. At present we know of the following events in BC. Let us know of any more and we will put them and any updates on our website calendar (www.hepcbc.ca):

**CAMPBELL RIVER, BC** - Thurs., July 25, FREE lunchtime BBQ - Details: AVI, 250-338-7400.

COURTENAY, BC - Fri., July 26, FREE lunchtime BBQ - Details: AVI, 250-338-7400.

NANAIMO, BC - Sat., July 20, FREE Hep C Awareness PICNIC - Details: Fran, <u>250-</u> <u>585-3201</u> or Email <u>hepctxpeersupport@hotmail.com</u>

**SURREY, BC** - Fri., July 26, Noon - 3 pm. CARNIVAL with FREE BBQ, confidential testing, info. booths, henna tattoos, SEMINARS with top physicians John Farley and Edward Tam. Location: Positive Haven, 10997 135A Street, Surrey. Details: Monika, 604-589-8678, ext. 240, or Joan, 604-576-2022.

**VANCOUVER, BC** - Tentatively something will be happening on Fri., July 28 - Contact: HepCBC at <u>250-595-3892</u> (leave message)

**VICTORIA, BC** - Fri., July 26, 11 am - 3 pm in Centennial Square. Speakers, music, yoga, snacks, and lots of info about HCV and local healthcare & service providers. Details: Hermione, <u>250-384-2366</u>, ext. <u>2270</u>.

#### AUGUST 10, 2013:

-- DEADLINE TO BECOME A REGULAR MEMBER OF HepCBC (\$10/year) who can vote at our 2013 AGM. To become a member, go to <u>www.hepcbc.ca/hepcbc-order-form/</u>.

-- To become a BOARD MEMBER, you will also have to apply for a free police check (email us ASAP for personalized form to take to your local station) and sign a confidentiality pledge (at AGM). Prospective Board Members can start attending meetings as nonvoting members at any time. Members must attend three consecutive meetings (before or after being elected as a Board Member) before being granted full voting rights on the Board.

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#### **CONFERENCES**

DDW - Digestive Disease Week 18-21 May 2013 Orlando, FL <u>www.ddw.org/</u>

2<sup>nd</sup> Latin American Meeting on Treatment of Viral Hepatitis 24-25 May 2013 Sheraton Hotel WTC Convention Center São Paulo, Brazil <u>www.virology-education.com/index.cfm/</u>

23<sup>rd</sup> Conference of the Asian Pacific Association for the Study of the Liver (APASL) 6-10 June 2013 Singapore <u>www.apaslconference.org/</u>

8<sup>th</sup> International Workshop on Hepatitis C Resistance & New Compounds 27-28 June 2013 Cambridge, MA <u>www.virtualmedicalcentre.com/</u>

AASLD - the 64<sup>th</sup> Annual Meeting of the American Association for the study of Liver Diseases 1-5 Nov 2013 Washington DC <u>www.aasld.org/Pages/Default.aspx</u>

HEP DART 2013 frontiers in drug development for viral hepatitis 8-12 December 2013 The Fairmont Orchid Big Island, Hawaii <u>www.informedhorizons.com/hepdart2013/</u>

3<sup>rd</sup> Global Workshop on HCV Therapy Advances New Antivirals in Clinical Practice 13-14 December 2013 Rome, Italy (t.b.c.) <u>www.virology-education.com/index.cfm/</u>



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

# 7000 AT RISK FROM DENTIST

Investigators examining the office of W. Scott Harrington in Tulsa reported feeling sick at what they found. Even though the office looked clean, sterilization was done incorrectly for years. Unlicensed employees were performing IV sedation. There were cross-contamination issues, and the drug cabinet was not kept locked. There was one drug that had an expiry date of 1993. Inventory logs were non-existent. The last apparent delivery of morphine was in 2009, but the drug had been used on patients throughout 2012. The autoclave should have been tested monthly, but hadn't been tested in over 6 years, according to a complaint. One of the clients was diagnosed with hepatitis C and the health department investigation led to the possibility of contamination at the dental office. Dentists in Oklahoma are inspected only if there is a complaint. In Ohio, on the other hand, random checks are done every 2 years.

