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Canada's Hepatitis C News Bulletin
www.hepcbc.ca

PATIENTS: GIVE FEEDBACK TO CADTH ON SOFOSBUVIR & LEDIPASVIR COMBO

Every new hepatitis C drug or treatment has to be approved by the Canadian government before it can be prescribed and sold in our country, and by each provincial drug plan before its cost will be covered in that province. People affected by hepatitis C (HCV+ people and their caregivers) do have a small but significant voice in this process. HepCBC has been preparing Patient Group Submissions to both CADTH (Canadian Agency for Drugs and Technologies in Health—federal level) and BC Pharmacare for several years. We collect individual submissions through our website and use the best examples and quotes from them to put together our group submission.

Recently CADTH asked us to do a Patient Group Submission for the Gilead combo of sofosbuvir (standalone tradename SOVALDI) and ledipasvir (formerly known as GS-5885) to be used to treat “Chronic Hepatitis C”. Note that this combo has not yet been approved by Health Canada.

The CADTH submission did not specify a particular genotype. So which genotypes could be cured by this treatment? This combination, sometimes with ribavirin added, has been tested mainly on genotype 1 patients, either without cirrhosis or with compensated cirrhosis, of whom 92% - 99% have achieved SVR. Moreover, the combo has demonstrated similar results with genotype 3 as well, and unusually good results (65% SVR) with genotype 1 advanced liver disease (de-compensated cirrhosis). Research is ongoing or planned with all of the other genotypes, as well. While adverse events are minimal with this combination, there are some important adverse drug interactions to be considered. For far more extensive background and genotype-specific information, go to: <http://hepcbc.ca/contribute-sofosbuvir-ledipasvir-submission-cadth/>.

But most important, no matter what
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COST OF HCV MEDICATIONS

Much ado has been made over Gilead's “\$1000 pill,” so we've done a little research into factors which affect the pricing of hepatitis C medications. Our list of contributing factors is not conclusive, but hopefully will get some conversations going.

ECONOMIES OF SCALE AND RESEARCH + DEVELOPMENT COSTS

The most obvious example is that a company, assuming their product is fairly inexpensive to produce and ship (such as most HCV medications), would make the same amount of money if they sell 500 treatments at \$100,000 each or 100,000 treatments at \$500 each. When considering there are 185 million people in the world with HCV, there would seem to be a huge potential for profit—definitely enough to pay for all the research and development costs, and much more if the treatment is made available and affordable to all.

HOW LONG WILL THE MARKET LAST?

There is a tremendous difference between HIV and HCV treatment “landscapes” in
(Cont'd on page 2)

URGENT: FOR APPROVED 1986-1990 CLASS ACTION CLAIMANTS

Many approved claimants under the Hepatitis C January 1, 1986 — July 1, 1990 Class Actions Settlement don't realize they may be reimbursed for their costs for treatments and generally accepted hepatitis C medications that are not recoverable under their public or private healthcare plan.

Michel Long of the Canadian Hemophilia Society (CHS) announced on September 2, 2014 that due to its collaborative effort with Gilead Health Sciences Canada, “Gilead's Momentum Support Program can now provide upfront payments to those eligible for treatment with Sovaldi (sofosbuvir) while the claimants wait for a reimbursement from the 1986-1990 plan. In addition to Sovaldi, the upfront payment can cover the other drugs which would be part of the combined treatment regimen. The Momentum Support Program is Gilead Sciences Canada's patient support program that can put patients in touch with a case manager who can support patients to access therapy, help seek financial assistance to pay for treatment, and provide education and support throughout the treatment. Case managers at Momentum have been prepared to support the particular situation of the 1986-1990 claimants.

