

hepc . bull 1

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEP C IN THE NEWS

IFN-FREE COMBO APPROVED IN CANADA

Gilead's Harvoni is Canada's first IFN-free combo for Hep C. It combines sofosbuvir and ledipasvir, authorized by Health Canada as of October 16, 2014. It can now be bought in Canadian pharmacies with a prescription, but it is only approved for use with genotype 1 patients. It's just one pill, taken once daily for 8, 12, or 24 weeks (depending on the state of the liver and prior treatments). Unfortunately, Canada's health insurance agencies are not yet reimbursing the cost. They need more data from investigations, which will probably take months. In the meantime, some private insurance may cover it, or patients may consult with Gilead's Momentum Support Program™ at 1-855-447-7977, where they may find they are eligible for help, based on the patient's income. (See more about the Momentum™ Program on page 7 of this issue)

Source: www.gilead.com/news/press-releases/2014/10/health-canada-issues-notice-of-compliance-for-gileads-harvoni-ledipasvirsofosbuvir-the-first-oncedaily-single-tablet-regimen-for-the-treatment-of-genotype-1-chronic-hepatitis-c

SIMEPREVIR (GALEXOS) NOW COVERED BY BC PHARMACARE

On October 29th, we learned that Janssen's simeprevir (trade name GALEXOS in Canada or OLYSIO in the USA) will now be reimbursed by BC PharmaCare. This drug is a great addition to the hepatitis C "medicine cabinet" and since it is covered, BC's patients most in need of this treatment will now be able to afford it. It would appear that this drug will probably replace two drugs with significant side-effects, boceprevir (VICTRELIS) and telaprevir (INCIVEK) in BC. We are not overjoyed at this news, however, as it comes with some downsides.

First, simeprevir is not being offered as a stand-alone drug which could be used in a

(Continued on page 2)

HEP C, IFN & SARCOIDOSIS

Dismayed, distraught, and in shock, my friend Joanne emailed me. She had just been diagnosed with sarcoidosis. I admit, I had heard about sarcoidosis somewhere, sometime, but never knew anyone who had it, and had no occasion to look it up. I did a quick search on the Internet before calling her.

What is it?

Sarcoidosis, an inflammatory disease, can affect many of the body's organs, but prefers the lymph glands and lungs. It often causes nodules or lumps ("granulomas") of inflamed tissue in the organs, which can change their structure and affect how they work. The symptoms can be stubborn cough, shortness of breath, fatigue, painful lumps or patches on the skin, blurred vision, red or teary eyes, painful joints, tender swollen lymph glands in the neck, armpits, groin, chest and around the lungs, hoarseness, painful cysts in the hands or feet, kidney stones, irregular heartbeat, inflammation of the covering of the heart, heart failure, hearing loss, seizures, meningitis, depression, dementia, psychosis, etc. These symptoms can come and go unexpectedly. Sometimes there are no symptoms, but the organs don't work properly. Sometimes symptoms are mild but last for a long

(Cont'd on page 5)

JACK BRUCE: DID HE OR DIDN'T HE?



May 14, 1943-October 25, 2014

Photo source: www.facebook.com/JackBruceMusic

We don't know if Jack Bruce did or didn't have Hep C. We do know he died "of liver disease" and he said, "In 2003 I was diagnosed with liver cancer as a result of my former drug abuse and I had a transplant,"¹ which happened in September 2003. We do know we would be proud to claim him as one of our famous lost talents. Why? Jack was a well-respected musician—lead vocalist, bass player, and song writer with the Hall of Fame '60s group Cream, together with "guitar wizard" Eric Clapton.² In just over 2 years, Cream sold 35 million albums. They began by playing traditional blues tunes, but soon added a psychedelic style that made them even more popular at the peak of that era. Many of us will remember "Sunshine of Your Love" and "I Feel Free." Their sound has been described as combining American blues and psychedelia.

