hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

AASLD NEWS

AASLD 2012 BOSTON
63rd ANNUAL MEETING
OF THE AMERICAN ASSOCIATION FOR THE STUDY OF LIVER DISEASES
(THE LIVER MEETING 2012)

GS-7977+GS-5885+RBV= 100% SVR4

On November 10, 2012 Gilead announced interim results from their Phase II 12 week ELECTRON trial, which combines the nucleotide sofosbuvir (GS-7977), the NS5A inhibitor GS-5885 and ribavirin (RBV) in GT1 patients. 100% of the 25 treatment-naïve subjects tested undetectable 4 weeks after completing treatment (SVR4). This data was presented on Tuesday, November 13th at the AASLD 2012

A Phase III trial (ION-I) is studying a fixed-dose combination of sofosbuvir and GS -5885 in treatment-naïve GT1 patients. The study has 4 arms: with or without RBV, and 12 or 24 weeks of treatment. 800 patients will be studied, including 20% diagnosed with cirrhosis.

More data was released from another 5 arms of the ELECTRON study:

Sofosbuvir + RBV for 12 weeks (no GS-5885)

GT1 treatment-naïve: 84% SVR12
GT1 null responders: 10% SVR12
GT2/3 treatment-experienced: 68% SVR12
Sofosbuvir+RBV for 8 weeks (no GS-5885)
GT2/3 treatment-naïve: 64% SVR12

Sofosbuvir + RBV 800mg for 12 weeks (no GS-5885)

GT 2/3 treatment-naïve 60% SVR8

Sofosbuvir + GS-5885 + RBV for 12 weeks

Interim results show that the 3 of the total 9 patients (previous null-responders) treated who have reached week 4 post –treatment still have undetectable virus.

Treatment was well tolerated, with only one drop out at week 8 because of an adverse event not related to the drugs. Even so, this patient achieved SVR4.

(**AASLD News** —*continued bottom of page 3)*

PHAC SURVEY ANSWERS

HepCBC Stakeholder Survey

Answers to PHAC's [Public Health Agency of Canada] Community Associated Infections Evaluation (to cover 2008 to present) – submitted October 23, 2012

What follows is a summary of the most important points in HepCBC's submission.

WHAT PHAC IS DOING RIGHT for the HCV COMMUNITY:

(1) **Publishing a free pamphlet:** *Hepatitis C Get the Facts*

(2) **Monitoring and reporting:**

(a) *Modeling the Incidence & Prevalence of Hepatitis C Infection & it's Sequelae in Canada*, 2007, found at *www.phac-aspc.gc.ca/sti-its-surv-epi/model/pdf/model07-eng.pdf*

(b) *Hepatitis C in Canada: 2005-2010 Surveillance Report* (NOTE: This is on our website because we could only locate the summary on PHAC website.) *http://hepcbc.ca/wp-content/uploads/2012/08/HCVCanada2012.pdf*

(3) **Supporting development of strong HCV knowledge exchange and media at the federal and regional levels through CATIE** (Canadian AIDS Treatment & Information Exchange) - though the AIDS part in their name seems anachronistic.

We are indebted to CATIE for developing, updating, and distributing excellent

(Continued on page 5)

INSIDE THIS ISSUE:

A SAD GOODBYE TO ARTIST AND FRIEND JADE HOOD 1951-2012

A few days ago in Victoria, friends and community of Jade Hood (born April 1951, died October 2012) gathered to celebrate this artist and strong fighter for social justice, Jade was a survivor of so much pain and suffering in her own life, but once she found her voice she made it her mission to speak out honestly and forcefully on behalf of the most vulnerable in society. She never lost her humour, her creativity, or her incredible humility. Thanks, Jade, for presenting at HepCBC's 2011 AGM, and allowing us to use your artwork on our pamphlets. Jade is the lovely lady on our homepage slideshow with the caption, "Use your creativity to develop a healthy spirit." Jade inspired so many people - especially women - to take command of their lives. She showed us how to share our stories, and to make sure misfortune and stumbles early in our journeys don't define who we are, limit how far we can go, or determine our final destination. Create your own moment of silence to honour what Jade stood for; thanks, we're going to miss her.