Given that many of the 86-90 claimants are hemophiliacs who were infected with HCV through blood products and persons who were transfused with tainted blood received in Canada between January 1, 1986 and June 30, 1990 and may still be in need of a treatment, we are trying to reach them and their health care providers to inform them about this opportunity to begin treatment now without having to wait for the Health Canada approved drugs to be on their provincial formulary. For those eligible to be treated with Sovaldi as part of their regimen, having to front large sums of money should no longer be an obstacle thanks to the new provisions made under Gilead's Momentum Program.” The CHS also is exploring a similar arrangement with Janssen for its HCV drug, sime-
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Donation enclosed \$ _____

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

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

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

HOW TO REACH US:

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LETTERS TO THE EDITOR

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

MARATHON

Mark this date on your calendar:

October 12, 2014 is the date of the Victoria, BC "Goodlife Fitness Marathon" (8k Road Race \$40, Half Marathon \$75, Full Marathon \$100. Remember, running is not the only option! You can WALK either the Half or Full Marathon, and you can use a WHEELCHAIR for any of the events.

To register, go to www.runvictoriamarathon.com/events/register.php

When asked if you want to join a TEAM, be sure to select our team, the "HepCBC Liver Warriors" from the dropdown list. If you don't see the team listed for the 8k or Full Marathon, you can create it by writing it in. If you join our team, please let us know by email to marathon.hepcbc@gmail.com.

Also, we are looking for Race Day, Info Booth, and Fundraising Volunteers! This is a great way to fight stigma, educate the public about hepatitis C, meet new friends, get in shape, demonstrate the benefits of exercise for the liver, raise money for HepCBC's hepatitis C outreach programs, and have fun!



HEPC 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

THANKS!!

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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, Roche Canada, Vertex, Gilead, Janssen, Boehringer-Ingelheim, AbbVie, Rx&D, VanCity, Country Grocer, and Thrifty Foods.

(COST OF MEDS—Cont'd from p. 1)

that HIV is a chronic disease, not a curable one, and HIV treatment is given continually over the patient's lifetime, providing pharmaceutical companies with a constant flow of profits. HCV treatment is an actual "cure" which means that if it works properly, money will be spent on treatment for an HCV+ patient only once. The company must make all of its profits from this one-time-only purchase.

WHO BENEFITS?

In countries like the UK where patients remain under the same pharmaceutical plan for life, there is a clear cost savings in treating patients, and the earlier they are treated (averting further liver damage), the better. In countries such as the USA, however, where patients are on private insurance plans in their younger years, and public plans (such as Medicare/Medicaid) once they are older or debilitated, the private insurance plans have little incentive to treat patients, since the companies will realize very few cost savings for treating a disease that often takes 30 or more years to manifest significant symptoms. The UK's ready willingness to cover HCV medications for its citizens, and American private insurance companies' reluctance to do so illustrates this point.

COVERAGE

A company can develop the best product and what it considers fair pricing, but still not pass the government approval process. This happened recently when the Australian government's Pharmaceutical Benefits Scheme (PBS) decided to reimburse prescriptions for Janssen's simeprevir while at

(Continued on page 3)

(COST OF MEDS - *Cont'd from page 2*)

the same time denying this coverage for Gilead's higher-priced sofosbuvir. Details: <http://hepatitisnewdrugs.blogspot.ca/2014/08/pbac-decisions-mixed-bag-for.html>. Why did PBS turn sofosbuvir down? Perhaps they were just trying to communicate to the pharmaceutical industry that they had a "bottom line," and were hoping to encourage competition. Precedents are certainly being set with the marketing of sofosbuvir which will influence pricing of future DAAs (direct-acting antivirals) from other companies down the line. If enough countries said 'no' to high pricing, perhaps it would result in lower costs across the board. However, if companies eventually feel they are not making sufficient profit, they could pull out of hepatitis C research and development, which would not be good for anyone.

INTERNATIONAL PRICING AND NATIONAL INSURANCE PLANS

When we see a \$90,000 USD treatment such as Sovaldi going for \$900 in another country, we reflexively assume this involves some kind of illegal theft of intellectual property or at least a 'patent-free' or 'premature-generic-drug' situation. However, this is not always the case. Pharmaceuticals such as Gilead are acutely aware their products won't sell if no one can afford them, so their representatives are going from country to country, negotiating contracts with government pharma plans (especially in countries like Egypt, with a very high incidence of hepatitis C). They secure pricing 'tiered' according to whether they are selling to a low, middle, or upper income country. This is understandable, but it only works fairly if there is a national drug plan which covers everyone. Otherwise, lower-income people in middle (and even upper) income countries cannot afford the cure. And even at \$900 for a cure, a poor, uninsured person in Egypt could not afford treatment unless the government paid. Therefore there is much resentment of this practice, particularly in those middle and upper income countries without national health plans.

