

Canada's Hepatitis C News Bulletin

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SOVALDI TM (sofosbuvir) AND GALEXOS TM (simeprevir) APPROVED BY HEALTH CANADA

Two long-awaited hepatitis C drugs have recently been approved for use in Canada by Health Canada: Janssen's **simeprevir** (**now Galexos**TM) on November 16, 2013 and Gilead's **sofosbuvir** (**now Sovaldi**TM) on December 20, 2013. Most Canadians, however, won't be able to get prescriptions covered until the drugs are approved by their province's Pharmacare plan; these additional drug reviews normally take 6 months or more. Details for each drug follow:

SovaldiTM (polymerase inhibitor)

Gilead Science's direct-acting antiviral (DAA) sofosbuvir (SovaldiTM) is a onceaday oral polymerase inhibitor. It will be available for patients in January 2014. The patient support program — Gilead Momentum Support Program — is scheduled to start on January 6th.

SovaldiTM is approved for genotype (GT) 1 and GT 4 patients, combined with pegylated interferon (pegIFN) and ribavirin (RBV), also called pegIFN/RBV, or just PR. It is also approved for GT 2 and GT 3 patients, combined with only RBV. It can be used even in those with compensated cirrhosis.

(SovaldiTM—Continued on page 4)

GalexosTM (NS3/4A protease inhibitor)

Janssen Inc.'s GalexosTM was the first DAA treatment for hepatitis C to be approved for once-daily use. Its side-effects are considered manageable. Taken orally once a day in combination with pegIFN and RBV, this NS3/4A protease inhibitor is approved for GT 1 only. It may be used in those with compensated cirrhosis, who are treatment-naïve or who have failed previous therapy with (pegylated or non-pegylated IFN and RBV. (GalexosTM—Continued on page 4)

MICHAEL'S STORY: THE SEQUEL

by Joan King

We just received this email:

"I am replying from the computer of John Jenkins. Please be advised that Mr. Jenkins passed away on November 25, 2013 from complications relating to Hep C."

-- Tannis Booth

"Michael" was, in real life, John Jenkins, of Campbell River, diagnosed in 1997. You may have known Michael from the hepcan and other lists as "Michael Peterson" or "searcher" (searcher ca).

"Michael's Story" was published on the front page of our January 2013 issue of the hepc.bull. I called Tannis this evening, and she has kindly given me permission to use his real name. John was a long-time member of HeCSC (1999 or earlier), and member and volunteer phoner and donor for HepCBC at least as far back as 2004. He was a member of the '86-90 Class Action suit. He kept in touch with me many times over the years. Also a patient of Dr. Anderson, Natalie, and Lori Lee, at the LAIR Clinic in Vancouver, he was pro-active with his health. He was one of the first to sign up for a Fibroscan.

He and his beloved life-partner Tannis were able to squeeze in an Alaska cruise in

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HEPATITIS C AND "THE REST OF THE WORLD" – HIGHLIGHTS OF FOUR CANADIAN CONFERENCES

In Sept./Oct. 2013, on behalf of HepCBC, I attended four informationpacked Canada-wide meetings with AIDS service organizations (ASO's), HCV groups, medical practitioners and researchers, aboriginal health representatives, human rights lawyers, prison outreach workers, federal and provincial/ territorial public health administrators, social workers, and advocates from HIV+ or HCV+ communities (such as myself). While HIV/AIDS tended to be their focus, most of the participants are trying to integrate HCV into their work, and the speakers tried to address this need. In turn, we in the HCV community can learn so much from their experiences and insights, so we don't have to re-invent the wheel but can, in significant ways, model future HCV programs on those now addressing HIV/ AIDS. The conferences:

•Canadian Treatment Action Council (CTAC)

Sept 16-17 2013 – Toronto

•Canadian AIDS Treatment Information Exchange (CATIE)
Sept 18-19 2013 – Toronto

•Action Hepatitis Canada (AHC) Sept 17 2013 – Toronto

•Pacific AIDS Network (PAN)
Oct 29-30 2013 – Vancouver

A summary follows of the ideas that most excited me, or which I thought could be of value to the HCV community:

(1) LOOKING AT HCV TREAT-MENT ACCESS AND PRICING FROM A GLOBAL PERSPECTIVE

Situation:

170-185 million people worldwide are HCV+.

Developing nations typically experience a 4-year delay getting new treatments.

(Continued on page 3)

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

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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.