After Cream split up, Jack Bruce's career went on. He recorded solo albums like "Songs For a Tailor" and "Shadows in the Air." "Silver Rails," his fourteenth solo album, was released earlier this year. His songs were performed by many artists, like Ella Fitzgerald, Jimmy Hendrix, and David Bowie.

In 2005, he joined former Cream musicians for concerts in New York and Lon-

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

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

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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.

THANKS!!

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(JACK BRUCE—Cont'd from p. 1)

don. Bruce continued touring with his Big
Blues Band. In 2012 they toured Cuba, and
played in London at the famous Ronnie
Scott's.

He is survived by his wife, Margrit, four
children and a granddaughter.

A statement released by his family said,
"The world of music will be a poorer place
without him but he lives on in his music
and forever in our hearts."²

Sources:

¹[www.telegraph.co.uk/finance/personalfinance/
fameandfortune/8932131/Former-Cream-bassist-Jack-
Bruce-I-squandered-too-much-money-on-drugs.html](http://www.telegraph.co.uk/finance/personalfinance/fameandfortune/8932131/Former-Cream-bassist-Jack-Bruce-I-squandered-too-much-money-on-drugs.html)
(Nov 5, 2014)

²[www.denverpost.com/healthcare/ci_26798243/jack-
bruce-bassist-60s-band-cream-dies-at?
source=skipframe-searchable.openedhost.com](http://www.denverpost.com/healthcare/ci_26798243/jack-bruce-bassist-60s-band-cream-dies-at?source=skipframe-searchable.openedhost.com)

³http://en.wikipedia.org/wiki/Jack_Bruce

(NEWS—Cont'd from page 1)

"cocktail" with other drugs. It is only cov-
ered if used in combination with interferon
and ribavirin, two drugs many HCV+ peo-
ple are very anxious to avoid (particularly
interferon). For example, Medivir is study-
ing the combination of simeprevir with
daclatasvir and sofosbuvir in people with
genotypes 1 and 4. See:

([http://finance.yahoo.com/news/medivir-
phase-ii-impact-study-121300504.html](http://finance.yahoo.com/news/medivir-phase-ii-impact-study-121300504.html)).

These three powerful direct-acting antivirals
(DAAs), from three different companies,
could be a super-cure, but Health Canada's
recent approvals of hepatitis C drugs usually
limit their use to particular combinations,
which means any additional combinations
with that same drug must go through an
entire new approval process, consuming

substantial time and money (adding to the
eventual cost of the drug). SEE ALSO the "In
Praise of Stand-Alone Drugs" article below .

A second downside is the very restrictive list
of access criteria:

- Genotype 1 ONLY
- EITHER no cirrhosis OR compensated cir-
rhosis (no de-compensated cirrhosis)
- EITHER treatment-naïve OR treatment-
experienced patients who are prior relapsers,
partial responders or null responders.
- Fibrosis stage F2 or greater on Metavir scale,
determined through biopsy, Fibroscan, or se-
rum biomarker panel (such as APRI).
- Patient has NEVER been treated with a HCV
NS3/4A protease inhibitor (such as boceprevir
[VICTRELIS] or telaprevir [INCIVEK])
- Patient is not currently being treated with an
NS5A/NS5B inhibitor (such as daclatasvir,
sofosbuvir, ABT-267, PPI-668, or ledipasvir).

More details: [http://hepcbc.ca/treatment-criteria-
simeprevir-galexos-british-columbia/](http://hepcbc.ca/treatment-criteria-simeprevir-galexos-british-columbia/).