DOES THE HEALTH PLAN COVER PHARMACEUTICALS?

In most countries that have national health plans, pharmaceuticals are covered. Canada is one of the few exceptions. This fosters in Canadians the same attitude of sensitivity and resentment to HCV drug pricing as is

found in countries without national health plans. Check out this article about how adding drug coverage to our health plans might even boost the Canadian economy: <http://www.troymedia.com/2014/08/22/how-a-national-drug-plan-can-boost-the-canadian-economy/>.

"SINGLE COMPANY" vs. "MULTI-COMPANY" COCKTAILS

Sofosbuvir in combination with several other drugs in an interferon-free combo is "in the pipeline." The sofosbuvir/ledipasvir combo is the first of these combos to reach Health Canada. However, a "two-company combo" of sofosbuvir/simeprevir is currently being used extensively in the USA (simeprevir - trade name GALEXOS - is a Janssen drug already approved in Canada in a combo with interferon and ribavirin). Another "two-company combo" of sofosbuvir/daclatasvir was approved August 27, 2014 by the European Commission (daclatasvir [trade name Daklinza] is a Bristol-Myers Squibb drug). Like most businesses, Gilead prefers that their products be combined with products from their own company. Following in Gilead's footsteps, other pharmaceuticals are also seeking to put together interferon-free combos which contain only their company's products; these include AbbVie, Merck, and Bristol-Myers Squibb. See: http://natap.org/2014/EASL/EASL_86.htm. Significant litigation and patent challenges also seem like an avoidable waste of time and money that could be better spent on R&D. See: www.firstwordpharma.com/node/1225537#axzz3BSXPuPvt.

This ugly side of HCV drug competition might not exist if we could get rid of the emphasis on a single company alone achieving the Holy Grail of HCV treatment: a single-dose, all-oral, pan-genotypic cure without side-effects. Some have suggested the use of "Patent Pools" to spread R&D risk and foster more cooperation among pharmaceutical companies; this is an avenue deserving exploration for future HCV drug development, perhaps even right here in Canada.

COMBOS vs. STAND-ALONE IN CANADIAN CONTEXT

We here at HepCBC wonder if there might be some time, cost, and public health benefit in regulatory bodies (at all levels) separately approving each component of a combo on a stand-alone basis,

rather than approving each of these (rather numerous!) upcoming single and multi-company combos as each comes along. For example, Canada recently did this for a stand-alone version of ribavirin, trade name IBAVYR, thus "un-bundling" it from interferon. Significant R&D money has gone into essentially parallel development of very similar "ingredients for the HCV Cocktail" simply to create a slightly different proprietary formula. Likewise, significant government (taxpayer!) time and money is spent approving, not only each ingredient, but each combination of ingredients. Approval on stand-alone basis could result in more diverse, flexible treatment choices for Canadian patients and their physicians, as well as fostering a more cooperative research & development environment. It would seem that HCV Treatment Guidelines which already are formulated and updated regularly by the Canadian Association for the Study of the Liver, could serve to guide doctors in selecting the best treatment "cocktail" for each unique patient's condition and financial or insurance situation.

TAKING AN INTERNATIONAL POINT OF VIEW

At this point, the full eradication of our awful virus, HCV, from the face of the earth is no longer an unrealistic goal. But that would require the most effective HCV drugs to be accessible and affordable to each of the 185 million of us throughout the world. This will require careful thought, good communication, and innovative solutions involving governmental bodies at all levels - particularly international - plus representatives of civil society, NGOs, and pharmaceutical companies. We have confidence an equitable solution will be discovered once all stakeholders (including HCV+ people!) agree it's time to "put our heads together."



