

hepc.bull

Canada's Hepatitis C News Bulletin

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HEP C IN THE NEWS

UPDATE: IFN—FREE COMBOS AVAILABLE IN CANADA & USA

Here is the news as of December 23, 2014, of interferon-free combos from pharmaceuticals Gilead, Janssen, Abbvie, and BMS!

Following its approval of IFN-free options **Sovaldi™** for genotypes (GTs) 2/3, and **Harvoni™** (**ledipasvir and sofosbuvir**) for GT1, the USA's Food and Drug Administration (FDA) approved two additional IFN-free combos, "**SIM-SOF**" (**simeprevir and sofosbuvir**) and **Viekira Pak** (also known as "**AbbVie 3D Combo**"). It also temporarily nixed BMS's **daclatasvir**. (Details and two IFN-free *Canadian* drugs below.)

On October 10, 2014, the FDA approved the first IFN-free and ribavirin-free regimen for chronic HCV, Gilead Science's **Harvoni™**, a combination of two Gilead drugs: sofosbuvir (also marketed as Sovaldi™) and ledipasvir. It was only approved for GT1, can be used even by those with compensated cirrhosis, and has approximately 94-99% chance of curing the virus in 12-24 weeks. Side-effects are minimal compared to GT1's current standard of care (IFN+RBV [plus one of: boceprevir, telaprevir, or simeprevir]). Pricetag: \$63,000 for 8 weeks or \$94,500 for 12 weeks in the USA.

On October 16, 2014 **Harvoni™** was approved by **Health Canada**. It costs approximately 15% less in Canada. Though it is not yet reimbursed by provincial or territorial drug plans, we know that many Canadians with private, extended medical insurance plans have been able to access Harvoni™ at little or no cost through a combination of their private plan plus co-pay assistance from Gilead's Momentum™ Patient Care program.

Source: www.newswire.ca/fr/story/1429222/health-canada-issues-notice-of-compliance-for-gilead-s-harvonim-ledipasvir-sofosbuvir-the-first-once-daily-single-tablet-regimen-for-the-treatment-of

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UPDATE ON JACKIE

POST TREATMENT RECOVERY AND A ROAD BIKE RACE MEDAL

[Editor: We have already met Jackie. She had two previous articles published in the April and November 2012 issues of the hepc.bull, under the pen name "Roseen." We are thrilled about her successes!]

I feel almost giddy every time I think about or talk about my first place medal in my first ever road bike race, at age sixty, and eight months after finishing my treatment. So how did I get here?

The first time I was treated for Hep C - Genotype 1, I relapsed after 72 weeks of determination through the side effects of interferon and ribavirin. To get through that treatment, I set goals, and for me, counting down each week was another goal met. I had the support of my husband who selflessly gave so much to me during that time. Almost every side effect possible descended on me, and still we persevered together. Throughout the treatment I kept thinking it was like a crap shoot, but I had to give it my best shot, or I'd never know if I'd beat the odds or not. Six months post-treatment, when I learned I had relapsed, it was disheartening, after remaining positive and determined throughout the treatment. Even more dis-

(Cont'd on page 2)



(CTV News)

JENNIFER PEEVER (1954-2014)

This issue of the *hepc.bull* is dedicated to the memory of Jennifer Peever (b. 1954, d. Nov. 4, 2014), a Canadian grandmother from Ottawa with hepatitis C whose daughter, Brenda, fought tirelessly for over three years to gain access for her mom to Sovaldi™, a new hepatitis C treatment with a price tag completely out of the family's range.

No one in the healthcare system disputed that Jennifer was dying and could likely be saved by this medication if it were administered quickly enough. However, bureaucrats, following current government and pharmaceutical industry policies, consistently ignored the 66,000+ signatures on Brenda's Change.org petition, and denied the family's applications for compassionate care.

There are many Jennifers and Brendas in Canada, still fighting for their lives, fighting for their dear ones, and it seems no one is listening. Here at HepCBC we hear their stories every day, and we are growing ever more impatient with those responsible for the high prices and the glacial pace with which these lifesaving drugs are being approved at federal level, and being placed on formularies for reimbursement at provincial/territorial levels.

For more information, see:

www.ctvnews.ca/health/woman-s-death-calls-attention-to-costly-hepatitis-c-medication-1.2105013 and www.ctvnews.ca/health/expensive-hep-c-drugs-may-be-funded-too-late-for-terminally-ill-woman-1.1701315

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

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

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.

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HOW TO REACH US:

EDITOR:
PHONE:
FAX:
EMAIL:
WEBSITE:

Joan King
(250) 595-3892
(250) 595-3865
info@hepcbc.ca
www.hepcbc.ca

HepCBC
#20 1139 Yates St., Victoria, BC V8V 3N2

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.

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, Judith Fry, and the newsletter team: Beverly Atlas, Diana Ludgate, Alp, Cheryl, Anamaria, S.J., L.P.