Unfortunately, Dr. Harrington had a large number of patients already infected with blood-borne diseases. He accepted lowerincome Medicaid patients who needed invasive procedures. About 7,000 patients who visited the dentist in Owasso (near Tulsa), Oklahoma during the past six years may have been exposed to HIV and hepatitis B and C, health investigators say. The health department is offering free testing to the patients, but one of them who was interviewed had received no word from officials. The doctor has surrendered his dental license and permits for medications and anesthesia.

What *CAN* you, as a patient, do? Make sure your dentist and staff wear gloves, masks and eye protectors. Watch that gloves are changed for each patient. Sterilized instruments should be removed from their wrappings after the patient is seated. Ask questions about the sterilization procedures. Use this article or a similar one as a means of bringing up the subject for discussion.

Source: www.cnn.com/2013/03/29/health/

SHAWNA FARMER ~ NOTARY PUBLIC

Shawna Farmer

# HEP C CLINIC AT PERCURO

Did you know that the Hepatology Clinic at PerCuro provides comprehensive HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region?

Specialized nurses assist with the procurement of financial coverage for treatment, ensure lab tests are scheduled appropriately, provide instruction in the self-administration of injectable medication, assist with the management of side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding the patient's HCV status, treatment and any other issues of concern.

This type of professional support is imperative now that standard of care therapy often involves three medications.

PerCuro also offers access to cutting edge clinical trials for both naïve and treatmentexperienced patients.

Every attempt is made to meet the individual needs of all patients. There is no cost involved.

#### Nursing Support improves outcomes. Contact 250-382-6270



I have two groups:

Hepatitis C Connections on Facebook is a group for discussion & support for people living with Hepatitis C and their caregivers.

I also have my volunteer website, a safe place to get together and 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 needs this info.



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Olympic Place BC V9Z 1E1

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

may need 2<sup>nd</sup> generation drugs, and one of the speakers at the conference seemed to suggest that the mutations hadn't disappeared after 1 or 2 years or more. At least there are new drugs being developed. The patient who is a null responder with cirrhosis, for example, must chose treatment carefully and be extremely careful to take the drugs exactly as prescribed. Some of the promising drugs are Merck's MK5172, Gilead's GS5816 (NS5A), and Achillion's NS5A. GS-7977 + VX135 is in Phase II studies. The Gilead drugs don't seem to be producing resistance. In two articles, Jules Levin reports that resistance to Sofosbuvir (S282T mutation) did not manifest in patients in the Quantum trial who initially were enrolled in a GS-0938-containing arm, but due to an ALT increase, were reassigned to the Sofosbuvir and RBV arm. Nor did this mutation manifest in any of the other patients who were in the non-GS-0938 arms. The results of the combination of BMS052 + GS7977 were greeted happily because, of the 90 patients who took it for only 12 weeks, 100% of GT1 patients and 91% of GT2 or 3 achieved SVR.

Sources: Jules Levin, NATAP www.natap.org/2013/EASL/EASL\_31.htm www.natap.org/2013/EASL/EASL\_35.htm

## AVIATOR TRIAL: HIGH SVR RATES

In case you hadn't heard, in January 2013, AbbVie split off from Abbott and has taken the promising "ABT" drugs with them. Data released about their Phase IIb Aviator Trial show 96% of treatment-naïve GT1 patients and 93% of previous null responders reached SVR24 with their IFN-free triple therapy: ABT-450/r (a protease inhibitor boosted with ritonavir), polymerase ABT-333 (a polymerase inhibitor), ABT-267 (an NS5A inhibitor), and ribavirin. Better yet, the rates at 12 weeks post treatment weren't very different from the rates at week 24, so 12 weeks of treatment for some patients may be enough. Patients with the unfavourable IL28B gene were included. Phase III trials have now begun, and data was presented, showing that 99% of treatment-naïve patients achieved SVR12, and 93% of prior null responders achieved SVR12 and SVR24. Out of 247 patients treated, there were 4 dropouts due to serious events-one, possibly related to the trial.