Dr. Eric Yoshida speaks at World Hepatitis Day Vancouver at the Vancouver Art Gallery, July 28, 2014 - HepCBC photo

September 8th: FREE WEBINAR ABOUT SOFOSBUVIR/LEDIPASVIR COMBO

Monday, September 8th from noon to 1:00 pm, PST (doors open 11:45 am). A “live connection” to a Webinar at HepCBC’s new office: #20 — 1139 Yates Street, Victoria, BC V8V 3N2. Dr. Paul Marotta with the University of Western Ontario and London Health Sciences Centre will present 'A Transformation in HCV Management – The Interferon-Free Era.' The presentation will review the current HCV burden and treatment landscape, and the future of interferon-free, all-oral treatment, including Ledipasvir/Sofosbuvir. The webinar will also include a Q&A session.

For those of you who cannot attend, we will put a **summary of the webinar up on our website** as soon as possible afterwards - watch for a link to it on this webpage: <http://hepcbc.ca/event/sofosbuvir-ledipasvir-webinar/>. If you have **questions you'd like us to ask on your behalf** during the Q & A session, email them to us at info@hepcbc.ca before 11:30 am PST on September 8th.

This webinar will give research data and other info about this drug combo now under review for federal approval by CADTH. HepCBC will be making a Patient Group submission to comment on this application, and seeks your input (see longer article in this issue). Attending this WEBINAR could help you send us a more informed submission.

Sept. 16th: CELEBRATE RE-OPENING of HEPCBC OFFICE!

Join with HepCBC's volunteers to celebrate the official re-opening of our office! On Tuesday, September 16th, from 11:30 am to 2:30 pm at Room #20, 1139 Yates Street, Victoria, BC V8V 3N2, just off Cook and Yates in the Lallicare Pharmacy Building. We will showcase our activities, history, educational materials, and plans for the future. Come see what we're up to and sample some snacks! Details: <http://hepcbc.ca/event/grand-re-opening-hepcbc-office/>

Sept. 16th: ANNUAL GENERAL MEETING of HEPCBC

On Tuesday, September 16th from 6:00 pm - 9:00 pm, join us for our AGM. HepCBC is delighted to announce this year's guest speaker will be GAIL BUTT, PhD and RN, Associate Director, Hepatitis Services, BCCDC, and Clinical Assistant Professor,

School of Nursing, UBC (now in the process of retiring, so we were lucky to talk her into this engagement!). Refreshments provided.

WHERE: Victoria's main Health Unit at 1947 Cook Street, Victoria, BC – Main Meeting Room. Doors locked this time of night. Entry at side door, around corner of building to right. Parking on street. Details: <http://hepcbc.ca/event/annual-general-meeting-hepcbc/> EVERYONE WELCOME!

NOTE: If you wish TO VOTE or to NOMINATE you had to be a member by midnight August 16, 2014. Nominations for the Board must be made by a member. Board members must become a HepCBC member, submit a Police Check, sign a Confidentiality Oath, and attend three consecutive Board meetings before they are eligible to vote at a Board meeting.

Sept. 20th: 3rd ANNUAL VIRCS MULTICULTURAL FOOD and HEALTH FAIR

On Saturday, September 20th from 9:00 am - 4:00 pm "Come to the Fair" in Victoria. This popular, tasty, fun, informative, and generally wonderful family-friendly fair, now into its third straight year, is sponsored by VIRCS (Victoria Immigrant and Refugee Centre Society). It will be held at the CDI College, 950 Kings Road, Victoria, BC V8T 1W6.

HepCBC will have a great booth once again. If you want to volunteer (especially if you are fluent in language(s) other than English!) please let us know. You will really enjoy this event, and we hope to see you there! Details: <http://hepcbc.ca/event/multicultural-food-health-fair/>.