SUBSCRIPTION/ORDER FORM

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

HepCBC
2642 Quadra Street
PO Box 46009
Victoria, BC V8T 5G7

Name: _____

Address: _____

City: _____ **Prov**. ___ **PC**_____

Home(___)_____**Work**(___)_____

Email: _____

☐Please email me a PDF copy, free of charge.

☐Membership + Subscription (1 year) ….**$20.00**

☐Membership Only ……..**$10.00**
(Doesn't include the *hepc.bull*)

☐Subscription Only ……..….**$10.00**
(Doesn't include membership privileges)

☐Peppermint Patti's FAQ ……**$15.00**

☐Resource CD ……...…...**$10.00**

☐"I enclose a donation of …….$_____ so that others may receive the bulletin."

TOTAL: _____

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

☐"I want to volunteer. Please contact me."

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

(Note: The hepc.bull is mailed with no reference to hepatitis on the envelope.)
You may also subscribe or donate on line via PayPal at *www.hepcbc.ca/orderform.htm*

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

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

Newsletter Ads: Maximum 4 per issue, if space allows. $20 for business card size ad, per issue. Payments will be refunded if the ad is not published.

HOW TO REACH US:

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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.

NEW!! FAQ version 9.0

Peppermint Patti's FAQ Version 9.0 is NOW AVAILABLE, Version 8 is available in FRENCH and SPANISH. The ENGLISH 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 *info@hepcbc.ca*

HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2012, the FAQ V9.0, 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: *www.hepcbc.ca/orderform.htm*

DISCLAIMER: *The* hepc.bull© *cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the editors, of HepCBC or of any other group.*

REPRINTS

Past articles are available at a low cost in hard copy and on CD ROM. For a list of articles and prices, write to info@hepcbc.ca .

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, Community Living Victoria, Victoria Positive Living Centre, Provincial Employees Community Services Fund, the Victoria Foundation, Dr. C. D. Mazoff, Lorie FitzGerald, Judith Fry, Allison Crowe, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Judy Klassen, Cheryl, Anamaria, S. J. and L.P.

Please patronize the following businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, VanCity, Shoppers Drug Mart, Market on Yates, Country Grocer, and Safeway.

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.

CUPID'S CORNER

This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad, write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a $10 donation, if you can afford it. Send a cheque payable to **HepCBC,** and mail to **HepCBC, Attn. Joan, 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 30

Youthful, early 50's single Caucasian male. 5'11", 200 lb non-smoker, outdoors, nature walks, camera, musical, science educ. Half life on hold since diagnosed. Time to break-out.

Searching intelligent, young at heart woman to share some time, hobbies, activities, friendship leading to...? Maybe just friends, maybe a family. Life rarely turns out as you wish or imagine.

Tell me about yourself—hobbies, website, photo?

Got Hep C? Single? Visit:

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

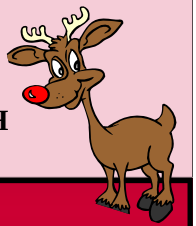
http://groups.yahoo.com/group/HepCingles2
www.hcvanonymous.com/singles.html
www.hepc-match.com/

NOTE: Before paying for full service HepC Match, be aware that the site is not kept up-to date. We have been advised that there are members there who are no longer active, and at least one who is no longer alive, and his listing remains, even though the owners have been notified.

TIP OF THE MONTH:

GOING ON TREATMENT?

- **GET YOUR EYES TESTED**
- **GET YOUR TEETH CHECKED**



Allison Crowe's Annual Christmas Benefit for HepCBC Sat., Dec 1, 2012 7:00pm Fairfield United Church

In her annual concert benefitting HepCBC and Artemis Place (life skills and academics for at-risk girls), Allison Crowe cooks up an organic blend of rock, jazz, folk, gospel and soul. Favourites—*It Came Upon a Midnight Clear, In the Bleak Midwinter, What Child Is This, The First Noel, Silent Night, and O Holy Night*—are performed with rare artistry and passion alongside the modern canon of Leonard Cohen, Joni Mitchell, Lennon & McCartney and original song selections (including the elegiac *Arthur*, and the epic, foot-stomping *Disease*).