Source: www.natap.org/2013/EASL/EASL\_03.htm

#### DACLATASVIR + ASUNAPREVIR + BMS-791325

This treatment, which used no IFN or RBV, has no injections, either. It includes an NS5A

inhibitor, a protease inhibitor, and a polymerase inhibitor. This results of this combination was introduced at EASL. BMS and the researchers believe that many options are becoming available which can make it easy to tailor treatments to the individual. This report presented at EASL reflected results from a Phase II trial, showing up to 94% SVR in GT 1a and 1b treatment-naïve patients. The trials showed similar results for both 12 or 24 weeks of treatment. The goal was to produce SVR at 12 weeks posttreatment (SVR12) Side effects were mild, with no discontinuations for intolerance. A Phase III is expected to start later this year. A Phase III trial of two of the drugs, asunaprevir + daclatasvir, is already in progress. Some trials with these products are being studied in GT4 and in GT1 null responders. Results aren't yet available.

#### Source:

www.natap.org/2013/EASL/EASL\_01.htm

#### SOFOSBUVIR PHASE III

Results from four Phase 3 clinical trials treating almost 1000 patients with sofosbuvir, a once-daily nucleotide NS5B inhibitor for the treatment of HCV infection, show that the drug is effective against all HCV genotypes, 1 through 6, treatment naïve or experienced. It shortens the time needed for treatment with pegylated interferon (peg-IFN) injections to 12 weeks. It doesn't need peg-IFN to treat GT2 or 3. It is easier to tolerate than today's approved protease inhibitors. The SVRs range from 50-90% in the four trials (NEUTRINO, FIS-SION, POSITRON and FUSION) Patients with SVR12 (sustained viral response 12 weeks after treatment) are considered "cured." The advantages include once-a-day dosing and shorter treatment time than standard treatment (12 or 16 weeks compared to 48 weeks). On April 8, 2013, Gilead applied to the US FDA for approval of sofosbuvir for GT 2 and 3, and sofosbuvir + pegIFN/RBV for treatment-naïve GT 1,4,5 and 6 patients.

Sources: <u>www.newswire.ca/en/story/1151293/</u> www.natap.org/2013/EASL/EASL\_02.htm

#### SIMEPREVIR (TMC435)

Janssen announced efficacy and safety results of two Phase III studies of its protease inhibitor simeprevir (TMC435) which boasted an SVR12 in 80 and 81% of treatment-naive GT1 patients (all stages of fibrosis), when combined with pegIFN/RBV, compared to 50% taking only pegIFN/RBV. Simeprevir is being developed by Janssen and Medivir. Janssen recently submitted new drug applications for simeprevir in

Japan and the United States and plans to submit one in the EU some time in 2013.

Phase III studies of simeprevir include QUEST-1 and QUEST-2 (both with pegIFN/RBV), treating almost 700 treatment-naive patients for either 24 or 48 weeks, according to response at week 12; PROMISE, for relapsers from previous IFN-based treatment; and ATTAIN for null-responders. At the same time, Phase III studies for simeprevir are taking place for GT4 patients co-infected with HIV/HCV, both treatment-naïve and treatment–experienced. So far 1,846 patients have received simeprevir in clinical trials.

Simeprevir is also being studied in Phase II IFN-free trials with/without RBV, combined with other products:

•Janssen has begun working with Vertex in a Phase II all-oral study of simeprevir and Vertex's polymerase inhibitor VX-135.

•Janssen plans to initiate a Phase II IFNfree trial of simeprevir, TMC647055 and Idenix's IDX719, a once-daily, pangenotypic NS5A inhibitor, with and without RBV.

It's really good to see that some pharmaceutical companies are working with others for the benefit of our community.

Source:

www.natap.org/2013/EASL/EASL\_05.htm

#### FALDAPREVIR

Boehringer Ingelheim's faldaprevir is a protease inhibitor. The drug is now in Phase III trials, called STARTVerso1, with 650 treatment-naïve GT1 patients from Europe and Japan. The drug, combined with PegIFN/RBV produced an SVR12 in up to 80% of patients. Most patients (87-89%) were allowed to stop treatment after 24 weeks.