IN PRAISE OF STAND-ALONE DRUGS

Bristol-Myers Squibb (BMS) recently withdrew
its US Food & Drug Administration (FDA) appli-
cation for the hepatitis C drug, asunaprevir. It is
probably a wise decision on BMS' part, because
asunaprevir is close in formulation and results to
several other "generation 2" NS3 protease inhibi-
tors*. Instead, BMS seems to be focusing on its
more unique product, the NS5A replication com-
plex inhibitor, daclatasvir, which they say in their
Oct. 7 press release, is "currently being investigat-
ed globally in multiple treatment regimens for
HCV patients with high unmet need...we believe
that daclatasvir-based regimens have the potential
to fill continued unmet medical need in the U.S.
and elsewhere in the world." (See link below)

HepCBC has recently been advocating "Stand
Alone" drugs (see Sept. 2014 *hepc.bull*, p. 3),
which doctors will be free to mix and match ac-
cording to the unique needs of each patient, quickly
adapting their changing HCV treatment "cocktails"
in response to the most recent results of rapidly-
evolving international research. We want patients
to have easy access to combinations such as sofos-
buvir + simeprevir (Gilead's and Janssen's drugs),
or sofosbuvir + daclatasvir (Gilead's and BMS'
drugs). That is why we supported the "un-
bundling" of interferon from a product now known
as IBAVYR (trade name for Pendopharm's stand-
alone version of ribavirin).

Complicating this in Canada is our federal drug-
review process which now seems to mostly look at
one-company, even one-pill combos, and the indi-
vidual provinces' PharmaCare review processes
(required in order for patients to be reimbursed for
the cost of the drugs) which must now approve
each hepatitis C treatment combo separately, rather
than each component of the cocktail. We really are
hoping that the government will consider stream-

(Continued on page 3)

(NEWS —Cont'd from page 2)

lining its rather cumbersome hepatitis C drug approval process.

READ MORE from BMS Oct. 7, 2014 press release: <http://news.bms.com/press-release/rd-news/bristol-myers-squibb-statement-about-asunaprevir-us&t=635482740339913288>.

*specifically, linear and macrocyclic noncovalent inhibitors of the NS3-4A enzyme

Read more about Stand-Alone drugs from an article in our September issue of hepc.bull (p.3).

DACLATASVIR'S "STAND-ALONE" MARKETING



Amadou Diarra, Bristol-Myers Squibb Vice President, Global Policy & Government Affairs. <http://www.bms.com/images/responsibility/hcv/amadou.jpg>

Our previous article notes the Bristol-Myers Squibb (BMS) marketing of daclatasvir as a 'stand-alone' hepatitis C drug which could be easily marketed and combined with other drugs instead of being packaged only with other drugs from the same company in a proprietary "package."

While our goal is the eradication of hepatitis C worldwide, we want to get the best drug(s) out to the greatest number of people, worldwide, as soon as possible. This means drugs are accessible and affordable even in the least developed countries, and can be combined in customized "cocktails" with other companies' drugs according to the latest research results, availability, and patient needs (such as genotype or liver damage). BMS' policy, which gives all stakeholders greater flexibility in both clinical and financial terms, is being actively promoted by BMS in a new policy paper in which they say:

"Bristol-Myers Squibb recognizes the significant public health challenge that hepatitis C (HCV) presents worldwide, including the substantial burden of the disease in the developing world. With more than 80% of the global HCV patient population living in low- and middle-income countries, there is great need for hepatitis C treatment options in these countries. The significant challenges facing many of these countries are not homogeneous, in particular the need for governments, non-governmental organizations, civil society and

industry to form coalitions.

As part of our Company-wide commitment to increasing access to medicines for patient populations in need, we have initiated discussions with government health authorities and other stakeholders in a number of developing countries to facilitate access to daclatasvir. Bristol-Myers Squibb's HCV developing world access approach will utilize tiered pricing, licensing agreements and working in collaboration with other stakeholders who share in our commitment to working toward the eradication of hepatitis C." (source: <http://www.bms.com/responsibility/access-to-medicines/Pages/HCV-developing-world-strategy.aspx>)