"Allison Crowe is a stunningly talented performer. Her voice celebrates the music with a bluesy rock-gospel intensity; her controlled vibrato, silken rasp, and powerful projection rivet your attention. This is no casual background music. Be prepared to be amazed." ~ *ChristmasReviews.com*
http://music.allisoncrowe.com/album/tidings

Peace on Earth ~ Goodwill toward All. Featuring: special guests TBA. Tickets available online now:
www.allisoncrowe.com/shoptickets.html

(**AASLD NEWS**—*Continued from page 1)*
Source: www.businesswire.com/news/rxtimes/20121110005009/en/Gilead-Announces-100-Percent-Sustained-Virologic-Response

AVIATOR TRIALS 83-100% SVR

Abbott presented results from their Phase IIb "Aviator" trial, showing promising SRV12 rates in 8- and 12-week arms, using DAAs (Direct-Acting Antivirals) ABT-450/r, ABT-267, and ABT-333, with and without RBV. The study examined non-cirrhotic treatment-naïve patients and previous null responders for 8, 12 or 24 weeks, regardless of IL28B genotype.

SVR_{12} results for the 12-week, triple-DAA regimen **with RBV**:
GT1 patients: 97.5% of treatment-naïve and 93.3% of null responders (GT1a patients: 96% of treatment-naïve and 89% of null responders and GT1b patients: 100% treatment naïve and null responders.)

SVR_{12} results for the 12-week triple-DAA regimen **without RBV** in treatment naïve patients:
GT1 patients: 87.3% (GT1a patients: 83% and GT1b patients: 96%)
Four of the 448 patients dropped out due to adverse events, leading to a lack of some data. The most common adverse events were fatigue and headache.

Enrolment is open for their Phase III trials. The news gets better and better for IFN-intolerant patients.

Source: www.natap.org/2012/AASLD/AASLD_29.htm

DCV/ ASV/ BMS-791325 X 12 Weeks = 94% SVR

The IFN/RBV-free triple DAA combo DCV (daclatasvir) + ASV (asunaprevir) + BMS-791325 showed excellent SVR with only 12 or 24 weeks of treatment in GT1 naïve patients, including GT1a and IL28b non-CC patients (the hardest to treat). There have been no breakthroughs or relapses to date. Previous trials with DCV+ASV were successful in previous GT1b null-responders. In this trial the goal was to shorten treatment time and obtain SVR in GT1a patients, while avoiding side effects. BMS-791325 is a non-nucleos(t)ide NS5B polymerase inhibitor. Some patients stopped treatment, but none due to side effects. Some didn't comply. Some didn't go for follow-ups.

Source: www.natap.org/2012/AASLD/AASLD_07.htm

MK-5172 PHASE II IFN-FREE

On November 2, Merck announced the initiation of clinical trials of its new NS3/4a protease inhibitor MK-5172. The trial will not use IFN, and will treat GT1 patients never before treated, with no cirrhosis. The first trial will treat patients for 12 weeks, combining MK-5172 with ribavirin (RBV) and MK-8742, an NS5A inhibitor now in Phase I trials. Only patients with IL28 CC host genotype will be treated. (More info: *http://clinicaltrials.gov* Search for NCT01717326 and NCT01716156.) MK-5172 has already proven effective (up to 93% SVR) against GT1a and 1b in Phase II trials. Results were presented at the AASLD 2012. The phase III trials will be available in Canada.)

Source: www.natap.org/2012/HCV/110812_02.htm

GS-7977 + RBV = 72% SVR4 IN HARDEST-TO-TREAT

[Note: The following results were presented at the AASLD Conference, and the information is preliminary until it is published in an

(Continued on page 4)

HEP C IN THE NEWS

SANDY DESTROYS RESEARCH

And I thought I wasn't affected by Hurricane Sandy… Do you remember those trimera mice that were genetically altered so that they could be used instead of chimps for Hep C trials? The news reports don't mention hepatitis C research directly, but thousands of such mice couldn't be rescued from the storm and floods. Years of research results, if they weren't stored safely, may have been lost. And to replace the mice will be time-consuming and expensive. Biological materials kept in cold storage at New York University Hospital are presumed to have been destroyed due to electrical failure.

"Graduate students and post docs, their careers depend on publishing successful scientific research and if they lose their animals that's going to set them back. I'm making it sound dire here, but it probably is," commented Erich Jarvis, a Duke University neurobiologist.