CANADIAN GOVERNMENT CALLS FOR CADTH "THERAPEUTIC REVIEW" OF HEPATITIS C GENOTYPE 1 TREATMENTS

HepCBC is one of several organizations participating in a comprehensive hepatitis C (genotype 1 only) "Therapeutic Review" called by pharmaceutical drug regulatory body CADTH (Canadian Agency for Drugs and Technologies in Health). Unlike reviews for approval of a specific drug or treatment, CADTH says this is an assessment of "the clinical and economic impact of new and existing drugs to treat chronic hepatitis C (HCV) infection...(and its)... findings and recommendations will inform drug reimbursement policies and the clinical use of HCV drugs in Canada."

HepCBC will be providing an online portal between Dec. 23, 2013 and Jan. 10, 2014 for genotype 1 HCV+ individuals and caregivers to submit their input into our Patient Group submission. Visit us at: http://hepcbc.ca/cadth-therapeutic-review-of-hcv-treatments-individual-input-page/.

As CADTH further explains, "Before 2011, dual therapy with pegylated interferon plus ribavirin (PR) was standard treatment for people with HCV. The development of the first direct-acting antiviral agents, boceprevir and telaprevir, dramatically changed the landscape of HCV treatment. Many patients now receive triple therapy with PR plus one of the new drugs. As more new drugs become available, information is needed on (1) how triple therapy compares to dual therapy, and (2) how the new drugs compare with each other. This review will look at available information on PR, telaprevir (Incivek), boceprevir (Victrelis), simeprevir (Galexos), sofosbuvir (Sovaldi), and faldaprevir."

In a separate conference call with CADTH, organizations were assured that though this therapeutic review would not be completed until autumn, 2014, it would in no way delay its regular review process of HCV treatments. CADTH said that a "pharmo-economic analysis" (for econotechies out there: cost-utility analysis and Markov transition-state model) would be part of this review, but that patient input isn't part of these computations at present. This is actually the first time CADTH has used patient input as part of a Therapeutic Review, so this is a pilot project for them.

Karen Lee, health economist at CADTH, explained at a Sept., 2013 CTAC conference how limited government budgets require assurance that treatments they cover

are cost effective. As our population ages, this involves researching ways of maximizing benefits of survival in terms of "Quality-Adjusted Life Years" (OALYs). To compare two similar treatments, CADTH compares not only the difference in drug cost but the difference in how many OALYs each will, on average, provide a patient. Then they compute this at the level of the entire population to determine which treatment is more effective in decreasing the "Burden of the Disease" across the entire population. For example, an HIV drug which cost \$2400 per QALY gained was considered an excellent bargain. Obviously, the earlier in a person's life HCV is treated, the more OALYs that individual will gain. Current HCV treatment criteria requiring proof of significant organ (liver) damage fails to recognize this way of maximizing benefit.

CIRRHOSIS REVERSAL POSSIBLE?

Our volunteer Cheryl, who has cirrhosis, took an interferon-free, ribavirin-free clinical trial with only asunaprevir and daclatasvir, for GT1b only, between July and December, 2012.

She had SVR in week 6 of treatment; the SVR has continued. Just prior to starting treatment, her Fibroscan score was 49.6 kPa (17 - 75 is cirrhosis).

On December 19, 2013 her score was 18.0 kPa. Just one person, but we're wondering how common this is. Anyone else?

THANKS!!

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

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, Bristol-Myers Squibb, Boerhinger-Ingelheim, AbbVie, VanCity, Shoppers Drug Mart, Market on Yates, Country Grocer, Safeway and Thrifty Foods.

(HCV & The Rest of the World—Cont'd from p. 1)

Treatment costs, even in North America, are higher than the annual salary of most families.

In many countries, including Canada, patients must prove they have significant organ damage before their drug costs will be covered. Ironically HCV treatment is more successful when given before damage has occurred, providing greater financial and health benefits, as well.

In developing countries, adulteration of generic drugs can result in greater or lower amounts of active ingredient(s). Therefore, assuring drug purity, composition consistency, and patient compliance, is imperative in order to prevent breakthrough and development of treatment-resistant strains.

Ideally, HCV testing would be easy to obtain (or automatic), free, anonymous, and fast. As this is seldom the case, the percent of undiagnosed cases is high.

Goal:

Eradicate HCV from the face of the earth by making the best treatment possible available to the most people possible, as soon as possible, worldwide.