This company seems to be on the right track. Similar to competitor Gilead Sciences, which has been playing catch-up in the public relations sphere after its stumbles with the marketing of HCV drug sofosbuvir (www.gilead.com/~media/Files/pdfs/other/Intellectual%20Property%20and%20Patient%20Access101014.pdf), BMS is focusing on pricing and production in the lower (and lower-middle) income countries now. However, *until patients in middle income countries such as Brazil or those of eastern Europe – and even the poor living in higher-income countries such as Canada – are able to access (afford) these medications, we will not see hepatitis C eradicated anytime soon. Right now the pricing in the higher-income countries, in particular, seems not to be based on an "economies of scale" model in which profits are made by lowering prices in order to expand the quantity of purchases. We believe this is the course that will eventually be recognized as not only the most moral, but the most profitable for all stakeholders including the pharmaceutical companies.*

Y-90 FOR LIVER CANCER

We just heard from a long-time friend, who has been battling Hep C for years. He relapsed from successful treatment and discovered he had a lymphoma in 2002 (Non-Hodgkin's Lymphoma or NHL—often linked to HCV infection). That was taken care of... until recently. He now has several lymphomas (lumps in the lymph nodes). Years ago, I looked up liver cancer treatments. One of them especially caught my eye, perhaps because it sounded like science fiction: the use of microspheres. It looks like they have been improved, and our friend has now been through Y-90 treatment for his tumours. He reported that the treatment is relatively easy to tolerate. He is waiting for a future IFN-less treatment and a possible transplant in

the future. Luckily, he is feeling well.

So what is Y-90? Its full name is intra-arterial yttrium-90 radioembolization, and it has been used since 2000 for treating liver cancer. It has recently been used in clinical trials with higher doses, and found to be safe. The advantage of Y-90 over chemotherapy is that it doesn't affect the quality of life (QOL) and can be used on outpatients. Using a catheter, the microspheres are injected into the liver artery through the groin, thus reaching the tumor fed by the artery. The radiation doesn't affect the rest of the body. There is less "down time." And it can be used after unsuccessful chemotherapy. It can be used in patients ineligible for the preferred treatment: surgical removal of the tumour(s). It doesn't provide a cure, but it extends survival rates with an acceptable QOL, without the fatigue from standard chemotherapy.

More research is being done, combining Y-90 treatments and chemotherapy, and using higher doses.

Source:

www.sciencedaily.com/releases/2011/03/110328092409.htm

JAPAN: 3 TAKING SIMEPREVIR DIE

It is always of deep concern when people die after taking treatment that is supposed to help them. We must put it into perspective, but take it as a serious warning. These patients had symptoms of organ damage. There were 19,000 people taking simeprevir since its approval in December. The Japanese health ministry has given orders to Janssen to change the packaging of the drug to say the patient should stop if so indicated by a blood test, and to notify hospitals and doctors of the change in writing. The warning advisories are being increased.

Source:

www.globalpost.com/dispatch/news/kyodo-news-international/141024/3-die-after-being-administered-hepatitis-c-drug

HAVE
YOU
HAD YOUR FLU
SHOT
?



Interviewees at Sept. 30, 2014 forum following *DEAL WITH IT* film viewing at University of Victoria. L to R, top row: Anita York, C.D. Mazoff, Douglas Laird, Nurse Hailey MacPhail, Nurse Chantal Vaillancourt; bottom row Nurse and HepCBC Pres. Rosemary Plummer (not in film), Cheryl Reitz, Dr. Wayne Ghesquiere, and Karen Felske.



HepCBC Liver Warriors Half Marathon Team, just before taking off, early morning Oct. 12, 2014 at Victoria Goodlife Fitness Marathon (L to R: Rosemary, Steve, Kathy, and Cheryl).



HepCBC Board Members Jenine (3rd from left) and Cheryl (far right) and friends participated in an education afternoon at AIDS Vancouver Island in Victoria on Oct. 28, 2014. We shared the various paths we'd taken that had led us to become HCV Activists.