Some of our favourite pharmaceutical companies had to shut down temporarily: GlaxoSmithKline, Roche, Bristol Myers-Squibb, Novartis, etc. Vertex seems to have been affected, but to a lesser extent.

Source: www.pharmatimes.com/article/12-11-02/Hurricane_Sandy_destroys_medical_research.aspx

"SLICK" AGUILAR NEEDS LIVER

Slick Aguilar, born in 1954 in Florida, has recently been told he has hepatitis C and needs a new liver. In case you don't know, he is the lead guitar player for Jefferson Starship. His band has set up a PayPal account to raise funds, since his insurance doesn't cover everything. Slick has played with stars such as Wayne Cochran, David Crosby, Buddy Miles, and KC & the Sunshine Band. He joined The KBC band in 1984. In 1992 he joined Jefferson Starship. You can see him on YouTube.

Source: www.jambands.com/news/2012/11/07/jefferson-starship-s-mark-slick-aguilar-in-need-of-a-liver-transplant
To donate: http://www.indiegogo.com/Slick-Aguilar

(Continued on page 4)

(HEP C IN THE NEWS—Continued from page 3)

INCIVEK NEWS

Incivek is now officially funded by Alberta's government. Details can be found here: *www.ab.bluecross.ca/dbl/publications.html* Incivek is funded in 7 provinces, and with private insurers. We hope the other provinces follow suit soon!

INCIVEK Care toll-free: 1-877-574-4298. *(See page 7 of this issue.)*

Vertex has stopped developing ALS-2158, a polymerase inhibitor, to promote a more effective one, ALS-2200, being tested with RBV, and shown to be well-tolerated (no drop-outs or serious side-effects.) Phase II trials will also combine it with Incivek (telaprevir).

In early 2013, Vertex will work with Janssen in a Phase II all-oral study of VX-135 (polymerase inhibitor) and Janssen's protease inhibitor, Simeprevir (TMC435), treating GT1 treatment-naïve patients in 12 -week treatment regimens with and without RBV.

Source:
www.pharmatimes.com/Article/12-09-26/Vertex_gives_one_HCV_drug_the_chop_advances_another.aspx?goback=.gde_3207213_member_169167087#%2EUGQdAMf0bZ4%2Elinkedin Nov 01, 2012

*(**AASLD NEWS**—Continued from page 3)*

established journal.]

GS-7977 is a nucleotide analog polymerase inhibitor, which was combined with RBV based on the weight of the patient, for 24 weeks in GT1, treatment-naïve patients in a difficult-to-treat population (mostly African-Americans, who do not respond as well as other groups to treatment). Most had GT1a virus, were overweight, or had a non-CC IL28b allele and advanced fibrosis. The results were promising, lowering the viral load to undetectable in about 72% of patients. The arm with a reduced amount of RBV was not so successful (56% SVR4). The primary goal was to report the number of patients with SVR12 (undetectable virus 12 weeks after the end of treatment), but not all patients have been off treatment for that amount of time, so SVR4 rates were used.

Source:
www.natap.org/2012/AASLD/AASLD_08.htm

hepcbc Hepatitis C Education & Prevention Society
Confronting hepatitis C since 1996

COME VISIT OUR RE-DESIGNED WEBSITE!! *HEPCBC.CA*

INVITATION TO INTERACT WITH HEPCBC'S NEW WEBSITE

It's still a "Work in Progress" but HepCBC's renovated website (still at *www.hepcbc.ca*) is looking better these days, and now invites your active participation to make it a representative voice of our HCV+ community. There are three main parts to the website:

(1) ***Home page*** features a "HepCBC News" blog on the bottom left – Viewer comments, likes, shares, forwards, etc., are invited! The "Treatment News" blog (bottom, centre) covers current HCV (and HBV) research results. To access this blog the first time, just click on any article and create a (free) account with Clinical Care Options. There is also a Calendar of Events plus links to all our free Publications, a Quiz, and our You Tube Video Channel!

(2) ***Information Pages*** are accessed through the Menu Bar at the top of every page, and include main categories: HCV Basics, Living with HCV, Resources, Media & Inspiration, Making a Difference, and About HepCBC. About half these pages are complete; the others are still under construction. Thanks for your patience! And we welcome any suggestions or corrections.