Possible solutions:

- •Establish 'patent-free' regions in poor countries to make low-cost drugs available.
- •Make generics available in all countries (while ensuring generics are priced at least 25% lower),
- •Use group bulk-drug purchasing/pooling (such as a Pan-Canadian Purchasing Alliance or a Public Procurement Program)
- •Achieve economies of scale by expanding testing and abolishing treatment criteria requiring proof of organ damage, thus increasing the number of potential customers
- •Encourage drug companies to work together instead of developing similar drugs in competition.
- •Develop/implement generic drug purity regulations and laws in all nations.

Questions:

- •How can we 'balance' our need to encourage research and protect intellectual property with the need to save human lives?
- •What is the appropriate amount that developed nations can/should 'subsidize' the costs of HCV drugs in developing nations?
- •Would policies which create a greater market--such as widespread test/treat campaigns and lowering treatment criteria-result in drug companies lowering their prices?

(2) LOOKING AT HCV TREATMENT FROM PEER NAVIGATION AND COMMUNITY PERSPECTIVES

Charles Osbourne of the Positive Living Society of BC (Vancouver) described a successful Peer Navigation program which connected HIV patients to a peer navigator within the first 24 hours following their diagnosis. Peers are selected who are excellent models of self-management. And stigma is not an issue when your 'navigator' is in the same boat. A future article in this bulletin will look into peer navigation programs in more detail.

Shannon Froelich of Positive Living North (Prince George) described results that occurred in northern and remote areas when community leaders became involved. This was echoed by native health representatives from the Prairies and Eastern Canada. Elders and healers are becoming involved in HIV education, testing, and treatment. Stigma against (again, HIV) testing dissipates when a community's chief and band councillors get 'point-of-care' (rapid result) testing publicly. "Frontline Warriors" are brought into remote communities to tell their own stories and get conversation about these uncomfortable issues started. HCV is slowly being integrated into these activities and services.

(3) USE OF TECHNOLOGY TO REACH THOSE IN REMOTE COMMUNITIES (AND KEEP THEM THERE DURING TREATMENT)

Technologies known as ehealth, mobile health (mhealth), ECHO projects, and telemedicine are being developed as models and include educational DVDs, providing patients with iPhones (and various treatment apps) or other access to the Internet, consolidating all medical records digitally, then making them instantly available online, and connecting medical staff and patients in small communities to those in larger centres and universities with various platforms for web conferencing, training, and diagnosis/treatment. Keeping patients at home within their supportive communities saves lives and money.

(4) COMPARING HIV/AIDS WITH HCV

- •Worldwide approximately 40 million are HIV+ while 170 million are HCV+ (over 4X as many have hepatitis C).
- •In North America, deaths from HCV have exceeded those from HIV since approximately 2007, with most HCV deaths occurring in the 'over 50' population.
- •In those countries in which HIV+ people can access the new HAART treatments (which patients take DAILY throughout their lives), HIV is being transformed from a fatal disease into a chronic one.
- •With direct-acting anti-viral drug regimens against HCV, which patients need to

- take ONLY ONCE in their life (over a period of several weeks) HCV is being transformed from a chronic disease into a curable one!
- •The representative from Canada's Research-Based Pharmaceutical Companies (Rx&D) noted that current clinical drug trials in Canada include 45 for HIV versus 67 for HCV.
- •13,000 Canadians are HIV/HCV coinfected; while this number represents 20% of HIV+ people, it only represents 5% of HCV+ people (see http://www.cocostudy.ca).

(5) DIVERSE POPULATIONS AND NEEDS OF HCV+ PEOPLE

Various populations of HCV+ people require such different treatment! For example, current users of IV drugs and MSM (men who have sex with men) are most in danger of getting and spreading HCV currently, so they need harmreduction supplies and regular testing. Treatment may be complicated by addiction, mental health, and adherence issues. In contrast, those currently in most danger of dying from HCV are older, not using IV drugs, and in need of one-timeonly testing and treatment. Those HCV+ people co-infected with HIV, TB (common on some First Nations reserves), or hepatitis B (common among immigrants from some countries) require substantially more complicated treatment. Those living in remote communities have significantly greater problems with confidentiality than those living in far more anonymous cities. Translating HCV information into various languages and getting it out to the people who need it remains an urgent challenge. In immigrant communities, fears of stigma, rejection by family, or deportation are big impediments to testing. Now, too, the treatment and side-effects of people with different genotypes complicates treatment a lot. Finally, the needs of those who have failed treatment are largely being ignored.