Source: www.natap.org

#### RECIPE

**CHILI SOUP** 

2 t .cumin seeds Chili flakes to taste 1 T . olive oil 1 red onion, chopped 140 g. red split lentils 850ml vegetable stock or water 400g can tomatoes\_ ½ can chickpeas rinsed & drained Small bunch cilantro, chopped 4 T. 0% Greek yogurt, to serve

Dry-fry cumin seeds and chili flakes until they start to jump; add oil, onion. Cook 5 mins. Stir in lentils, stock & tomatoes. Bring to boil. Simmer 15 mins. Blend soup, pour back into pan. Add chickpeas. Heat, season, stir in cilantro. Top with yogurt.

Source: www.bbcgoodfood.com/recipes/333614/redlentil-chickpea-and-chilli-soup



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# OUR HEP C HERO: MICHAEL HOUGHTON

The world-famous virologist Michael Houghton, of the University of Alberta, has been named recipient of the prestigious international 2013 Gairdner Award for "groundbreaking research on hepatitis C". The Gairdner Foundation announced the 7 award recipients in Toronto at a breakfast on the 20<sup>th</sup> of March. Dr. Houghton and his colleagues worked at Chiron (now part of Novartis) and the US Centers for Disease Control in 1989, when the hepatitis C virus was first identified. He was then able to formulate new testing techniques now used throughout the world to keep supplies of blood free of HCV. Then in February last year, he and his teammates at the U. of Alberta developed a vaccine from one genotype effective against all known HCV genotypes which opened up possibilities of developing a future vaccine, saving millions of people from being infected.

And he turned down the award.

In a statement, he said he was honoured to have been named a recipient of the award, but felt it was unfair to accept it since he worked in a team including Dr. Qui-Lim Choo and Dr. George Kuo, and they did the work together. He went on to congratulate the recipients of the other awards.

And, importantly, he added, "Finally, I would urge every baby boomer in Canada and in the USA to get tested for HCV as recommended by the CDC and the Canadian Liver Foundation since it is known that this age group experiences a high prevalence of infection and many individuals are unaware that they carry the virus, which ultimately can lead to serious liver disease if left untreated."

By the way, that award he turned down was for \$100,000.00.

#### Source:

http://ca.news.yahoo.com/blogs/geekquinox/



#### (GLORIA—Continued from page 1)

sufferers. She wasn't shy. She was interviewed in the news a few times (*Vancouver Sun, Comox Valley Echo, Victoria Times Colonist* and *Postmedia News*). She made a difference, as is evident from the numerous comments of members of the Yahoo! hepcan list and comments and thanks left by her Facebook friends.

Gloria was diagnosed in 2002 and was probably infected from an ear piercing years before that. She went through 48 weeks of standard IFN/RBV treatment in 2004-2005, but failed to respond. She was already almost cirrhotic when she began that treatment. Then in 2009, suffering from late stage cirrhosis--when most people are preparing to die--she was offered a spot in a clinical trial. This was the chance she, along with many others, was praying for. "I had only four hours to make up my mind but I jumped at the opportunity," said Gloria. She eradicated the virus, thanks to the new drugs and that clinical trial which accepted her! Tragically, at week 36 of her 48-weeklong treatment, she was diagnosed with "probable" liver cancer. Only about 20% of cirrhotic patients progress to liver cancer. Gloria was quickly scheduled for major surgery at Vancouver General Hospital after she finished the trial. 15 months later, the cancer returned. Still she did not give up. She pointed out to us all that the liver doesn't announce that it is sick. She had no signs, even with liver cancer, that her liver was dying, since the liver has no nerves and doesn't feel pain. Gloria wanted to inspire us to fight for our own health. She had a purpose, a message: "The reason I tell this story, is to try to impress upon people to be tested. I mean every adult. As my life draws to a close, I would just like to know that a great deal of folks in this Valley take it seriously and GET TESTED!"