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Bristol-Myers Squibb, Roche Canada, Vertex, Gilead, Janssen, Boehringer-Ingelheim, AbbVie, Rx&D, VanCity, Country Grocer, and Thrifty Foods.

(Jackie—Cont'd from page 1)

heartening at the time was the fact there were no other treatments available for me. So I decided to continue to eat healthily, to continue to exercise regularly, and to return to doing the things that I enjoyed. There was no point in dwelling on the fact that I still had Hep C. It was always lurking in the back of mind, and I wanted to stay as healthy as possible, knowing that it might one day make me very sick or that I might live long enough to die of some other ailment related to old age—often referred to as natural causes. I think this paid off...

In January of 2012, I began "round two". I was treated with the "triple mix" - boceprevir, interferon and ribavirin. At 24 weeks, my test indicated an SVR (sustained viral response) and I was soooo relieved. I think I'm cured, but until I have the same result at 48 and 72 weeks, I will still have Hep C lurking in the back of my mind. Round two was just as bad, and worse with the side effects. I had lost so much weight that my skin was sagging on some parts of my body. Along with the weight loss was muscle loss, and by the time I finished the treatment, I was pretty weak. I was determined to get back my strength and ability to "live life", not just for myself, but for my husband too.

As soon as I finished the last daily dose of pills and the last week of Interferon, I felt better. About a week later, my sense of smell and taste had returned to almost normal. My appetite for real food returned, and I happily said good-bye to Ensure. Two weeks later, I began to exercise, as I wanted so much to be able to

do the things I'd done before, especially the things I shared with my husband. Bike riding was and is a large part of our lives, and I was determined to "get back".

I didn't have the energy nor the strength to go to the group exercise classes I used to enjoy, so I began at home. I purchased some exercise videos and began my journey back to being active. First was yoga, which I had done before, so I could easily follow the video and gently get my body active. Then I used a walking video, with one pound weighted balls. Next were cardio and muscle building videos. Every day I set goals for accomplishing a little more and a little more, gradually building up to a point where I felt I could make it through an exercise class at the fitness club. About seven months after the treatment I said to my husband, "I'm back." I finally felt like my old self.

In the meantime, I had gotten a new road bike. This allowed me to set new goals. I just had to get stronger and not let this beautiful new bike go to waste. I began riding it on the trainer, and then I was ready to take it out on the road. It is very hilly where I live, so my husband and I went on a little vacation to places with flatter terrains so I could get used to riding on my own. (We ride a road tandem as well.) Sweet! It was such a fantastic feeling to get on my bike and ride. Soon I was ready to set new goals again. There was a road bike race coming up. My husband had participated in it a couple of times already, and I decided to register, and then I'd have to train for it. I went on-line, filled in the registration and payment information, held my breath—and clicked on SEND.

For this event, participants had to register for a peleton (group of riders) with an average speed that one could ride. I registered for the slowest peleton and in my age category. Now, I was committed and had to train for my first ever bike race! I rode my bike on the trainer at home, and on the weekends, my husband and I would ride the race route so I could become familiar with it and the challenges I would face. A couple of days before the event, all participants received an e-mail with details and requirements for the race. I discovered then that any participants who did not keep up with the peleton speed would have their bib (with their number on it) taken away and would no longer be a participant in the race. A little bit of panic set in, and I e-mailed asking if tandem bikes would be allowed in the race. Of course, the response was no. I had to face the race head on and give it my best shot. The worst that could happen was

(Continued on page 3)

(Jackie —Cont'd from page 2)

I would be stripped of my bib.

Race day arrived, and I was anxious, but ready. My peleton was the last to start, and I was determined to finish the course. I got into "my zone," rode the race entirely on my own, and focused on my goal. I dropped a chain on the first really tough hill, jumped off, and without thinking about the grease and dirt, I got on my gloves, put the chain back on, got on my bike, and crested the hill. I was determined to finish the race, with the help of my husband's coaching tips swirling around in my head. I gave it my best shot.

At the end of the race, I had improved my average speed and finished the course faster than in any of my training rides. I was completely satisfied. To top it off, I was the only female racer in the 60 - 69 years of age category, so I won a first place medal. Now you know why I get giddy every time I think or talk about my first place medal in my first ever road bike race.

I am very, very grateful to my husband, my daughter, my immediate and extended family, and my wonderful friends who gave me their love, support, and prayers during my treatment. I am also very thankful to the doctor who treated me and to his staff who are also very caring and supportive. If there is any advice I can give to someone going through treatment, it would be to set goals even if the goal is for one day at a time. Hang in there, as there is life after the treatment is finished.

I was treated first by Dr. Rasul in Mississauga, ON who had a hepatology nurse, Karen, working with him. She was an amazing support, however after 72 wk of treatment I wasn't cured in 2008-09. I relapsed in 2009. Dr. Rasul had enough faith in me to do the 72 week treatment, and for that I'm grateful, in spite of not being cured.