This article barely touches on the many issues discussed in these conferences. I hope it gives you at least a taste of my experience, and that one of these years, you can attend one or more of these amazing events yourself! I did make a speech about the needs of HCV+ people at the end of the CATIE conference, which can be accessed here: http://www.catie.ca/en/forum/webcast-archive/closing-plenary#reitz

-- Cheryl Reitz, HCV+ Volunteer (but just celebrating 12 months of cure!) and HepCBC Board member

(SOVALDITM —Cont'd from page 1)

There is data at the second link, below, about its use with GT 5 and 6, with HCV/HIV, and with patients awaiting liver transplants. Clinical trials showed response rates between 50-90% combining SovaldiTM with PR or RBV alone in a 12-16 week treatment.

The US has just approved SovaldiTM as well, but it will probably cost our neighbours to the south \$1000 a day, totalling about \$84,000.00, for the treatment. Hopefully in Canada, the drug will be approved for reimbursement by the provincial health authorities--soon! It is now under review. The SovaldiTM co-pay assistance program will provide financial assistance for eligible patients who need help to pay for the treatment.

The info sheet states, "SovaldiTM must not be administered as a monotherapy and must only be used in combination with either peginterferon alfa/ribavirin or ribavirin." This is unfortunate, since the results of a trial reported at the latest DDW showed the combination of SovaldiTM with Janssen's protease inhibitor simeprevir (GalexosTM), with or without RBV (no IFN) produced an SVR8 (no virus at 8 weeks post-treatment) for most of GT 1 non-responders. And of course, many people have a hard time tolerating IFN. [Editor: So why put them through the IFN if the combo with DAAs works so well?]

The above trial studied a difficult-to-treat group; many patients had unfavourable IL28b genes and 60% had advanced fibrosis. Even with this difficult group, the SVR rates were 93-96%. But how do you get two pharmaceutical companies to work together? Will there be a way that specialists could prescribe these two medications "off-label" to use together, perhaps combined with RBV, and still have coverage?

For those who are interested, there are some very good, all-oral, IFN-free clinical trials available right now. Contact your local Hep C clinic or support group, or check www.clinicaltrials.gov for more information. (Take a look at this one, for example: NCT01973049) An advantage to clinical trials is that they provide free medication. Be sure you find one that is Phase II or III.

INFO LINE for SovaldiTM: 1-866-207-4267

Sources: www.businesswire.ca/news/caen/20131216005435/en/Health-Canada-Issues-Notice-Compliance-Sovaldi%E2%84%A2-Sofosbuvir

www.gilead.ca/pdf/ca/sovaldi pm english.pdf http://www.foxnews.com/health/2013/12/09/fdaapproves-1000-day-hepatitis-c-pill/

http://www.hivandhepatitis.com/hepatitis-c/ hepatitis-c-topics/hcv-treatment/4126-ddw-2013interferon-free-simeprevir-sofosbuvir-suppresseshepatitis-c-with-or-without-ribavirin

CLINICAL TRIALS: ABBVIE

AbbVie Inc's all-oral, interferon-free, 12-week hepatitis C therapy cured 96 percent of 394 Genotype 1 patients, half of whom were previous 'null responders' to standard treatment of pegylated interferon-ribavirin. More information below from press release:

"NORTH CHICAGO, Ill., Dec. 10, 2013 /PRNewswire/ -- AbbVie (NYSE: ABBV) released phase III results for the investigational three direct-acting-antiviral (3D) regimen plus ribavirin in patients with chronic, genotype 1 (GT1) hepatitis C virus (HCV) infection. In the 394-patient SAPPHIRE-II study, 96 percent of patients who previously failed pegylated interferon and ribavirin treatment, including approximately 49 percent of who were prior null responders, achieved sustained virologic response at 12 weeks (SVR12) with the regimen. The majority of patients were GT1a, considered a difficult-to-treat subtype, and the SVR12 rates of GT1a and GT1b were 96 percent and 97 percent, respectively. Virologic relapse or breakthrough was noted in 2 percent of patients receiving the 3D regimen plus ribavirin. In addition, the discontinuation rate due to adverse events was 1 percent.

