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Canada's Hepatitis C News Bulletin

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SANJIV'S STORY (Part IV)

Sanjiv and Kavita: The Present Day



Editor: We are proud to present Part IV of Sanjiv's Saga. The first part was published in our August 2008 issue. The second part appeared in our November 2010 issue, and continued as Part III in the December 2010 issue.

Sanjiv has just sent us an update, and here it is, in his own words:

The silver lining The fruits of perseverance!

Prior to initiating therapy with protease inhibitors I was advised to have a new liver biopsy to determine the state of my liver. With reluctance from my last experience, I underwent the procedure which revealed that my liver was in better shape (measured in terms of fibrosis score) as compared with the biopsy done six years ago confirming that my endeavors of persisting with therapy and all other efforts had resulted in my liver getting better. I was happy and was raring to get going with new drugs!

Fifth attempt with HCV therapy September 2011 – The Tsunami

In September 2011, I started therapy for a fifth time by adding "boceprevir", a protease inhibitor to the regular cocktail of interferon and ribavirin. Compared with the earlier attempts, this one proved to be the toughest in terms of severity of side effects and management of anemia. I was however determined and with a positive frame of

mind I completed the harsh treatment of 48 weeks in August 2012. All through it, it seemed that I would get cured as I had become virus undetectable early on but this was not to be and in November of 2012, I relapsed and naturally, I was terribly disappointed!

Sixth attempt with HCV therapy January 2013 – The Extended Vacation

No one goes into battle thinking they are going to lose, and then wins. Perhaps this outlook is what has taken me so far; I find it difficult to entertain the possibility of an unsuccessful outcome – it may get delayed but it will come. I may have lost many battles but I find it hard to consider the possibility of losing the war. Yet it is a possibility that I should consider, there are no certainties; it is a tough one. I think it is important for us to stay in touch with the positive perspective that defines a winner! I think this is true for anyone who faces life-threatening challenges.

At the juncture of witnessing failure for the fifth time, I had two choices, i.e., to wait a few years for the launch of the new, more effective oral drugs under development or to take my chances and try enrolling in a clinical trial. I chose not to wait as

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URGENT PETITION! NEW DRUGS MAY BE TOO LATE

The new Hep C drugs may be covered too late for this Ottawa woman. Brenda Peever's daughter has turned to an online petition to get urgent support for her seriously ill mother:

By Don Butler, *Ottawa Citizen* February 16, 2014

Article/photo [here](#):

<http://www.ottawacitizen.com/health/hepatitis+drugs+funded+late+Ottawa+woman/9514730/story.html>

Please [sign](#) this Petition:

Ensure that the new Hepatitis C cures sofosbuvir and simeprevir are made available for patients nearing end of life with stage 4 liver cirrhosis and no private insurance! Time is of the essence!

<http://www.change.org/petitions/canadian-agency-for-drugs-and-technology-in-health-ensure-patients-in-the-end-of-life-stage-of-liver-cirrhosis-have-access-to-the-new-hepatitis-c-cures>

Related Letters, CTAC <-> CADTH:

<http://ctac.ca/uploads/Presentations,%20Posters%20and%20Reports/CADTH%20Letter%20-%20Queuing%20-%20Jan%2014%202014.pdf>

<http://ctac.ca/uploads/Presentations,%20Posters%20and%20Reports/B%20%20Huskins%20CTAC%20Feb%20102014.pdf>

RECRUITING PARTICIPANTS SOON:

Ledipasvir/sofosbuvir Fixed-Dose Combination + RBV in Subjects With Advanced Liver Disease or Post-Liver Transplant, Genotype 1 or 4. Locales: UBC Hospital and Vancouver Gen Hosp; others in Edmonton, London ON, Toronto, and Montreal.

ClinicalTrials.gov Identifier: NCT02010255
Last updated: February 11, 2014

Participants will be randomized to receive 12 or 24 weeks of dosing with the LDV/SOF FDC tablet+ribavirin (RBV).

Details: <http://www.clinicaltrial.gov/ct2/show/NCT02010255?term=hepatitis+c&state1=NA%3ACA%3AON&rank=112>

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"I want to volunteer. Please contact me."

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

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

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Download the *hepc.bull* free at <http://hepcbc.ca/hepc-bull-monthly-newsletter/>

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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.

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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.

PERCURO HEP C CLINIC



PerCuro Hepatology Clinic provides comprehensive HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region.