Then I was treated by Dr. Bovell in Guelph, ON, who is soooo smart and compassionate, but didn't have a hepatology nurse.

Amazingly, his receptionist/secretary/does everything. Gail headed a support group. Nurses Gail and/or Niamh were always at the meetings that were held monthly, after office hours. I attended this support group during my first treatment, as it was closer to home. Dr. Bovell also gave some evening presentations in a meeting room, where patients and family were invited. He shared the most recent information about Hep C and the latest developments around the world. Amazing! However, during the second treatment I felt so sick and weak that I

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(NEWS—Continued from page 1)

On **November 5, 2014**, the FDA approved the second IFN-free regimen (also RBV-free) for chronic HCV GT1 patients, informally called "**SIM-SOF**", a combination of Janssen's simeprevir (Galaxos™ in Canada or Olysio™ in USA) and Gilead's sofosbuvir (marketed as Sovaldi™). The recommended treatment duration is 12 weeks for patients without cirrhosis or 24 weeks for those with cirrhosis. The success rate is extremely high, even for those with cirrhosis. Minimal side-effects are similar to Harvoni™. Price tag: up to \$150,000 for 12 week treatment in USA.

CANADA: "SIM-SOF" is being used "off-label" in Canada by some physicians, but has not been approved by Health Canada, nor is it covered by any public insurance plans. Cost is unknown.

NOTE: As "SIM-SOF" contains simeprevir, it is usually recommended that patients be pre-screened for the presence of virus with the "NS3-Q80K polymorphism"; if found, this treatment may not be the best option for that patient.

Read more: <http://www.investor.jnj.com/releasedetail.cfm?ReleaseID=881192>

On **December 3, 2014**, the FDA turned down one promising treatment from Bristol-Myers Squibb (BMS): FDA denied BMS's application for a stand-alone version of **daclatasvir** (known as **Daklinza™** in much of the world). The reason was that most of the (GT1B only) research trials upon which the daclatasvir application was based were in combination with another BMS drug, **asunaprevir**. BMS had withdrawn its stand-alone application for asunaprevir on October 8, 2014, saying that it was not deemed an appropriate drug for the current US market. In other countries, daclatasvir is used for GTs 1,2,3, and 4. Without an application in place for asunaprevir, the FDA said it could not proceed on an application for daclatasvir supported by data from the daclatasvir/asunaprevir combo trials. The FDA has requested additional data from BMS on daclatasvir in combination with several other antiviral agents. Francis Cuss, EVP and CSO at BMS, said that BMS remains committed to making daclatasvir-based regimens available to those difficult-to-treat patients who most need them, and that BMS will cooperate with the FDA to make these regimens available in the USA as soon as possible.

CANADA: HepCBC has heard from BMS that it remains committed to developing a Canadian market for its daclatasvir + asunaprevir combo (for genotype 1B only).

Read more: <http://www.clinicalleader.com/doc/fda-denies-bristol-myers-squibb-s-daclatasvir->

[for-hcv-citing-asunaprevir-0001](http://www.clinicalleader.com/doc/bristol-myers-squibb-withdraws-nda-for-asunaprevir-daclatasvir-in-hcv-0001) and <http://www.clinicalleader.com/doc/bristol-myers-squibb-withdraws-nda-for-asunaprevir-daclatasvir-in-hcv-0001>

On **December 19, 2014**, the FDA approved the third IFN-free regimen (but not RBV-free in some cases) for chronic HCV GT1, AbbVie Pharmaceutical's **Viekira Pak™** (previously called "AbbVie 3D Combo"). Viekira Pak™ combines four AbbVie drugs: paritaprevir, ombitasvir, dasabuvir and ritonavir, plus - in most cases, the addition of an older drug - ribavirin. This combo has shown success rate of 95-100%, even with cirrhotic and post-liver transplant patients, and 92% for those co-infected with HIV. It is taken for 12 weeks by most patients, but for 24 weeks by some GT1A cirrhotic patients. RBV must be added to the combo in all GT1A patients, in all patients with cirrhosis, and in all post-liver transplant patients. Side-effects are minimal; while RBV is added in many cases, the shorter treatment time somewhat reduces the impact of RBV's known unpleasant side-effects. Price tag: \$83,319 for 12 weeks, 12% lower than Gilead's Harvoni™.

CIRRHOSIS: AbbVie's Viekira Pak™ is ok for those with Child-Pugh score A. Although it is not recommended in those with moderate hepatic impairment (Child-Pugh score B), it is not contra-indicated, either. It is definitely contra-indicated in patients with severe hepatic impairment (Child-Pugh score C). Discuss with your doctor!

Read more: <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm427530.htm> and <http://www.businessweek.com/news/2014-12-19/abbvie-wins-u-dot-s-dot-approval-to-sell-new-hep-c-competitor>

On **December 23, 2014**, Health Canada approved Viekira Pak™, to be sold in Canada as **Holkira Pak™**. It will most likely not be available to those dependent on provincial insurance plans for many months. Anticipated price: If AbbVie copies Gilead's 15% discount in Canada, Holkira Pak™'s. Canadian price would be \$70,821 for 12 weeks; this figure should be interpreted very speculatively as the pricing of hepatitis C drugs worldwide is highly controversial and unpredictable at present.