"SAPPHIRE-II demonstrates that treatment-experienced genotype 1 HCV patients achieved high rates of virologic response with AbbVie's interferon-free, alloral 3D regimen plus ribavirin," said Scott Brun, M.D., vice president, pharmaceutical development, AbbVie. "Completion of the two placebo-controlled SAPPHIRE studies is an important step in AbbVie's HCV clin-

(Continued on page 6)

(MICHAEL: THE SEQUEL—Cont'd from page 1) spite of their health problems. They moved to Courtenay in 2008. She was diagnosed with stage 4 cancer and began treatment back in 2009, and my partner was going through cancer treatments at the same time. We compared notes and shared worries. She had 1-2 years to live then. John had a scope, ultrasound and CT scan done in 2009, and his AFP levels had gone up. This is a possible sign of liver cancer. (Have you had your AFP done lately?) He shared his experiences with Pegasys back in 2010. His cirrhosis was still compensated then. Unfortunately, he relapsed.

By Jan 2010, John's AFP levels had doubled from the year before...but his scan showed no tumour. His local "hep-god" recommended low-dose maintenance, and they were finally able to get coverage for it, so in April 2010 John started a 15-month treatment of Pegasys low-dose maintenance

This was his fifth time taking interferon; he'd been on Pegasys maintenance for 8 months a few years previously. His first week's prescription cost \$441.00, and as a member of the '86-90 class action, he was covered but had to wait for reimbursement. "I feel so bad for patients who can't get coverage," he wrote.

We chatted and bragged about grandkids, "Back to ice cream, I told Aleshia (grandaughter) that I would take her for ice cream too...Being a grandparent is special ... I spent most of my time with my gran and grandad. learned to drive tractor, milk cows etc. .. Yes, they were farmers and hold some treasured memories for me"

John complained about severe brain fog on the hepcan list March 27 of this year, and he cried with us over the passing of Gloria Adams in April. If only John-and Gloria-had had the opportunity we now have with the 2nd generation drugs! "This disease is not for sissies. 'Bye for now." --Michael

(GALEXOSTM—Cont'd from page 1)

Galexos[™] is given along with pegIFN/RBV for 12 weeks, followed by pegIFN/RBV alone for an additional 12-36 weeks.

Efficacy is comparable to or better than that of current triple therapies for GT 1, with side -effects the same or fewer. Patients only have to take GalexosTM once a day, and needn't take it with any special food such as fats.

HepCBC welcomes this new addition to the HCV "Treatment Toolbox"!

"Patients with hepatitis C and their physicians need new, more tolerable treatment options for this complex and difficult-to-treat disease," said Dr. Morris Sherman, Associate Professor of Medicine at the University of Toronto. "Data from clinical trials have shown that in combination with pegylated interferon and ribavirin, GALEXOSTM can give patients, even those who have failed previous treatment with pegylated interferon and ribavirin, a chance to cure the disease with a manageable side-effect profile."

http://www.newswire.ca/en/story/1264711/new-treatment-for-hepatitis-c-approved-by-health-canada-priority-review-gives-physicians-and-patients-an-effective-and-tolerable-treatment-choice http://www.catie.ca/en/treatmentupdate/treatmentupdate-198/hepatitis-c-virus/simeprevir-peginterferon-ribavirin

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Sources:

OTHER HEPCBC PROJECTS

HepCBC is also involved in seven more projects you may want to join in on as a volunteer; if any of these interest you, let us

- (1) Distributing pamphlets and pamphlet holders in your local doctors' offices, clinics,
- (2) Setting up information tables and booths at community events. Just recently, a group of Infectious Disease physicians had a conference in Victoria, and we set up a table with samples of educational materials they could give to all newly-diagnosed patients.
- (3) HepCBC is part of a BC Cancer Agency Liver Cancer (hepatocellular carcinoma or HCC) action group trying to come up with ways of addressing the current HCC epidemic, largely a result of aging Baby Boomers with (often undiagnosed) hepatitis C. Your ideas are welcomed!
- (4) World Hepatitis Day (WHD) is July 28th. It's never too early to plan a great HCV event to bring awareness and fight stigma in your community. Let us know if you need help or ideas. We usually participate in Victoria and Surrey, plus last year we helped get events going in Nanaimo and Vancouver! We also put ads in newspapers announcing WHD events province-wide.
- (5) HepCBC is looking forward to its team the HepCBC Liver Warriors' fourth year participating in the Victoria Goodlife Fitness Marathon. We use this event to demonstrate the value of exercise for people with liver disease, fight stigma, raise money, get healthy, and have fun! Consider joining us Oct. 12, 2014 OR joining (or starting) a walking or running event in your community. Having a goal is key!
- (6) We are looking forward to working with other groups throughout the province to encourage and develop Peer Navigation programs connecting newly-diagnosed, those undergoing treatment, pre-transplant, and post-transplant in particular with HCV+ peers who can help steer them in the right direction and provide a great model of 'how to do it' because they've already been there. Some people and groups are already doing this, and there is much to learn from them.
- (7) There is a great need for HCV+ people in remote communities to access the same level of information, treatment, and other services as HCV+ individuals in urban areas or the Lower Mainland. We are looking for people in these communities who have ideas about ways to help (including using new information technologies), and for volunteers in Vancouver willing to provide help to patients coming from outside Vancouver, particularly to transplant patients who are required to have a dedicated 'team' of volunteers.