Sept. 25th: - UVIC STUDENT SOCIETY'S ANNUAL VOLUNTEER FAIR

On Thursday, September 25th from 9:30 am - 4:30 pm at the University of Victoria's Student Union Building, Michele Pujol Room, students will see that HepCBC is actively seeking dedicated volunteers. This year, we are going to try to find a few EXCELLENT, ENTHUSIASTIC, and ENERGETIC people to help us with our outreach and support projects. Details: <http://hepcbc.ca/event/univ-victoria-volunteer-fair-hepcbc-booth/>. Come say hi to us at the info booth, ask questions, and fill out our forms. You won't regret it! And check out our website's volunteer information section here: <http://hepcbc.ca/volunteer/>.

Sept. 25th-26th: BCCDC's 'INTERDISCIPLINARY VIRAL HEPATITIS WORKSHOP'

On Thursday and Friday, September 25th-26th at the Holiday Inn Vancouver Centre, 711 West Broadway, Vancouver, BC., the BC Centre for Disease Control is hosting sessions: Anatomy, physiology and pathology of the liver; Epidemiology/prevention of hepatitis A, B, and C; Management and treatment of hepatitis B and C; Interpreting of viral hepatitis serology; HCV/HIV co-infection; Viral hepatitis in children; Viral hepatitis and nutrition; Hepatitis C stigma and discrimination; Hepatitis C and addictions; and Creating cultural safety for aboriginal people. Cost: \$224.

Register at: www.bccdc.ca/resourcematerials/trainingandevents/Hep_Education_InterdisciplinaryWorkshop.htm 604-707-5661.

Details: <http://hepcbc.ca/event/bccdc-interdisciplinary-viral-hepatitis-education-workshop/>

Sept. 30th in VICTORIA and Oct. 1st in SURREY: "DEAL WITH IT" FILM and FORUM

In VICTORIA on Tuesday, September 30th from 7:00 pm - 9:00 pm at UVic Student Society's CINECENTA Theatre, Student Union Bldg, Victoria, BC V8P 5C2. Free or by donation. Host: HepCBC. Details and DOWNLOADABLE POSTER: <http://hepcbc.ca/event/deal-film-forum-victoria-bc/>.

In SURREY on Wednesday, October 1st from 6:30 pm - 9:00 pm at SFU Surrey campus, Westminster Theatre, adjacent to the Surrey Central SKYTRAIN station. Light refreshments provided. Free or by donation. Co-hosted by Simon Fraser University and HepCBC. Details and DOWNLOADABLE POSTER: <http://hepcbc.ca/event/deal-film-forum-surrey-bc/>.

The new Canadian documentary film by Bang Albino Films, "DEAL WITH IT: Untold Stories of Hepatitis C in Canada," will be followed by a panel discussion with hepatitis C patients and medical staff. Through interviews with patients and healthcare providers, the film documents the despair and the hope of everyday Canadians with this disease. The director Mark Ashdown and several people whose stories are featured in the movie will be attending. These two events were made possible by funding from Janssen Pharmaceuticals.

(Continued on page 5)

(CALENDAR—Continued from page 4)

Oct. 5th: SUBMISSION DEADLINE for SOFOSBUVIR/LEDIPASVIR CADTH PATIENT GROUP REVIEW

Submit your patient input to HepCBC by MIDNIGHT, Sunday, October 5th. Answer the questions on <http://hepcbc.ca/questions-cadth-sofosbuvir-ledipasvir/>. Then email (in body of email, or as an attached text or Word file) to: office.hepcbc@gmail.com.

Details: <http://hepcbc.ca/2014/08/urgent-request-patient-input-interferon-free-hcv-drug-combo/>.

(FEEDBACK—Continued from page 1)

your view is, we want to hear and include your perspective! This is what will help us make a good submission, and hopefully this will result in those Canadians who desperately need these drugs being able to access them. Here are the questions we'd like you to answer in your individual submission: <http://hepcbc.ca/questions-cadth-sofosbuvir-ledipasvir/>

ANSWER AS MANY OF THE SUBMISSION QUESTIONS AS POSSIBLE in an email (or attached Word file if you wish).