That's it for now! We are anticipating another exciting year in the development and approval of hepatitis C drugs. HepCBC remains committed to making these treatments accessible (affordable!) to anyone in the world who would benefit from them, in order to eradicate this terrible disease from the face of the earth.

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TREATMENT INEQUITY A CHALLENGE FOR REMOTE COMMUNITIES

Most people with hepatitis C living in rural and remote communities of Canada are not being treated, and many are never tested for hepatitis C, their condition generally ignored for decades until liver damage begins to cause symptoms. Even then the medical system often mistakes signs of chronic HCV for cirrhosis caused by alcohol only. Patients frequently report being given inaccurate information, such as “Your HCV is not serious” or “HCV is untreatable.”

Chronic hepatitis C is one of the leading causes of end-stage-liver-disease requiring a liver transplant, and many people die while on the transplant waiting list. It is also one of the leading causes of liver cancer, often caught too late for effective treatment. Tragically it is only at this juncture that many rural patients are finally sent down south, to die in a hospital bed alone.

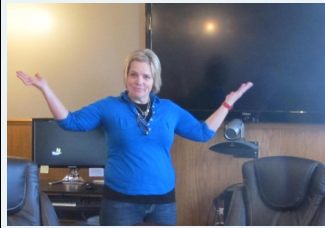
If they could be tested and treated for HCV earlier, they might be able to be productive far longer, and enjoy many more years of being there for their children and grandchildren. While there are many HCV+ people in urban areas who also fit this profile, the situation is far more dire in our remote, rural (and often aboriginal) communities where patients and the specialists who might treat them are separated by hundreds of kilometres. Our examples are from British Columbia, but those in the hinterlands of any of Canada's provinces and territories will recognize similar problems.

Two nurses and an HCV+ patient advocate with HepCBC's “HCV Outreach Roadshow” traveling from the ‘urban south’ to BC's northwest corner in April/May 2014 were familiar with the ECHO Project of the University of New Mexico's School of Medicine. We were searching for ways in which ECHO's “Telemedicine” techniques might be applied to treating HCV+ patients in Canada's remote communities, as a way of equalizing the level of care HCV+ patients were offered in Canada's urban and rural settings. We were impressed to see high-tech “Telehealth” rooms in many of the health units we visited, a hopeful sign!

Hepatology nurse Sandra Barnes works in Dr. A. A. Harmour's clinic in Prince George, British Columbia. To illustrate the challenges she faces in supporting and treating his hepatitis C patients, she explained: “My patients are spread out over an area approximately the size of France, with very poor infrastructure. In contrast,

Vancouver's Eastside Pender Clinic can easily open its doors to a marginal demographic because they're concentrated; a lot of services and the support infrastructure are right there.”

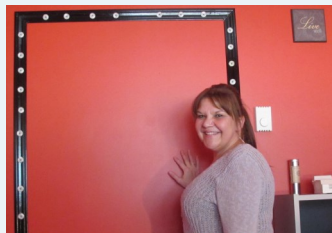
Sandra showed us the clinic's Telehealth room (below) in which specialists from the urban south can talk to patients, caregivers, and medical staff in Prince George. They can remotely supervise test-



ing and diagnosis, assess side-effects, and prescribe treatment and care, as well as train local staff in new techniques; they provide face-to-face patient care without the time, expense, and bother of travel. Keeping patients in their own community means they do not have to leave their jobs, secure home environment, friends, family, and trusted caregivers in order to get the care they need. The savings in transportation and accommodation expenses are tremendous. “Is this facility used for treating hepatitis C?” we asked. “Yes, but not as much as it could be,” Sandra answered.

Like other hepatology nurses, she is delighted that upcoming hepatitis C treatments have far fewer side effects, are oral only, and go on for only a few weeks (compared to previous treatments of almost a year). Due to these new conditions, adoption of new treatments could make it far more likely for HCV patients to be treated primarily by a GP -- or even by specially-trained nurses -- and that specialists would only be involved in the care of those with cirrhosis, other serious conditions, or experiencing extreme side-effects. This opens up the great possibility that patients in rural communities could soon gain access to a similar quality of HCV treatment as that given to patients in urban settings.

Cynthia Munger (r), Community Health Representative (CHR) of the Stellat'en First Nation



(in the T'silhqot'in area between Williams Lake and Bella Coola) also showed us her community's Telehealth room, which they use regularly for communication with a physician based in Abbotsford.