HEPCBC PATIENT GROUP SUBMISSIONS SINCE 2011

We have now posted all twelve of the patient group reviews HepCBC has submitted to CADTH (the federal drug review panel) and to BC PharmaCare since 2011. Read these interesting documents, full of authentic voices representing BC's extremely diverse hepatitis C patient and caregiver community at <http://hepcbc.ca/patient-group-submissions-bc-pharmacare-cadth/>.

VOLUNTEERS NEEDED IN COMMUNITIES THROUGHOUT BC

If people with hepatitis C in BC are going to get AFFORDABLE ACCESS to the BEST hepatitis C drugs out there, we need to work together. We must speak with one loud voice to the provincial and federal government, and to the pharmaceutical companies. That means old and young, long-time citizens and newcomers, people who have/have never used drugs, hepatitis C-only or co-infected with HIV (or hepatitis B), and Genotypes 1 – 6! Volunteering with others in the same boat is a great way to start meeting like-minded people.

HepCBC has the resources now to work with volunteers (we are also very happy to work with other groups) in communities throughout BC in the following projects – email info@hepcbc.ca if you want to volunteer to:

(1) Distribute and stock hepatitis C info pamphlet holders in local doctors' offices, clinics, labs, social service agencies, etc. – we will mail you the holder and pamphlets if you can keep them stocked and updated. We also have posters you can print out through <http://www.hepcbc.ca/posters/>.

(2) Show the movie *DEAL WITH IT: Untold Stories of Hepatitis C in Canada* (63 minutes) to a group in your community – a class, a church group, a service or cultural club, your union or business group, your library, immigrant settlement society, etc. You provide the venue and equipment, the cookies (!), and do the advertising. We will mail you either DVD or Blu Ray copy by Canada Post, and you mail it back to us within a day or so of your event. It's best to give us 2-3 weeks advance notice, just in case of problems. Order via email to info@hepcbc.ca or via phone 1-250-595-3892.

(3) Start up a local HCV peer-support group. Email us if you want us to publicize it in our bulletin and website, or if you

need any advice or materials to get you started.

(4) We're also looking for people (medical and those with 'lived experience') who might be interested in doing public speaking about hepatitis C - especially in remote communities.

(5) Finally, let us know if you are interested in sharing ideas about hepatitis C peer navigation, or exploring treatment of rural/remote HCV+ people via e-health as HepCBC sees these as ways of making treatment more easily and broadly accessible in our province.

LIVER WARRIORS TEAM COMPLETES ITS 4th VICTORIA HALF-MARATHON

The Victoria Marathon was absolutely beautiful. Thanks for all the good wishes you have sent from all over Canada, even from India. Maybe next year you'll be able to join us in the 5th year of the HepCBC Liver Warriors team, either as participants or on our cheering team - possibly manning info booth if we decide to do that again. Below are the results:

CONGRATULATIONS to former HepCBC President and liver-transplant survivor Steve Farmer, who ran the Half Marathon in 2 hr, 17 min. (age-corrected 1 hr., 54 min.) yesterday!! The three of us ladies (Kathy, Rosemary, and Cheryl) weren't quite as impressive as we walked much or most of the time. Nevertheless, all of us walked the 21.5 km course in less than 4 hr., 18 min. Not bad as most of us are or have been living with HCV and our ages range from 56 - 66! We are still accepting DONATIONS at www.canadahelps.org/en/charities/hepcbc-hepatitis-c-education-and-prevention-society/hepcbc-liver-warriors-2014-donation-page/.

Thanks in particular to Kathy, who could have made a much better score if she'd gone on her own. But she decided to walk and to keep the two slowest of us company for most of the event. Nevertheless once she got up to her regular speed, she achieved an amazingly good result (age-adjusted 2 hours, 59 minutes!)