"Every now and then, there is a quantum leap in science and technology. We are seeing that here. Victory is in sight." — Dr. Eric Yoshida, Head of Gastroenterology at UBC and VGH, and of the BC Hepatitis Program.

(Editor's note: Almost a year ago, when I started my 5<sup>th</sup> attempt at treatment, Gloria posted on the hepcan list, "Oh - how much I hope that I'm still here when Joan announces she finally killed the beast. Just toooo exciting." Unfortunately, Gloria just missed that news. I like to think she knows.)

Sources:<u>www.vancouversun.com/health/</u> 6/28/2011

<u>www.canada.com/Telling+rest+story</u> 07/27/ 2012

# **SVR HONOUR ROLL**

We often hear only the stories of those who are suffering with Hep C. Our responders go back to "real life" and want to forget about their struggles with Hep C. Have you responded to treatment and remained undetectable for a minimum of 12 weeks\* after finishing treatment (i.e., SVR or Sustained Viral Responder)? Let us help you celebrate. You can give others hope. Please take a minute and send us your name, genotype, date of SVR, and type of treatment to post here, and we'll add your name (or initials). Congratulations to our friends:

 GJ - Dec 1998 - IFN/RBV 52 wks—Dr Anderson /Natalie Rock , Vancouver, BC.
 Jeanie Villeneuve - Oct 2000 -Schering IFN/RBV

3. **Kirk Leavesley** (GT1) – 2004 – Roche 4. **Darlene Morrow** (GT1 relapser) Mar 2004 -Hyperthermia/Induction + pegIFN/ RBV.

5. Beverly Atlas (GT1a) - 2006 - Albuferon/ RBV 44 wks

6. **Daryl Luster** (GT1a) - Feb 2011 - IFN/ RBV/RO5024048 48 wks

7. **Cheryl Reitz** (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/ Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.

8. **Gloria Adams** (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks -Drs Erb & Yoshida, Vancouver, BC.

9. Anita Thompson (GT1a treated 3 times) Cirrhosis — April 2013—Pegasys/ Boceprevir 48 wks. Dr. M. Silverman in Whitby, ON.

10. Joan King (GT1b treated 5 times)
SVR12 Apr 2013 - Asunaprevir/Daclatasvir
24 wks Dr., Vancouver, BC.
11. This could be YOU!

#### We know there are more of you. Please send your name to Joan at *info@hepcbc.ca* and help raise the hope of those still infected.

\* "Recently, the U.S. Food and Drug Administration (FDA) regulators revised this time point from SVR-24 to SVR-12, since most post-treatment relapses (when HCV RNA becomes detectable after treatment completion) occur within 12 weeks. Thus, SVR-12 became the new primary outcome for clinical trials studying peginterferonbased regimens."

Source: http://i-base.info/ htb/20643

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#### MUSIC HELPS

Just listening to music can erase anxiety and boost serotonin. If you work out in time to music with a fast tempo, your workout increases in intensity and can motivate you because it's more fun. It's still more fun if you can sing along. Even 15 minutes a day of music can lower your blood pressure and heart rate. It can slow your breathing. It can reduce cortisol and boost our endorphins. Dancing along can provide even more benefits, like lowering levels of dopamine, and stopping the sugar and carb cravings. Music played with workouts not only makes them more fun, but people stick to their routine better, and as a result, lose twice as much weight and body fat as those who exercise without music.

Choose your music wisely. Heavy metal won't do much to reduce anxiety, pain, breathing rate or heart beats. Classical and spa music do a better job with that. Research seems to show that you should choose music that matches your ideal heart rate. (There are free metronome apps. Steinway & Sons has a "Tap" feature that lets you tap a beat and tells you what speed it is.) Music has been shown to lower blood pressure, and emotions created by joyful music help blood vessels work better. Stressful music, though, can actually reduce blood flow. Beware! Did you know that music increases interleukin-1 levels? This affects our immune system. Scientists in



Florida say that 20 minutes of classical music each day can reduce your pain from arthritis by half in just 14 davs.