Unfortunately, both Nurse Barnes and CHR Munger told us that there are very few people using Telehealth to treat the many HCV+ people spread out over dozens of remote communities in BC's north. Ironically, Telehealth rooms and expensive equipment exist in most of the Community Health clinics, even in tiny communities. Increasingly more people every year are using them to get treatment locally in a variety of clinical program areas including oncology, mental health/psychiatry, renal, rheumatology and wound care, but liver disease isn't on the list. Why couldn't this same infrastructure be used to treat those with hepatitis C, especially when so many people in aboriginal, rural, and remote communities are dealing with this disease? (BELOW: Cynthia Munger, CHR)



For one, even in urban areas, there are few gastroenterologists or hepatologists who treat HCV; in remote areas they are almost non-existent. Adding remote-access patients to their workload would increase the strain on an already stressed system. Second, sophisticated diagnostic equipment (Fibroscan, Ultrasound, etc.) is generally unavailable. But significantly, local medical personnel and patients, when asked this question, often blamed themselves for not demanding HCV treatment more insistently. They attributed their reluctance to:

-- Patients' fear of stigma and confidentiality breaches are huge barriers to access in tiny communities; many of these HCV+ people are afraid to admit their status publicly, which they assume they'll have to do in order to get tested or treated. Many do not trust that their personal data and test results will be kept private (imagine if the only nurse in town is also your aunt, or the person who files all the test results is your brother-in-law!). Family often do not even want hepatitis C to be listed as the cause of death on a loved one's death certificate.

-- Patients' lack of familiarity with Telehealth equipment and use makes them suspect confidentiality may not be observed by a remote doctor or nurse.

-- Patients' and medical personnel's lack of

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awareness that life-saving treatment is available - or if they are aware, most of these folks have only heard of the older treatments with interferon which had terrible side effects and cured less than half of those who took it. Most don't know that 95% - 100% effective cures are rapidly becoming available with few if any side effects.

-- Patients' and medical personnel's lack of awareness that with new treatments, patients won't have to leave town or quit their jobs, or use a needle, and their treatment needn't be obvious to anyone they don't want to know.

However, HCV treatment access barriers also exist on the other (urban physician) end of Telehealth as well. For example, recently HepCBC heard from a social worker living in a small community in the Interior who had been exposed to HIV from a workplace needlestick injury. He was prescribed a highly-toxic post-exposure treatment which caused an acute drug-induced liver injury. Confined to bed, he is resting and slowly recovering. Before the needlestick injury, he had been scheduled for his own 6-month post-HCV treatment appointment in Vancouver. He was also scheduled to accompany one of his HCV+ clients to a pre-liver transplant interview there as well. Now incapacitated and unable to attend either appointment, he asked his nurse to use existing video health links to connect the Telehealth room at his local hospital with the one at his Vancouver hospital for both these appointments.

The nurse replied that unfortunately the two liver specialists he'd mentioned work out of clinics which don't have video-conferencing, and currently there is no protocol for them to access the Telehealth rooms at nearby Vancouver hospitals. And this wasn't the only obstacle. While MSP would cover the Telehealth visits, and appropriate physician billing codes exist, there are legal and confidentiality issues that need clarification, users need to be trained in the technology, HCV remote treatment protocols must be developed, and scheduling needs to be efficiently and centrally coordinated.

Doctors have neither the time nor the power to create these new policies. And this isn't yet the urgent health priority it should be given the needs of those who, because of where they live, are living with (and many dying way too soon from) undiagnosed or untreated hepatitis C. HepCBC is looking for ways to encourage policy-makers to revisit the use of Telehealth in light of the urgency of the hepatitis C epidemic and the ease with which this disease can now be cured, even in our province's most remote corners.

TIME FOR ALL-NEW TREATMENT PARADIGM?

Let's look at two events separated by two months, thousands of kilometres, and an international border, but totally related:

On October 8, 2014 in Vancouver, Josephreen Luk, the daughter-in-law of a 60-year-old Vancouver woman with cirrhosis, told a reporter that her husband's mom, who contracted HCV in 1983 from a tainted transfusion, had been told by her doctor she was in danger of developing liver cancer without treatment, but that the current treatments would not work for her. Instead, he

prescribed 24 weeks of Sovaldi. When they discovered the \$100,000 price tag would not be covered by their publicly-funded healthcare insurance (BC PharmaCare), they were devastated. The doctor agreed. As Josephreen put it, "Basically he said, 'If you have money, you'll live. If you don't, you'll die.'"