HEPCBC JOINS FIRST NATIONS "GATHERING WISDOM" HEALTH FAIR

A First Nations Health representative suggested that HepCBC should display hepatitis here especially for this fair. Contact us if C materials (from many sources) in an information booth at the "Gathering Wisdom" First Nations health fair Oct. 22-24, 2013 in to print out). Vancouver. We were able to secure the booth with assistance from Gilead Sciences, AbbVie, and the BC Centre for Disease Control@UBC.



1st Nations Health Fair Booth

Four HepCBC volunteers gave out pamphlets and red/yellow ribbons while meeting new friends from all over the province!

Particularly we wish to acknowledge and thank Terry Optekamp, Community Health Rep of the Chippewas of Nawash Health Centre of northern Ontario (a presenter at the Sept. 2013 CATIE conference), who gave us permission to reproduce a Medicine Wheel showing the needs of those with hepatitis C.

This health fair was part of a very significant event: commemorating this year's official ceding of medical authority and resources from the federal and provincial governments to the British Columbia First Nations Health Authority.

> Northern & Remote Community at increased risk due to:

Stigma and Isolation UncertainTesting will be Confidential Distance from Treatment Centres Lack of Peer Support Fear of Disclosure Consequences Inability to access Transplant Services Lack of Accessible Information



HepCBC created the three posters shown

you want a poster (a pdf



MEDICINE WHEE





Volunteer Anita York at Booth

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DEAR EDITOR: WE HAVE TIPS, TOO!

The article by Sandy J. in last month's newsletter was very popular. It sparked some interest from our readers. It seems that many who have gone through it have their own discoveries. I'm including some in this edition, and would like to invite our readers to participate in a "TIPS" column. When there are enough, we'll include them. Who knows better than those who have gone through it?

"Look for a white spot between the blue and red veins. Inject there, and you probably won't bleed."

"For the first injections, numb the area with ice."

"Try diphenhydramine for sleep, or Gravol for Telaprevir/Incivek, though sometimes you may want zopiclone/immovane on top of the diphenhydramine." [Editor: Ask your doctor before taking any medication during treat-

"I noticed receding gums while on pegIFN/ RBV. I used mouthwash with alcohol and brushed twice a day."

"I had mouth sores with IFN. I used Biotene mouthwash and toothpaste, and magic mouthwash when it was really bad. I had to give up potato chips and drink through a straw. Here's a recipe for 'Magic Mouthwash':

1/3 Maalox

1/3 liquid Benadryl

1/3 lidocain viscous 2% solution

(You may need prescription. Talk to your pharmacist.)

"I often get a rash on my neck if I do not use isopropanol after shaving whether on TX or not."

"Try Tylenol or Tylenol with codeine for aches and pains."

"An electric bed warmer, the first few nights. You can get severe chills with pegIFN!"

"Cut way down on sugar and go on yogurt (or probiotics) to maintain healthy gut flora."

"Drink lots of water!"

"See your doctor if a rash starts and keep an eye on it, especially if you're taking a protease inhibitor!"

"Don't forget to drink coffee (3 cups a day), vitamin D3 and vitamin B12.

"Set your alarm. Try to take the meds at the same time. Take them with you if you're going out."

(CLINICAL TRIALS—Continued from page 4) ical development program. We look forward to the results of studies looking at AbbVie's 3D regimen with and without ribavirin in different patients, as well as data from our dedicated study in patients with cirrhosis.