SEND YOUR SUBMISSION BEFORE MIDNIGHT Sunday OCTOBER 5th to: office.hepcbc@gmail.com. If you do not wish to answer some of the questions, it is ok (though the more you can answer, the better for us). Just answer the ones you are comfortable with.

NOTE ABOUT POTENTIAL REIMBURSEMENT: Sofosbuvir (stand-alone trade name SOVALDI) has already been approved by Health Canada as part of a two or three-drug combo for the treatment of chronic hepatitis C (CHC) virus infection: along with interferon/ribavirin for genotypes 1 and 4, and along with ribavirin alone (stand-alone trade name IBAVYR) for genotypes 2 and 3. However, Quebec is the only province in Canada to reimburse patients for Sovaldi through its Pharmacare program so far. Some Canadian patients' private plans cover all or part of this treatment; in addition, Gilead's "Momentum" compassionate plan targets all or part of the co-pays required by private plans. Ledipasvir has not yet been approved anywhere in Canada, but we are assuming that **if the sofosbuvir/ledipasvir combo gets approval at the federal level**, Gilead's Momentum program would continue to cover at least part of private insurance co-pays, but that those of us dependent on provincial drug plans such as BC Pharmacare would have to pay out-of-pocket, or await a separate review process to get reimbursed for this drug combo.

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(URGENT 1986-90—Continued from page 1)

previr (GALEXOS).

Those in Quebec are already covered for Sovaldi and Galexos given with interferon and/or ribavirin, so this accommodation would not apply to these treatments in Quebec. However as new drugs such as the Ledipasvir/Sofosbuvir combo are approved by Health Canada and the CDR, claimants anywhere in Canada could access these drugs before they were available on their provincial formulary, due to this program. Ref: <http://www.hemophilia.ca/en/hcv-hiv/hcv-treatment-support-for-1986-1990-claimants>.

Pamphlet: http://www.hemophilia.ca/files/Hep8690%20Brochure_E%208%205x14.pdf

SOVALDI CRITERIA

CANADIAN DRUG REVIEW SETS CLINICAL CRITERIA AND CONDITIONS FOR SOFOSBUVIR (SOVALDI)

On August 20, 2014 the Canadian Drug Review (CDR) Canadian Drug Expert Committee (CDEC) recommended that Gilead Science's drug sofosbuvir (SOVALDI) "be listed for the treatment of chronic hepatitis C (CHC) virus infection in adult patients with compensated liver disease, including cirrhosis" when certain specific clinical criteria and conditions are met. These criteria and the associated treatment formulae and duration include:

Genotype 1: Treatment naive. And fibrosis stage F2, F3, or F4. Used in combination with Peg-IFN and RBV. Funding for 12 weeks treatment maximum.

Genotype 2: Previous treatment experience with Peg-IFN/RBV or a medical contraindication to Peg-IFN/RBV. And fibrosis stage F2, F3, or F4. Used in combination with RBV (IBAVYR). Funding for 12 weeks treatment maximum.

Genotype 3: Previous treatment experience with Peg-IFN/RBV or a medical contraindication to Peg-IFN/RBV. And fibrosis stage F2, F3, or F4. Used in combination with RBV (IBAVYR). Funding for 24 weeks treatment maximum.

CDEC added a condition that the price of this drug must be reduced, though they do not specify the degree or amount of the reduction.

Now it is up to the provincial drug plans to decide whether, and if so how, to list this drug. The only province which lists it now is Quebec, which established quite different criteria: access to Sovaldi is provided in Quebec to anyone who is treatment-naïve, genotypes 1, 2, 3, or 4, regardless of fibrosis score.