Play calming music while

you're driving to reduce stress even in the middle of traffic. A walk in the sunshine is even nicer when accompanied by music. (I wonder if joining a marching band would help...)

Source: http://ca.news.yahoo.com/boost-weightloss-immunity-happiness-music-130000282.html

#### **INCIVEK CARE**

Vertex's Incivek Care Patient Assistance Program supports patients with the reimbursement process for Incivek (telaprevir) treatment (Incivek, pegIFN, ribavirin). It will give you an efficient assessment of your options and eligibility. You may qualify to receive co-payment and other financial assistance to supplement your private and provincial drug program coverage. The program also provides dispensing and home delivery options, and expert treatment advice. Call the Support Line at 1-877-574-4298. (Select option 2 for English, then 2 for Incivek Care.)

# MERCK CARE<sup>TM</sup>

MerckCare<sup>TM</sup> is a program to help people who have been prescribed PEGETRON<sup>TM</sup>, VICTRELIS<sup>TM</sup> or VICTRELIS TRIPLE<sup>TM</sup>. The program provides:

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

MerckCare<sup>TM</sup> provides all of these services free of charge.

To enroll in MerckCare<sup>TM</sup>, you can call 1-866-872-5773 or your doctor or nurse can submit an enrollment form for you. Reimbursement Specialists are available from 8:00 a.m. to 8:00 p.m. EST Monday to Friday, excluding statutory holidays.

## PEGASSIST

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM - 6 PM EST) by calling: 1-877-PEGASYS or 1-877 -734-2797. Patients can also obtain a program enrollment form from their nurse/ physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting RCMP Blood Probe Task Force TIPS Hotline treatment, i.e., deductibles and/or copayments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

# NEUPOGEN VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependent 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

Lookback Programs, Canada: 1-800-668-2866

Canadian Blood Services, Vancouver, BC

1-888-332-5663 (local 3467) or 604-707-3467

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

Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362

Manitoba Traceback: 1-866-357-0196

**Canadian Blood Services, Ontario** 1-800-701-7803 ext 4480 (Irene) Irene.dines@Blood.ca

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

#### **CLASS ACTION/ COMPENSATION**

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

#### CLAIMS ADMINISTRATOR

1986-1990

Administrator 1-877- 434-0944 www.hepc8690.com info@hepc8690.com

Pre-86/Post-90

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

Settlement Agreement: www.pre86post90settlement.ca/PDFs/SA/

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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. leanne.cunningham@avi.org 250-830-0787 Contact

• Comox Valley Harm reduction, counselling, advocacy. 355 6<sup>th</sup> St., Courtenay. Contact Sarah sarah.sullivan@avi.org 250-338-7400

• Nanaimo Counseling, advocacy. 201-55 Victoria Rd Contact Anita for details. 250-753-2437 anital.rosewall@avi.org

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

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

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

Burnaby HCV Support Contact Beverly 604-435-3717 batlas@telus.net

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

Chilliwack PCRS Hep C Prevention, peer support, harm reduction. Meetings 3rd Mon monthly, 45904 Victoria Avenue, Chilliwack . Contact Kim Lloyd 604-798-1416. lbirdsall@pcrs.ca www.pcrs.ca

**Comox Valley Positive Wellness North Island** Treatment/Pre & Post-treatment Support Group 2<sup>nd</sup> & 4<sup>th</sup> Wed., 615-10th St, Courtenav. Lunch. Contact Chervl

Cheryl.taylor@viha.ca 250-331-8524.

**CoolAid** Community Health Centre, **Victoria**. Meetings each Wed 10 AM and Thu **1:30** PM. 713 Johnson St. Support for all stages of treatment BC support. Contact Wendy 250-557-2487, 1-888-(deciding, during, after). Contact Roz <u>rmilne@coolaid.org</u> for treatment or group info.