SAPPHIRE-II is a global, multi-center, double-blind, randomized, placebocontrolled study to evaluate the efficacy and safety of 12 weeks of treatment with ABT-333 (250mg), ribavirin (weightbased), both dosed twice daily, and the fixed-dose combination of ABT-450/ ritonavir (150/100mg) co-formulated with ABT-267 (25mg) and dosed once daily in non-cirrhotic. GT1a and GT1b HCVinfected, treatment-experienced adult patients who previously failed treatment with pegylated interferon and ribavirin.

The most commonly reported adverse events in both the 3D and placebo arms were headache, fatigue and nausea. ..Virologic relapse or breakthrough was noted in 2 percent of patients receiving the 3D regimen plus ribavirin."

Source:

http://abbvie.mediaroom.com/2013-12-10-AbbVie-Demonstrates-96-percent-SVR-12-inits-Phase-III-Study-of-Treatment-Experienced-Patients-with-Genotype-1-Hepatitis-C

SOUPAPALOOZA!

Penticton harm reduction peers, in conton & District Community Resources Society will be hosting another Soupapalooza on Thursday Jan 16, 2014 from 12pm-2pm. This will be held at Saint Savior's Church at 150 Orchard Ave. Penticton. BC. Various community organizations and outreach workers will be present to bring awareness to the community and those less fortunate so they have an idea of who and where to turn when they are in need of services. There will be snacks and coffee as well as some door prizes. We hope this one will be as successful as the last.

Merry Christmas and Happy New Year.

Melanie Gale, BSW, RSW Harm Reduction Outreach Worker

PENTICTON & DISTRICT COMMUNI-TY RESOURCES SOCIETY

since 1966

330 Ellis Street, Penticton, BC, V2A 4L7, Phone: 250-492-5814, Fax: 250-492-7572

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:

- 1. **GJ** Dec 1998 IFN/RBV 52 wks—Dr Anderson /Natalie Rock , Vancouver, BC.
- 2. Amberose 2000 GT 2A/2C Schering IFN/ RBV 24 wks
- 3. Jeanie Villeneuve Oct 2000 Schering IFN/RBV
- 4. Kirk Leavesley (GT1) 2004 Roche
- 5. Darlene Morrow (GT1 relapser) Mar 2004 -Hyperthermia/Induction + pegIFN/RBV.
- 6. Beverly Atlas (GT1a) 2006 Albuferon/ RBV 44 wks
- 7. **Steve Farmer** 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
- 8. Gloria Adams (GT1b relapser) Fall 2009 IFN/RBV/Telaprevir 48 wks -Drs Erb & Yoshida, Vancouver, BC.
- 9. Don Crocock (GT1) Stage II Dec. 2010 IFN/RBV - 48 weeks
- 10. Daryl Luster (GT1a) Feb 2011 IFN/ RBV/RO5024048 48 wks.
- 11. **Donna Krause** (GT1 partial responder) junction with Interior Health and Pentic- SVR -Nov 2011- Pegasys/Copegus, Danoprevir/Ritonavir/R05024048 24 wks - Dr. Erb, Vancouver.
 - 12. Cheryl Reitz (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
 - 13. Anita Thompson (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
 - 14. Leon Anderson (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC -Vancouver.
 - 15. Joan King (GT1b treated 5 times) SVR24 June 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
 - 16. Sandy J. (GT 1a treatment naïve) SVR12 Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island.

We know there are many more of you. Please send your name and information to Joan at Making a difference in the community info@hepcbc.ca and help raise the hope of those still infected.

CONFERENCES

7th Paris Hepatitis Conference 13-14 January 2014 Paris, France www.aphc.info/home.php

AGA Clinical Congress of Gastroenterology and Hepatology 2014 17-18 Jan 2013 Miami FL

www.gastro.org/education-meetings/education-meetings-v2

German Association for the Study of the Liver 30th Annual Meeting 2014 24-25 Jan 2014 Tubingen, Germany www.medical.theconferencewebsite.com/conference-info/GASL-2014

Stockholm Liver Week 2014 5-7 Feb 2014 Stockholm, Sweden www.leverveckan.se/en

Canadian Digestive Diseases Week 7-11 Feb 2014

3rd Canadian Symposium on Hep C Virus;

CAHN; CASL /CAG

7-11 Feb 2014

Toronto, ON, Canada

www.ncrtp-hepc.ca/
www.livernurses.org/cahn-2014

www.cag-acg.org/cddw

12-15 March 2014
Asian Pacific Association for The Study of the
Liver
Brisbane, Australia
http://apas12014.com/

EASL - The International Liver Congress 2014 9-13 April 2014 International Convention Centre ExCeL London, United Kingdom www.easl.e

1-3 May 2014
The 3rd World Congress on Controversies in Clinical Management of Hepatitis
Berlin, Germany
http://www.comtecmed.com/chep/2014/

DDW 2014 3-6 May 2014 McCormick Place Chicago, IL www.ddw.org

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 CARETM

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

- assistance with reimbursement 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.