(3) ***Viewer Interaction Pages*** are created by viewers, who submit content which is put online after approval by our website editors. These include: Personal Stories, Creative Space to share your fiction, essays, humour, scripts, poems, prayers, recipes, reviews, photo/art/music/video hyperlinks, etc. There is also a space for your "In Memoriam" entries. We still need to re-input the entries from our old website. This is high priority, so look for it soon. There is a Release Form we will ask you to sign which allows you to retain all rights to your content, but grants permission to HepCBC to publish it as well (hyperlinks to materials already in the public domain will not require this form).

Thanks so much to Merck and Roche for their support of this website re-design.

INVITATION TO WATCH VICTORIA MARATHON UPDATE VIDEO

Our new "HepCBC Liver Warriors" video can be viewed on our You Tube channel at *http://www.youtube.com/watch?v=-FKC39ChTes.* Hope you enjoy it and will consider joining a walking or running marathon in your community next year! Even if it just encourages you and your friends to get out and take pleasure in walking or running occasionally, the exercise will be great for your liver and general physical health. And those endorphins are super for your brain and mental health as well.

avi.org AIDS vancouver island

YOGA AT AVI, VICTORIA

Ahhh! A laid back, gentle class for people who have chronic health conditions. Every Tuesday, 10:30 am at Bayanihan Hall, 1709 Blanshard St., Victoria, BC.

Julia Breese is returning to teach us. (*http://garudayoga.ca/*) Wheelchair accessible. Free. More info: 250-384-2366 ext 2270

HEP C CLINIC AT PERCURO
VICTORIA, BC

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 treatment-experienced 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

SURVEY ANSWERS—*Continued from page 1*)

free HCV educational materials. We also greatly appreciate opportunities to attend conferences with other organizations which deal with blood-borne infections (such as recent Pacific AIDS Network/CATIE conference in Richmond, BC). These are great opportunities for exchanging knowledge and fostering collaborations in areas where our needs and activities intersect.

(4) **Engaging the local/grassroots level non-profit HIV/AIDS community** to deal with co-infection with HCV and overlapping areas in general harm-reduction and HCV-prevention activities. Their client outreach services to street population (both HCV mono-and HCV/HIV co-infected) is excellent.

WHAT PHAC COULD DO BETTER FOR THE HCV COMMUNITY:

(1) **Interface with grassroots organizations.**

(a) **Limit concept of blood-borne infections.** While the idea of consolidating "Blood-Borne Infections" into one group works well at the federal and to some extent, regional levels (through CATIE), it does not work well at the local/grassroots level in which most of the face-to-face contact with clients occurs**.** ***Client-specific means disease-specific, so to meet their clients' needs, grassroots organizations tend towards disease-specialization.*** PHAC's acceptance of that model could be mutually beneficial.

PHAC should acknowledge - then engage - provincial and local-level HCV organizations and support their valuable education, prevention, and support activities. At present this is a missed opportunity which is detrimental to the public health. At present, complications of HCV are responsible for more deaths than HIV/AIDS in the US. The situation may be similar in Canada, though the data seems unclear, possibly due to cause-of-death reporting discrepancies. HCV can take decades longer than HIV/AIDS to manifest itself, so the true public health consequences of HCV took longer to become a concern. Consequently HIV/AIDS non-profits have developed earlier, resulting in stronger infrastructures and linkages within PHAC. It is time to acknowledge and correct this situation.

(b) **Support volunteers**. The contributions of volunteers, especially peer volunteers, in the HCV community are being ignored. PHAC would be wise to make use of and strengthen existing grassroots-level HCV organizations and give volunteers the supports they need. This support should include operational funding as well as project funding. Project funding only works once operational funding is in place. If the day-to-day expenses are not covered, ill-conceived, money-wasting "make-work" projects result.

Volunteers, often infected, ill, and/or elderly, are presently giving their all, with no personal benefit, to HCV-specific non-profits. At present the only way these organizations can get PHAC support is for "projects": nothing for office, executive director, or day-to-day operations. This makes it difficult for them to function and almost impossible to go beyond the current activity level (consisting mainly of support groups, phone support, patient pamphlets placed in doctor offices, website, booths at local activities, and anti-stigma activities such as parades and marathons). It also frustrates their attempts to apply for grants, create projects, attend/organize conferences, and maintain relationships with other organizations at horizontal (parallel) and umbrella (top-down) levels, which are normally handled by a paid executive director.