Reference: www.cadth.ca/media/cdr/complete/cdr_complete_sovaldi_august_20_2014.pdf



Leah Giesbrecht, Communications Director of Positive Living BC
World Hepatitis Day Vancouver 2014
- photo credit POSITIVE LIVING BC



Vancouver Staff of Canadian Liver Foundation at World Hepatitis Day Vancouver 2014
- photo credit POSITIVE LIVING BC



World Hepatitis Day Vancouver 2014 PLANNING COMMITTEE members came from HepCBC, S.U.C.C.E.S.S., Lower Mainland Purpose Society, First Nations Health Authority, and the BCCDC. At podium: Master of Ceremonies Sandi Mitchell of BCCDC - photo credit ALP



Protest against Gilead, NYC, Sept 4, 2014



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 week 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, shelters

Please contact:

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

HEPATITIS C CIRRHOSIS SUPPORT GROUP

By 2013 my HCV related liver damage had progressed to compensated cirrhosis. I have just completed 48 weeks of interferon, ribavirin and Boceprevir and was undetectable at end of treatment. We still live with liver damage though which motivated me to form a group on Facebook for those dealing with end stage liver disease. The privacy settings are at maximum that FB offers so it is a "secret" group and will not show up on FB search engines and no one outside of group members will see what you post.

Here is the description:

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

MANITOBA CLF PRESENTS UPCOMING SPEAKERS:

September 18th 1:30 – 3:00pm. *Sherry Sobey* speaking about Organic Products to help your body (particularly products to help itchiness). In the Canadian Liver Foundation Office.

October 2nd 1:30 – 3:00pm. *Dr. Reece Malone* speaking. Contact the Canadian Liver Foundation for location.

October 9th 1:30 – 3:00pm. *Pharmacy Intern* speaking about Liver Disease itchiness and over the counter prescriptions. In the Isabelle Stewart Building.

November 20th 1:30 – 3:30 pm. *Dr. Wong* speaking. In the Reh-Fit Center (1390 Taylor Ave.)

These are open events!

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 responded to treatment and remained undetectable for a minimum of 12 weeks after finishing treatment? Celebrate and give others hope. Please send us your info. We'll add your name (or initials). Congratulations to our friends:

1. **GJ** - SVR Dec 1998 - IFN/RBV 52 wks - Dr Anderson /Natalie Rock, Vancouver, BC.
2. **Amberose** - 2000 (GT 2A/2C) - Schering IFN/RBV 24 wks
3. **Jeanie Villeneuve** - Oct 2000 - Schering IFN/RBV
4. **Kirk Leavesley** - (GT1) - 2004 - Roche
5. **Darlene Morrow** - (GT1 relapser) - Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.
6. **KG**—[NEW] 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- Pegasys/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 - April 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 treatment veteran - multiple previous attempts including Incivek over 10+ years.) Jan 2014. GS-7977/GS-5885 (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.

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

CONFERENCES

12-13 September 2014
AASLD/EASL Special Conference on Hepatitis C
Sheraton New York Times Square Hotel
New York City, New York
www.aasld.org/additionalmeetings/hcv/Pages/default.aspx

13 September 2014
Latin-American Association for the Study of the Liver (ALEH)
Cancun, Mexico
www.aleh2014.com/

13 September 2014
Prague Hepatology Meeting 2014
Prague, Czech Republic
www.congressprague.cz/en/kongresy/phm2014.html

17-19 September 2014
9th Australasian Viral Hepatitis Conference 2014
Alice Springs, Australia
www.clocate.com/conference/9th-Australasian-Viral-Hepatitis-Conference-2014/31436/

9-11 October 2014
Viral Hepatitis Congress 2014
Frankfurt, Germany
<http://www.viral-hep.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.)

COMPENSATION

LAW FIRMS

1986-1990

Bruce Lemer and Company
Vancouver, BC
Phone: 1-604-609-6699
Fax: 1-604-609-6688
www.lawyers-bc.com/classactions/clalawy.htm



Pre-1986/ Post-1990

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/class/settled/hepc/

Lauzon Belanger S.E.N.C. (Quebec)
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204
<http://lblavocats.ca/en/class-actions/hepatitis-c/active/red-cross.php>

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

LOOKBACK/TRACEBACK

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

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

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

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

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

Manitoba Traceback: 1-866-357-0196

Canadian Blood Services, Ontario
1-800-701-7803 ext 4480 (Irene)
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

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/