<http://www.theprovince.com/health/have+money+live+Hepatitis+sufferers+hope+fast+drug+approval/10274891/story.html>

And...on December 9, 2014, a class action lawsuit was filed in the USA on behalf of the Southeastern Pennsylvania

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SVR HONOUR ROLL

Have you been undetectable for a minimum of 12 weeks after treatment? Give others hope. Congratulations to our friends:

1. **GJ** - SVR Dec 1998 - IFN/RBV 52 wks - Dr. Anderson/Natalie Rock, Vancouver, BC.
2. **Amerose** - 2000 (GT2a/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. **KG**-Transfused 1987 (GT2a/2c treatment naïve) 2003-4 IFN/RBV 24 wks. Still undetectable in 2014.
7. **Beverly Atlas** - (GT1a) - 2005/2006 - Albuferon/RBV 44 wks
8. **Steve Farmer** - 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
9. **Gloria Adams** - (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks - Drs. Erb & Yoshida, Vancouver, BC.
10. **Don Crocock** - (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 weeks
11. **Daryl Luster** - (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
12. **Donna Krause** - (GT1 partial responder) SVR Nov 2011- Pegays/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks. Dr. Erb, Vancouver.
13. **Cheryl Reitz** - (GT1b previous partial responder) SVR12 Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquiere, Victoria, BC.
14. **Anita Thompson** - (GT1a treated 3 times) Cirrhosis - Apr 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
15. **Leon Anderson** - (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
16. **Joan King** - (GT1b treated 5 times) June 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
17. **Sandy J.** (GT 1a treatment naïve) Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. Now SVR24.
18. **Andrew P.** - (GT 1a many prev treatment attempts over 10+ years, including Incivek Jan 2014.) Sofosbuvir/Ledipasvir + RBV 24 wks

19. **Diane Stoney** - Transfused 3/21/79 (GT 1a treatment naïve) 2/4/2014 - 12 wks placebo, then 12 wks on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC
20. **Coreen Kendrick** - (GT 1a treatment naïve) Mar 10, 2014 MK5172/MK8742 12 weeks Dr. Ramji, Vancouver, BC.
21. **Jack Swartz**—(Treated 3 times) Apr 2014 IFN/RBV/Victrellis, Dr. S. Wong, WHSC.
22. **Del Grimstad** July 2014, 12 weeks Simeprevir/Solvaldi
23. **Linda May** (GT 1b transfused, treatment-naïve) 12 wks Asunaprevir/Daclatasvir . Dr. Tam, LAIR Centre.
24. **Jackie**—(GT1 relapser) - SVR24 June 2013 - IFN/RBV/Boceprevir 48 wks. Dr. Keith Bovell, Guelph, ON.
25. **Bob** (GT1a/HIV relapser) SVR24 Nov 2014 pegIFN/RBV/Incivek 24 wks, Dr. Montaner, Salt Spring Island, BC.

Please send your name and info to Joan at info@hepcbc.ca

(Jackie—continued from page 3)

couldn't attend anything. Apparently, patients are feeling so unwell with the triple treatment that there are not enough patients to hold a meeting. Fortunately, Gail is always a great support when you call her, and she got me through some rough days. KUDOS to Gail! Dr. Bovell said few patients can afford the newest treatments; very, very sad.

In the near future, better and more tolerable treatments will be available. I urge the government at the federal and provincial levels to treat those who do not have insurance to cover the cost of the drugs. It is the right thing to do for so many reasons.

Jackie in Southern Ontario



(NEWS-Continued from page 5)

Transportation Authority (SEPTA) against Gilead Sciences. They charge Gilead with unfairly pricing their hepatitis C treatment Sovaldi™. SEPTA's health fund has spent at least \$2.4 million this year on hepatitis C treatments, and claims Sovaldi™ is 'hemorrhaging' the agency as it fulfills its task of providing needed medical care to its many HCV+ employees. 3% of Philadelphia's residents have HCV. Other payers, patient groups, etc., are invited to join this class action alleging that Gilead is taking an unreasonable amount of profit which threatens to bankrupt the nation's healthcare insurance payors.

Sources: <http://www.newsworks.org/index.php/local/the-latest/76172-septa-files-class-action-lawsuit-over-expensive-hepatitis-c-drug>

and <http://www.prnewswire.com/news-releases/class-action-lawsuit-challenges-the-exorbitant-pricing-of-gileads-hepatitis-c-drug-sovaldi-300007372.html>

Gilead has not yet commented on this lawsuit, however we're all familiar with the charts and graphs showing us the justification for current pricing of the new hepatitis C treatments which offer a 90% or greater chance of a cure without needles or debilitating side-effects, and taken over just a few weeks period. The arguments generally go like this:

(1) The previous generation of hepatitis C treatments had a far lower success rate, required weekly injections, came with often horrific side-effects, and had to be taken for almost a year. When comparing the cost of the new treatments vs. the previous generation, we see that the total costs are only slightly higher. Why all the fuss?

(2) Let's face it: The financial cost (not to mention the human and societal toll) of liver cancer or a transplant is far higher than the cost of even the most expensive treatment.

(3) This expense is one-time-only. If we compare it to the lifetime cost of treating chronic diseases such as HIV, which can require \$10,000 or more per year to treat, we can see the cost of the new HCV medications is pretty minimal.

(4) Fewer side effects will result in fewer medical staff hours spent per patient per treatment, and require less specialized care. As a result, medical personnel could actually treat more patients for the same price.