(2) **Publicize employee risk factors & employment guidelines.** Specific information regarding the infection routes of HCV should be provided to employers to allow them to accurately assess whether an employee\s HCV+ status would present any health risk to others. Federal guidelines should be issued to prevent inappropriate banning of HCV+ individuals from employment where their status does not put anyone at risk.

There seems to be little cooperation or knowledge exchange between federal-level public health and labour-oriented agencies. Those infected by various blood-borne infections, in particular, need potential employers who are educated about their specific disease and its mode (s) of transmission. At present, employers increasingly ask potential employees if they have ANY "infectious diseases", and if applicants truthfully reveal their HCV status, they are frequently excluded from positions for which they pose absolutely no threat to others. "Blood-borne disease" is a convenient label for public health purposes, but other transmission routes are generally known to exist, and employers' lack of information results in unnecessary stigma and discrimination.

In addition, employers—as well as the general public—lump all the kinds of hepatitis together. The results of this are similar to the grouping of "blood-borne diseases": unnecessary stigma and discrimination in the workplace. More specific information for employers is critical. Accurate and disease-specific information as part of public health-informed employment guidelines should be disseminated broadly to employers, and updated regularly along with all the other labour standards. A meeting or two between the federal ministries of health and labour would serve to identify areas in which the needs of BLOODBORNE-DISEASE PATIENTS and POTENTIAL EMPLOYEES intersect. Possibly creating a "Blood-borne Disease" liaison position to maintain communication between health and labour industries would be helpful. (And if there is one at present, it is not working effectively!)

HepCBC will post any responses from PHAC to our website and to the *hepc.bull*. Your comments are welcome!

I want to help HepCBC continue to support our community!
Please mail your cheque and the form below to:
HepCBC, 2642 Quadra St, PO Box 46009, Victoria BC, V8W 1J6

HepCBC Hepatitis C Education and Prevention Society is a Registered Canadian Charity: 86800-4979-RR0001

□ As a volunteer (we'll forward you information)

□ Here is my tax-deductible donation of
$30 _____ $50_____ $100_____ Other_____

Name: _____

Email: _____

Address: _____

Phone: _____

New treatments for HCV are focusing on combinations of direct-acting antivirals (DAA's) that target the viral protease, polymerase and NS5A enzymes. They may or may not be combined with pegylated interferon and/or ribavirin (peg/RBV).

In general, new compounds are tested first in healthy subjects to assess safety. Then they are tried in a small group of patients for a few days to assess proof of concept, safety, and to some degree, effectiveness. Later larger trials are usually restricted to treatment-naïve patients (those who have not been exposed to Peg/RBV or any DAA). These trials usually assess dosage and treatment duration and also look for adverse effects. The next series of trials may explore specific genotypes depending on how the drug works on specific genotypes in previous trials. Patients who have been exposed to Peg/RBV are usually accepted in this stage of the game (Phase II), but not necessarily.

By the time Phase III trials take place, just about everyone can get in, perhaps with the exception of null responders to Peg/RBV or those who have been exposed to a DAA. These patients go to the very end of the line in clinical trials, and MAY be admitted to trials toward the end, before the drug is submitted for approval. You do NOT want to be a null responder or a DAA-experienced patient if you really want to get into a clinical trial.

Efforts are being made to reduce the number of compounds required and the duration of treatment. The days of 48 weeks of treatment are over, with many now aiming for 24 and even 12 weeks. We have seen in the past with Peg/RBV that shortening treatment time can and often does lead to reduced response rates. Genotype (GT) 2 and 3 seem to do well enough with 24 weeks while GT1 requires 48 weeks. Questions remain whether current trials with DAA's, in which treatment ends at 12 weeks, will be effective in all participants in the trial. One good example is the Electron study, in which one of the study arms treated GT1 patients who had a null response to previous treatment with Peg/RBV. Ten null responders were in this arm and took GS-7977 and RBV for 12 weeks. Other arms included patients with GT2 and 3, and treatment naïve GT1 patients. The viral loads of all arms drastically reduced during treatment. However only 1 out of 10 (10%) in the null-responder arm experienced SVR12 (no virus 12 weeks after end of treatment). The virus quickly rebounded after treatment stopped in these patients. In the other arms SVR rates were between 60 to 84%. Would a longer treatment time have produced a better outcome for the null arm?