MerckCareTM 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 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 and Company Vancouver, BC Phone: 1-604-609-6699 Fax: 1-604-609-6688

www.lawyers-bc.com/classactions/clalawy.htm

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

http://lblavocats.ca/en/class-actions/hepatitis-c/active/red-cross.php

Kolthammer Batchelor & Laidlaw LLP #208, 11062 – 156 Street, Edmonton, AB T5P-4M8 Tel: 780-489-5003 Fax: 780-486-2107 http://www.kbllaw.com/

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) <u>Irene.dines@Blood.ca</u>

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 Hepatitis C@kpmg.ca

tion: 1-888-840-5764 <u>Hepatitis Calepone ca</u> Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764

CLAIMS ADMINISTRATOR

1986-1990

Administrator 1-877- 434-0944 <u>www.hepc8690.com</u> <u>info@hepc8690.com</u>

Pre-86/Post-90

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

Settlement Agreement:

www.pre86post90settlement.ca/PDFs/SA/

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-

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 <u>leanne.cunningham@avi.org</u> 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

ANKORS Hepatitis C Project (Boundary, Nelson, West Kootenay) Hep C Info, support for prevention, testing, treatment and living well with Hep C. Women's gathering monthly. 101 Baker St, Nelson.

Contact Laura 1-800-421-2437 250-505-5506 ankorshepc@ankors.bc.ca

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 Powell River Hepatology Service Powell Treatment/Pre & Post-treatment Support River Community Health, 3rd Floor-5000 Group 2nd & 4th Wed., 615-10th St, Courtenay. Lunch. Contact Cheryl 250-331-8524. Cheryl taylor@yiha ca

CoolAid Community Health Centre, Victoria. Meetings each Wed 10 AM and Thu 1:30 PM. 713 Johnson St. Support for all stages of treatment

(deciding, during, after). Contact Roz rmilne@coolaid.org 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: 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-
- 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,, meeting info. Contact Lisa 1-866-637-5144 <u>limortell@shaw.ca</u>

Mid Island Hepatitis C Society Contact midislandhepc(a)hotmail.com

Nanaimo Hepatitis C Support Meetings 1st & Thu 3-5 PM 437 Wesley St. (access off Franklyn St) Contact 250-585-3201,

hepctxpeersupport@hotmail.com

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

Positive Wellness North Island-North Island Liver Service Info, support, treatment/ pre-post treatment groups. Doctor or selfreferral. 1-877-215-7005 250-850-2605.

•Courteney: 2nd Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)

•Campbell River: Treatment/pre&posttreatment support group 1st & 3rd Thu monthly 10-12pm, Sunshine Wellness Centre, Discovery Room, Campbell River Hospital. Caroline: caroline.miskenack@viha.ca, 250-850-2620

Penticton & District Community Resources Society, Harm Reduction Program, Meetings 497-3560, 1-800-387-3701 or every 2nd Tues, 12:30-1:30 PM. 330 Ellis hepccommcoord@gmail.com, Street. Contact Melanie: 250-488-1376 or 250-

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 #108-32883 S. Fraser Way, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or plfvcentre@plfv.org

Joyce Ave. Contact Melinda 604-485-3310 Melinda.herceg@ych.ca

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/ <u>Network-BC</u>/ wendy@wendyswellness.ca www.wendyswellness.ca

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@yandu.org www.vandu.org

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

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:

Contact Jeanie for info/ appointment

jeanievilleneuve@hotmail.com

Hamilton Hepatitis C Sup-port 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-

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 hars@kingston.net www.hars.ca

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room. 659 King St. East (Enter off King St) Kitchener. 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 <u>dminiel-</u> lv@publichealthgrevbruce.on.c

<u>a</u> 1-800-263-3456 Ext. 1257. **Barrie Hepatitis Support** | 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

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 **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: info@hepns.ca 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 15th of the month. It's free!