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. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-3891

•Fraser Valley Support/Info: 604-576-2022

Kamloops ASK Wellness Centre. Chronic illness health navigation/support.

info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098 www.askwellness.ca

Kamloops Hep C support group, 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: Phone support,, meeting info. Contact Lisa 1-866-637-5144 limortell@shaw.ca

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Support Meetings 1<sup>st</sup> & 3rd Thu 3-5 PM 437 Wesley St. (access off Franklyn St) Contact 250-585-3201, hepctxpeersupport@hotmail.com

Nelson Info & support for prevention, testing, treatment and living well with hepatitis C. Women's gathering monthly. Contact Laura 1-800-421-2437, 250-505-5506, ankorshepc@ankors.bc.ca

New Westminster Stride "HepC" Support Group each Fri 10 AM except 4<sup>th</sup> Fri. of the month. Nurse Practitioner, refreshments. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

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

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

Penticton & District Community Resources Society, Harm Reduction Program, 330 Ellis Street, Penticton. Contact: 250-488-1376 or 250-492-5814

Positive Haven Info, harm reduction, support drop in, clinic. 10697 135A St. Surrey. Contact Monika 604-589-9004.

Positive Living Fraser Valley (Abbotsford) Hep C support, Drop-in centre 31943 S. Fraser Way Suite 200, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or plfvcentre@plfv.org

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

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

Queen Charlotte Islands/Haida Gwaii & Northern 557-2487, <u>http://health.groups.vahoo.com/group/</u> <u>Network-BC/</u>www.bfl 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 <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 Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211, or call 604-522-1714 (Shelley), 604-454-1347 (Terry), to talk or meet for coffee.

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

YouthCO HIV/Hep C Society of BC. Drop-in T&W 12-3, Fri. 9-12. Call for appts M-F 10-6. 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart stewartc@youthco.org, Briony brionym@youthco.org www.youthco.org

Whitehorse, Yukon-Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 blo<u>odties@klondiker.com</u>

# **ONTARIO:**

Contact Jeanie for info/ appointment jeanievilleneuve@hotmail.com

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

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

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, Teen Health Centre-Street Health Program Office, 711 Pelissier St., Suite 4, Windsor. Contact Andrea Monkman 519 -967-0490 or hepcnetwork@gmail.com. http://hepcnetwork.net

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

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room. 659 King St. East (Enter off King St) Kitchener. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Hep C Support 186 King St, London. For those infected as well as affected by Hep C. Contact: 1-866-920-519-434-1601, 1601.

www.hivaidsconnection.com

Niagara Region Hepatitis C Care Clinic Education, Counseling and Support - Individual / Group, Treatment, Community Outreach, harm reduction. Contact 905-378-4647 ext 32554 HCCC@niagarahealth.on.ca

www.niagarahealth.on.ca/ *services/hepatitis-c-care* 

Oshawa Community Health Centre Hepatitis C Team Drop-in, lunch provided each Thurs. 12-1 PM, 79 McMillan St. www.ochc.ca Contact 1-855-808-6242

Owen Sound Info, support. Contact Debby Minielly dminielly@publichealthgreybruce.on.c

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a 1-800-263-3456 Ext. 1257. Barrie Hepatitis Support 519-376-9420, Ext. 1257, www.publichealthgreybruce.on .ca/

**OTHER PROVINCES** 

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700 healthlinepeel@peelregion.ca St. Catharines Contact Joe 905-682-6194

Toronto CLF 1<sup>st</sup> Mon. monthly Oct.-June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932.

<u>bpotkonjak@liver.ca</u> www.liver.ca

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

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

York Region Hepatitis C Education Group 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 905-940-1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

#### **OUEBEC:**

Quebec City Region Contact Renée Daurio 418-836-2307

reneedaurio@hotmail.com

#### ATLANTIC PROVINCES

**Hepatitis Outreach Society** of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767

Online Peer Support: <u>info@hepns.ca</u> www.hepns.ca

#### **PRAIRIE PROVINCES:**

Manitoba Hepatitis phone and email support and outreach. Info Line: 1-204-779-6464 or contact Kirk at info@mbhepc.org. Direct line: 1-204-389-5814

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/ AIDS Network of S.E AB Assoc, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca



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



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