In another trial with BMS-790052 and BMS-650032 (NS5A and a protease inhibitor) previous null responders were on dual therapy (2 DAA's only) or quad therapy (2 DAA's with Peg/RBV).

Only 2 out of 9 GT1a patients in the DAA-only arm achieved SVR, while 9 out of 10 did so in the quad arm. Patients with GT1b did far better because GT1b virus does not acquire the mutation(s) that produces resistance as easily as the GT1a virus. In another similar study, the dual DAA-only form of the treatment cured 90% of GT1b patients.
(www.natap.org/2012/HCV/011212_05.htm and www.natap.org/2011/AASLD/AASLD_17.htm)

Those entering clinical trials should consider:
* What is the outlook for those who failed to achieve SVR?
* Will they be eligible in future trails now that they have been exposed to a DAA?
* Will they be eligible for new approved treatments if there is a risk they carry a resistant strain of the virus?
* Will the pharmaceutical company have a rescue option for them, with a stronger/longer treatment or will they just say, "Gee, too bad. Thanks for participating, and good luck"?
* Remember, null responders and those exposed to DAA's end up at the end of the line in future clinical trials. To date, I am aware of only ONE trial that accepted previous protease failures, and this was, surprisingly, a phase II trial! The trial was initially for treatment-naïves but they added 2 arms for previous nulls and protease failures. (*ClinicalTrials.gov Identifier: NCT01359644 GS-7977 and BMS-790052 with/without ribavirin).*

With the introduction of the new DAA's, we saw the development of resistant strains of the virus in which the compounds had reduced or little effect. Substitutions in key positions within the nucleotide sequence of the viral RNA generate viral enzymes with amino acid substitutions in key positions in the respective enzyme. The viral enzymes are the targets of most of today's DAA's. Often when resistance develops during treatment with a specific DAA (e.g., telaprevir, or BMS-790052), that resistant strain will show a resistance of some degree to other compounds in that class of DAA. For example, a virus with resistance to telaprevir will show resistance to other protease inhibitors such as boceprevir, TMC435, R7227... but the good news is that there are 2nd generation DAA's coming out that show increased activity against resistant strains.

How do we develop a treatment that is effective for everybody without causing new strains of drug-resistant viruses from exploding in the population and developing an untreatable patient? Some trials are combining compounds that, by themselves, are known to generate a resistant viral population in certain patients, and these resistances are often tied to a specific genotype. NS5A inhibitors that are known to be less effective against genotype 1a's are being used with protease inhibitors and or non-nuc polymerase inhibitors which, when used alone, also generate resistant viral populations in certain patients. Will combining these compounds generate a magic bullet or will we see still more treatment failures and a viral population resistant to multiple DAA's?

I would strongly urge the potential clinical trial participant to learn as much as possible about the new compound(s) and past results before thinking about committing to a clinical trial. The patient should understand how effective the drug has been against the genotype they carry, as well as the possibility of resistance. The length of time of the dosing should also be considered, especially if s/he is considered "hard to treat." Questions such as "will the study length be long enough in 1a nulls", or "will resistance be an issue with genotype x" cannot be answered without "breaking a few eggs," but do you want to be one of those eggs?

Trial participants must sign a waiver stating that they are aware of the risks and understand that the treatment is experimental, with no guarantees, but they often do not know the important questions to ask, and I would doubt the study coordinators/nurses would have all the answers if they did. We wouldn't need clinical trials if we had all the answers. The risk of entering a trial that leaves the participant essentially untreatable for a number of years is real and has happened to hundreds if not thousands of previous trial participants.