TREATMENT CHEAT SHEET (CANADA)

DRUGS:	PR	PR/DDA	PR/DAA2	HARVONI
APPROVED:	Yes	2011	2013	2014
COVERED:	All Canada	Many provinces*	BC/ON/QC+*	QC
GT:	Non-GT1	GT1	All	GT1
METHOD:	Inj weekly/pills daily	Inj weekly/pills daily	Inj weekly/pills daily	1 pill daily
DURATION:	Up to 48 weeks	Up to 48 weeks	GT1 24 wks	8-12-24 wks**

PR: pegylated interferon + ribavirin
 DDA: direct-acting antiviral (Victrelis or Incivek)
 DAA2: 2nd Gen DAA (Galexos or Sovaldi)
 GT: Genotype
 Harvoni: Sovaldi + ledipasvir

*www.catie.ca/en/treatment/access-hiv-and-hepatitis-c-drugs-federal-provincial-and-territorial-drug-access-program (Some provinces have programs to help those in need, who are not covered by private insurance.)

** based on prior treatment, viral load, fibroscan

TRANSPLANT PATIENT'S NEW HURDLE

We recently got an update from our friend "Dale" who lives in Kamloops and is awaiting a liver transplant. As we have noted in previous articles, patients who live outside Vancouver must clear incredible hurdles before getting a transplant. Besides having to leave their family and home community for several months, and obtaining lodging to cover the pre-transplant and post-transplant period, they must prove that they have the resources to either provide – or hire - a live-in person to provide support such as cooking, cleaning, laundry, changing bandages, giving medications, and driving the transplant patient to appointments. This person must also provide "social support" by keeping the patient in a healthy frame of mind including ensuring they remain free of disallowed substances. Dale was struggling with finding such a person until his social worker agreed to sign a statement volunteering to be his caregiver and "social support" person for the pre-transplant period.

However, the social worker could not commit to providing such care for the two-to-three month post-transplant period. Because of this, the transplant committee in Vancouver recently required Dale to provide proof of access to \$30,000 cash to cover hiring a full-time caregiver for up to three months. It now looks like this hurdle has been crossed; what an amazing accomplishment!

Both Dale and his social worker praised Hope Air (www.hopeair.org), which provides free air transportation to them when they go to Dale's appointments, and to the Happy Liver Society (www.happyliversociety.org/), which provides a very low-cost lodging for liver transplant patients from out of the Vancouver area. However it should be clear why so few people from BC's more rural and remote communities are getting transplants!

(SARCOIDOSIS- *Cont'd from page 1*)
time.

What causes it?

It's a kind of autoimmune disease. The body produces an immune response to fight off some "invader" and it goes on to kill off body parts, as well.

How do you know?

All the symptoms and lab results happen in other diseases, so there is no specific test. X-rays and CT scans can show lung and lymph node problems. The bronchial tubes can be examined and biopsied with a bronchoscope, and checked for infection.

How is it treated?

Anti-inflammatories like prednisone can reduce inflammation and relieve the cough and fatigue, but may not be the best thing for those with Hep C. Other drugs used are hydroxychloroquine or methotrexate, among others.

Is it serious?

In many cases, it appears and disappears without the patient being aware of having had it. 30% have serious lung damage. It becomes a chronic disease in some. It may destroy the organ affected. Rarely, it can be deadly, usually from damage to the vital organs.

Going back to Joanne: It all started with her right foot, back in May. It still hurts her. The MRI and bone scan showed a white mass from an old injury, but the doctors weren't sure what it was. They said there was an increased blood flow and uptake throughout the right foot, which may be related to osteoporosis or CRPS (complex regional pain syndrome.) It's not healing.

Then her left wrist started hurting. She's left-handed. A lump appeared and her doctor told her it was a sebaceous cyst...nothing to worry about. (Sound familiar, anyone?) Joanne said she wanted it removed. The doctor said it wasn't necessary but would consider it. She repeated that she wanted it removed, since she is left-handed and the pain bothers her. She insisted it be removed. It was interfering with her work. During the procedure, the doctor, astounded, announced that the lump was not what he expected and asked for permission to biopsy it, and of course, she said yes. It wasn't cancer, but, unfortunately, the tests showed sarcoidosis. The lump started to grow back a week after the surgery.