(5) Without research and development on the part of pharmaceutical companies, life-saving drugs such as Sovaldi™

would never have been discovered. There are always far more 'dead-ends' in research than successful products, and the cost of all this research must be factored in to the end-cost to consumers.

The arguments above are all excellent, and no one can take issue with them. There is, however, one very important detail omitted: the number of people who can and should be treated. The previous treatments were given only to a very small percentage of the HCV+ population each year (1.5% in Canada), barely keeping up with the number of newly-reported cases. In the first years of hepatitis C therapies, this was such a low number that the drugs were in the same price category as 'orphan drugs', provided to so few patients that their high cost did not significantly impact the healthcare system.

Source: <http://lab.express-scripts.com/insights/specialty-medications/harvoni-orphan-drug-pricing-for-a-nonorphan-drug>

As treatments improved, and more physicians prescribed the lifesaving medications to more of their patients, the burden on healthcare systems increased, resulting in both public and private plans imposing increasingly more onerous 'treatment criteria' to limit prescriptions to only those showing a certain amount of liver damage (not too little, not too much!). With the new 'game-changing' generation of HCV drugs, all the 'warehoused' patients who have been awaiting improved treatments will now be requesting prescriptions for the new drugs.

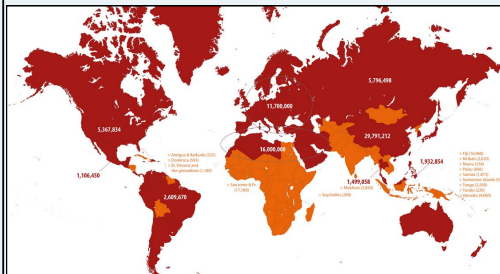
In response, we anticipate one of two changes to this paradigm: Either the insurance payors will impose stricter treatment criteria to further limit the number of 'orphans' who are allowed to have these drugs. Or the drug companies will change their current 'orphan drug pricing' to that of 'non-orphan drugs' – perhaps through a realization they can make more profit by lowering their prices and selling to a larger population, or as a result of competitors' lower pricing, or even because of legal actions such as the class-action suit started by SEPTA.

At HepCBC we are betting on that second paradigm change. Lower costs will simply save more years of life. Not only will more patients be treated, but by treating them earlier (when the drugs are most likely to prevent HCV-related disability, cancer and liver failure), more quality years of lives will be saved as well. In the end, it will likely be more profitable for the pharmaceutical companies, too. Besides, this is the most moral course of action, the one most likely to result in the future eradication of hepatitis C from the world.

HOW MUCH FOR HARVONI IN TUVALU?

Forgive the whimsical title. Gilead has been negotiating production, patent, pricing, and marketing agreements with other pharmaceutical companies, governments, and healthcare payers all over the world during the last year or two. This has resulted in a vastly different price for their products in different nations. Variants of this course of action are being followed by the other major drug companies as each of their drugs get approved.

While HepCBC applauds how this has greatly increased access to these life-saving drugs internationally, particularly among the lowest income nations, we would like to point out that these agreements do not cover most people in the world with hepatitis C, and that unless a country has a good publicly-funded health insurance plan, the poor — even in middle and upper-income countries — will still be unable to access these drugs.



ABOVE: The map above shows (in red) where the 73 million people with HCV live who are excluded from Gilead's low priced 'voluntary licensing' agreements.

Source: www.hepcoalition.org/news/article/gilead-s-license-on-hepatitis-c



ABOVE: HepCBC Board Member Jenine Daubney (l) and HepCBC President Rosemary Plummer, R.N. (r), called for expanded hepatitis C testing and more equitable access to new treatments at a recent benefit concert in Sidney, BC by Allison Crowe. Jenine spoke eloquently about how treatment had turned her life around.

CONFERENCES

27 February 2015

4th Canadian Symposium on HCV
National CIHR Research Training Program
Banff, AB
www.ncrtp-hepc.ca/

12-15 March 2015

24th Conference of APASL
2015 Istanbul
www.apasl2015.org/

25-28 June 2015

The Global Viral Hepatitis Summit
15th International Symposium on Viral Hepatitis
and Liver Disease (AASLD Endorsed)
Berlin, Germany
www.isvhld2015.org/

2-4 September 2015

World Hepatitis Summit
World Hepatitis Alliance
Glasgow, Scotland
www.worldhepatitisalliance.org/en/world-hepatitis-summit-2-4-september-2015.html

13-17 November 2015

The Liver Meeting® 2015
San Francisco

MOMENTUM™ SUPPORT

To learn more about SOVALDI™ or the Momentum Program™ in Canada, the patient should speak to his/her doctor or nurse or call the Gilead Sciences Canada medical information line at 1-866-207-4267. Eligible patients may receive an integrated offering of support services for patients and healthcare providers throughout the entire treatment journey, including:

- Access to dedicated case managers/reimbursement navigators to help patients and their providers with insurance-related needs, including identifying alternative coverage options through private, federal and provincially-insured programs.
- The SOVALDI™ Co-pay assistance program, which will provide financial assistance for eligible patients who need help paying for out-of-pocket medication costs.
- Medication delivery services.
- Compliance and adherence programs.