For more reading*:* *www.ncbi.nlm.nih.gov/pubmed/20006612*
http://investors.gilead.com/phoenix.zhtml?c=69964&p=irol-newsArticle_pf&id=1757156
www.hcvadvocate.org/hepatitis/Basics/New%20Antivirals.pdf
HCV drug resistance *www.hcvadvocate.org/news/newsLetter/2010/advocate0210.html*

CONFERENCES

The 6th Paris Hepatitis Conference (PHC)
14-15 January 2013
Palais des Congrès de Paris
Paris, France
www.colloquium.eu/site/-Homepage,2334-

Canadian Digestive Diseases Week (CDDW) and Annual Canadian Association for the Study of the Liver (CASL) Winter Meeting
1-4 March 2013 Laurel Point, Victoria, BC
www.cag-acg.org/annual-conference-cddw

23rd Conference APASL (Asia Pacific Assoc. for the Study of the Liver)
7-10 March 2013 Singapore
www.apaslconference.org/

21st Annual Conference of Indian National Association for Study of the Liver
22-24 March 2013
HICC, Near Hitec City, Hyderabad, India
www.inasl.org.in/indexhome.php?do=menu2&lmid=17

International Liver Congress 2013 - 48th Annual Meeting of the European Association for the Study of the Liver (EASL)
April 24-28, 2013
Amsterdam, the Netherlands
www.easl.eu/liver-congress

2013 8th International Workshop on Hepatitis C Resistance & New Compounds
June 27-28, 2013
Cambridge, MA
www.virtualmedicalcentre.com/conferences/2013-8th-international-workshop-on-hepatitis-c/2540

National hepatitis Health Promotion Conference 2013
14-15 November 2013
Sydney, Australia
www.hepatitisaustralia.com/events/hepatitis-health-promotion-conference

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™

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

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

MerckCare™ provides all of these services free of charge. To enroll in MerckCare™, 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 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.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

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

CLASS ACTION/ COMPENSATION

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

CLAIMS ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

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

Settlement Agreement:
http://www.pre86post90settlement.ca/PDFs/SA/hepc_settleagreement.pdf

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-2873

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

- **Campbell River**: Drop in, needle exchange, advocacy. 1371 C - Cedar St. Contact *leanne.cunningham@avi.org* 250-830-0787
- **Comox Valley** Harm reduction, counselling, advocacy. 355 6th St., Courtenay. Contact Sarah *sarah.sullivan@avi.org* 250-338-7400
- **Nanaimo** 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*

Comox Valley Positive Wellness North Island Treatment/Pre & Post-treatment Support Group 2nd & 4th Wed., 615-10th St, **Courtenay**. Lunch. Contact Cheryl *Cheryl.taylor@viha.ca* 250-331-8524.

CoolAid Community Health Centre, **Victoria.** Meetings each Wed 10 AM. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz *rmilne@coolaid.org*

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231 *dggrimstad@shaw.ca*

Cowichan Valley HCV Support Contact Leah 250-748-3432 *r-l-attig@shaw.ca*

HepCBC *info@hepcbc.ca*, *www.hepcbc.ca*

- **Victoria Peer Support**: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 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, 2nd and 4th Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support and meeting info. Contact Elaine 250-768-3573, *eriseley@shaw.ca*, Lisa 1-866-637-5144 *ljmortell@shaw.ca*

Mid Island Hepatitis C Society Contact *midislandhepc@hotmail.com*

Nanaimo Hepatitis C Treatment Support Contact Fran 250-740-6942. *hepctxpeersupport@hotmail.com*

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

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

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

- **Courteney**: 2nd Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)
- **Campbell River:** 2nd 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: Unit #1 2712 Clearbrook Rd., M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or hepcsupport@plfv.org

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

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

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-2487, 1-888-557-2487, *http://health.groups.yahoo.com/group/Network-BC/* *wendy@wendyswellness.ca* *www.wendyswellness.ca*

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

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

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 *bloodties@klondiker.com*

OTHER PROVINCES

ONTARIO:

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

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

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

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

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, 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: 519-434-1601, 1-866-920-1601, www.*hivaidsconnection.com*

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.ca* 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, *www.publichealthgreybruce.on.ca/*

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

St. Catharines Contact Joe 905- 682-6194

Sudbury Circle C Support Group 1st Tues. monthly. Contact Ernie 705-522-5156, *hepc.support@persona.ca* or Monique 705-691-4507.

Toronto CLF 1st Mon. monthly Oct.—June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. Contact Billie 416-491-3353, ext. 4932. *bpotkonjak@liver.ca* *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*

QUEBEC:

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:

Manitoba Hepatitis C 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 *info@hepcbc.ca* by the 15th