What other symptoms has she had? Her lungs have hurt off and on for over a year. A cough she had last winter lasted 3 months. Her joints were sore and still are, off and on. And her foot wasn't healing. She got her lungs x-rayed yesterday. She is a non-smoker. One of the worst symptoms has been her eyesight, which is failing. She

is looking into that and getting a referral to a specialist. Interferon has been known to produce retinal problems.

So what does this have to do with hepatitis C? Well, Joanne doesn't have it...anymore. She has enjoyed a sustained viral response AKA cure from her genotype 1 viral infection since 2005, thanks to pegylated interferon plus ribavirin. Unfortunately, the medical literature is riddled with information about interferon and sarcoidosis and other autoimmune diseases.

What does it have to do with Hep C?

A Google search shows 12,800 results for "sarcoidosis + untreated hepatitis C", and 282,000 results for "sarcoidosis + interferon". This isn't exactly scientific, but it does make one think. An excellent article in the *New England Journal of Medicine* (www.nejm.org/doi/full/10.1056/NEJMra071714), says: "Sarcoidosis has been reported to develop after interferon alfa therapy for hepatitis C. Some studies have suggested that hepatitis C infection itself may increase the risk of sarcoidosis, but it appears more likely that treatment with interferon alfa increases interferon- γ and interleukin-2, thus promoting granuloma formation."

Joanne did all the right things. She didn't take "no" for an answer. She is getting a second, and if need be, a third opinion. She will be fighting this, like she fought her Hep C. And part of her fight is to make it our fight, too. Do YOU have these symptoms? Please GET CHECKED!! What else can you do? Get regular checkups. Eat a well-balanced diet. Drink enough water. Get enough sleep. Exercise regularly. Keep your weight under control. Don't smoke or drink alcohol.

Source:

www.webmd.com/lung/arthritis-sarcoidosis

[Editor: These days, when there is more effective treatment that doesn't include that drug, why is anyone being prescribed interferon...unless it's a case of rescue therapy for non-response to the 2nd generation direct-acting antivirals? Why do the drug plans insist that the new drugs (except with recently approved Harvoni, which is only approved for GT 1) be taken together with IFN?]





VANCOUVER INFECTIOUS DISEASES CENTRE - VIDC

We are the largest centre in Canada for the treatment of HCV in active IDUs, and participate in most of the clinical trials of new antiviral agents. We have developed unique ways of engaging IDUs in care and getting them on trials through our innovative "pop-up" clinics on the Downtown East Side of Vancouver.

Vancouver ID Centre
201-1200 Burrard St
Vancouver, BC V6Z2C7
Telephone: 604-642-6429
(Trials for IDUs, "Pop-up" Clinics)
www.vidc.ca

TORONTO COMMUNITY HEPATITIS C PROGRAM

955 Queen Street East
Toronto, M4M 3P3, ON
(416) 461-1925

This program is for hepatitis C-positive people who have had difficulty accessing treatment and care for their Hep C. Priority is given to people who are uninsured, use substances and/or have mental health issues. The program is centered on group support. People attend a weekly group focused on information about HEP C, treatment and healthy living. TTC and food are offered. The group is a closed group and runs on a 16 to 18-week cycle. The Hep C Clinic runs at the same time.

Hep C Patients can have access to:

- Physicians
- Hep C Treatment Nurse
- Nurses
- Case Manager
- Infectious Disease Specialist
- Psychiatrist
- Hep C Coordinator
- Hep C Community Support Workers.