NEUPOGEN

Amgen has a program for patients who have been prescribed Neupogen. Dependent on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge **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.

MERCK CARE™

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.

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.

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.)

IBAVYR™

Pendopharm has established the IBAVYR™ Patient Support Program. The program will assist patients who have been prescribed IBAVYR™ (ribavirin tablets) with reimbursement navigation, financial assistance and pharmacy services. Case managers will support patients with insurance-related matters and assess eligibility for financial support. Pharmacy services include adherence support, medication delivery and counseling.

To enquire or to enroll, you can call 1-844-602-6858 Monday – Friday 7am to 11pm EST.

BIOADVANCE®

JANSSEN's GALEXOS™ Patient Support Program: Your personal BioAdvance® coordinator can help compile all the forms and documents required by insurance companies and may follow up with your insurance company on your behalf to request insurance coverage. If you don't have private insurance, your BioAdvance® coordinator, on your behalf, will investigate public assistance programs that can help pay for your treatment. In addition, your BioAdvance® coordinator will keep in touch with your doctor and other members of your healthcare team, working with them to help you throughout your course of treatment. You can access the services of BioAdvance® through your physician, who will refer you when he/she prescribes treatment with GALEXOS™.

COMPENSATION

CLASS ACTION/ COMPENSATION

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

CLAIMS ADMINISTRATOR 1986-1990

Claimants may be reimbursed for costs of treatments and accepted hepatitis C medications not covered by public or private healthcare plan while they wait for reimbursement from the 1986-1990 plan.

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

Pre-86/Post-90

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

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



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, harm reduction, needle exchange, advocacy. 1371 C - Cedar St.

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

• **Comox Valley** Harm reduction, counseling, advocacy. 355 6th St., Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400

• **Nanaimo AVI Health Centre.** Counseling, advocacy. **NEW: 102-55** 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 Shomcliffe Rd. Contact Shane, 250-949-0432 shane.thomas@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 Hemi-one.jeffervis@avi.org

ANKORS Hepatitis C Project

Hep C Info, support for prevention, testing, treatment and living well with Hep C.

• **Boundary, Nelson, West Kootenay** Women's gathering monthly. 101 Baker St. Nelson. Contact Laura 1-800-421-2437 250-505-5506 ankorshepc@ankors.bc.ca

• **East Kootenay** 209 16th Ave N, Cranbrook, Contact Michelle 250-426-3383 1-800-421-2437 ankorshcv@gmail.com

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

Chilliwack PCRS Hep C Prevention, harm reduction. 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416. lbirdsall@pcrs.ca www.pcrs.ca

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

Cowichan Valley HCV Support Contact Leah 250-748-3432 r-lattig@shaw.ca

Haida Gwaii support. Contact Wendy wendy@wendyswellness.ca www.wendyswellness.ca

HepCBC info@hepcbc.ca, www.hepcbc.ca Call for office hours.

• **Victoria Peer Support:** 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9AM-10 PM.

• **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 Cheri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support, meeting info.

Contact Lisa 1-866-637-5144 ljmortell@shaw.ca

Mid Island Hepatitis C Society Contact mid-islandhepc@hotmail.com

Nanaimo - Central Island Hepatitis Service:

Nurses & doctors available for info, support, treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-2607, sarah.hughes@viha.ca or shelby.munk@viha.ca

New Westminster Stride with Purpose "HepC" Support Group 1st&3rd Fri monthly 10:30-11:30. BBP Nursing Team, refreshments/lunch. 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 self-referral. 1-877-215-7005 250-850-2605.

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

• **Campbell River:** Treatment/pre&post-treatment 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 every 2nd Tues, 12:30-1:30 PM. 330 Ellis Street. Contact Melanie: 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 #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

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

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

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 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 and Hep C Society of BC. Call for appts or drop in M-F 10-6. 205-568 Seymour St,

Vancouver 604-688-1441, 1-855-YOUTHCO Stewart info@youthco.org, www.youthco.org

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437

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 hepccoord@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 hars@kingston.net

www.hars.ca

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room,

659 King St. E 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.hivaidconnection.com

Niagara Region Hepatitis C Care, Port Colborne and St. Catharines Clinics. Education, counseling, individual/group support, treatment, 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

dminiel-ly@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

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

bptonkonjak@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 reneeaurio@hotmail.com

CAPAHC support group meetings 3rd Thurs. monthly 6-8PM, 5055 Rivard St., (Montreal) Contact 514-521-0444 or 1-866-522-0444

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 C

phone and email support and outreach. Contact Kirk at info@mbhepc.org. Direct line: 1-204-231-1437

Manitoba CLF each Thu 1:30-3. 375 York Avenue, Suite 210, Winnipeg, Contact Bianca 204-831-6231 bpengelly@liver.ca

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 of the month. It's free!