We offer:

- Hep C information and treatment
- Advocacy
- Support
- Informal counseling
- Harm reduction counselling and supplies
- Group support
- Patient accompaniments
- Referrals to doctors, nurses, counselors / case managers, detoxes, housing workers and shelters

Please contact:

Hepatitis C Treatment Nurse
Shannon Taylor
416-461-2493 ext. 846
staylor@srhc.com

HEPATITIS C CIRRHOSIS SUPPORT GROUP

Hepatitis C Cirrhosis Support is a secret group for people living with Hepatitis C stage 4 & 5 compensated and decompensated cirrhosis, end stage liver disease and liver cancer. Anyone infected with HCV is welcome. Please introduce yourself when you join us and share what you are comfortable with. Ask any questions you may have and we will do our best to help. We are all in this together.

The group link does not show on Facebook unless you are a member. Please e-mail me to be added.

wendy@wendyswellness.ca

Thanks.

Wendy Mackay
Haida Gwaii
B.C.
www.wendyswellness.ca

HEP C CLINIC AT PERCURO



The Hepatology Clinic at PerCuro provides HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region, according to their individual needs. Specialized nurses help procure financial coverage for treatment, ensure lab tests are scheduled, teach self-administration of injectable medication, help manage side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding the patient's treatment and any other issues of concern.

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

PerCuro also offers access to cutting edge clinical trials for both naïve and treatment-experienced patients.

There is no cost involved.

Nursing Support improves outcomes.
Contact 250-382-6270

MANITOBA CLF PRESENTS DR. WONG

November 20th

1:30 – 3:30 pm. **Dr. Wong** speaking at the Reh-Fit Center (1390 Taylor Ave.)

This is an open event! Contact:

Bianca Pengelly
Regional Coordinator, Manitoba

Phone: 204-831-6231

bpengelly@liver.ca

375 York Avenue

Suite 210

Winnipeg, MB R3C 3J3

Website: www.liver.ca

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. **Amberose** - 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 [NEW]**- July 2014 12 weeks Simeprevir/Solvaldi
23. **Linda May [NEW]** (GT 1b transfused, treatment-naïve) 12 weeks Asunaprevir/Daclatasvir . Dr. Tam, LAIR Centre.

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

CONFERENCES

5-6 November 2014

1st INTERNATIONAL MEETING ON
HEPATITIS CURE & ERADICATION
Toronto, Ontario

www.virology-education.com/event/upcoming/1st-international-hepatitis-cure-eradication-meeting-2014/

7-11 November 2014

AASLD - The Liver Meeting
Boston, MA
www.aasld.org

12-13 January 2015

8th Paris Hepatitis Conference
Palais Des Congrès
Paris, France
www.aphc.info/home.php

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/

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.

COMPENSATION

LOOKBACK/ TRACEBACK



Canadian Blood Services
Lookback/Traceback & Info Line: 1-888-462-4056

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

Canadian Blood Services, Vancouver, BC
1-888-332-5663 (local 3467) or 604-707-3467

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

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

Manitoba Traceback: 1-866-357-0196

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

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

CLASS ACTION/ COMPENSATION

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

CLAIMS ADMINISTRATOR 1986-1990

URGENT NEWS: SEE PAGE 1 in SEPT 2014 ISSUE

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

Pre-86/Post-90

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

Settlement Agreement:

www.pre86post90settlement.ca/PDFs/SA/

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, counselling, advocacy. 355 6th St., Courtenay. Contact Sarah sarah.sullivan@avi.org 250-338-7400

• **Nanaimo AVI Health Centre.** 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 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 Hermione.jeffers@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. birdsall@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 dggrimsiad@shaw.ca

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

Haida Gwaii support. Contact Wendy [wendyswellness.ca](http://www.wendyswellness.ca) www.wendyswellness.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 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 Cherri 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 midislandhepc@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.miskanack@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 admin@bloodties.ca



OTHER PROVINCES

ONTARIO:

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

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

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

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

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 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 dminielly@publichealthgreybruce.on.ca 1-800-263-3456 Ext. 1257, 519-376-9420 Ext. 1257, www.publichealthgreybruce.on.ca

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700

healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

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

reneedaurio@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@hepnsc.ca

www.hepnsc.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!