Specialized nurses assist with the procurement of financial coverage for treatment, ensure lab tests are scheduled appropriately, provide instruction in the self-administration of injectable medication, assist with the management of side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding the patient's HCV status, treatment and any other issues of concern.

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

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

Every attempt is made to meet the individual needs of all patients. There is no cost involved.

**Nursing Support improves outcomes.
Contact 250-382-6270**

MARATHON

HepCBC Seeking Walkers, Runners, Volunteers, Donors!

This will be the FOURTH YEAR for the HepCBC LIVER WARRIORS Team! On October 12, 2014 the annual Goodlife Fitness Victoria Marathon will be held in Victoria, BC. Events will include: Full Marathon (walk or run 42.2k), Half Marathon (walk or run 21.1k), 8k "Road Race" and a Kid's Run. We hope to raise awareness about hepatitis C, fight stigma, raise money for HepCBC, publicize the benefits of exercise for liver health, improve our personal fitness, and have fun! If you can't walk or run, consider volunteering, collecting donor pledges, or fundraising. If you can't come to Victoria, consider starting a team in your local community.

2014 Registration starts soon: <http://www.runvictoriamarathon.com>. The registration fee increases every few weeks, so be an Early Bird. Select the "HepCBC Liver Warriors" team from the dropdown list. Email marathon.hepcbc@gmail.com to let us know you have registered! Start regular training early in the spring, and you'll be in great shape by October. It's fun to be on a team for training as well as race day; let us know if you'd like to do practice walks or runs with others.

For more info: <http://www.hepcbc.ca/marathons-walks/>



Independent film company Bang Albino has produced a compelling new film by Mark Ashdown about hepatitis C, which we hope will be shown widely in Canada! Several of us were privileged to be in attendance at the world premiere at the Hockey Hall of Fame during Digestive Diseases Week 2014 in Toronto. Joining twenty or so others from throughout the country who were eager to tell Mark their stories, six HepCBC volunteers were interviewed in the film: Patient Advocate/Hepatology Nurse Fran Falconer, Douglas Laird, Cheryl Reitz, Karen Felske, Dr. Chaim-David Mazoff, and Anita York.

Details from Bang Albino:

"*Deal with it* exposes the state of Canada's Hepatitis C epidemic...Misunderstood by the general public and government agencies, hepatitis C has never garnered the appropriate attention or resources that a serious public health threat demands. Through gripping interviews with patients and healthcare providers, *Deal with it* documents the despair and the hope of everyday Canadians struggling to navigate their way through systemic and societal hurdles to deal with a chronic viral disease for which there's not only an effective treatment – there's also a cure."

Though partially funded by the pharmaceutical industry, the film does not dwell on treatment, but rather on the lives of those affected by HCV. The film is approximately one hour long. The public version of the film will be released around April 1, 2014. If you want to organize a screening in your community, email dealwithit@bangalbino.ca.

THANKS!!

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

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

(Sanjiv's Story—Cont'd from p. 1)

a passive bystander, letting the liver damage continue. Thus, with help from one of the best in the field, Kavita and I relocated to the US to enroll on a Gilead-sponsored clinical trial. To my pleasant surprise, the all-oral drug trial had minimal side effects which allowed Kavita and me to make the best of this period by travelling through the US. The drugs under development (i.e., the second-generation DAAs, NS5A inhibitors, protease inhibitors, nucleotide analog polymerase inhibitors) are God-sent for hepatitis C patients, as they have few side effects, are proving to have excellent cure rates, and have shortened the treatment duration from 48 to 12 weeks. Once commercially available, they are almost guaranteed to cure and perhaps eradicate Hepatitis C in the times to come.

Coping with a damaged liver and its treatment

From everything I have read and experienced, each person's journey with medical challenges is personal and will be qualitatively different from others. In a period of 8 years I endured over 350 shots of pegylated interferon and consumed thousands of ribavirin and other capsules wherein excessive toxins were built up in my body. My body weight went down from 65 kgs in 2005 to 49 kgs in 2007 but now remains stable at 60 kgs. HCV therapy (akin to chemotherapy) does not just kill the virus — it affects the healthy cells too. It attacks the muscle, skin, teeth, the linings of the throat and stomach and leaves one vulnerable to infections. The long duration of therapy robbed me of healthy blood cells and had cut down my hemoglobin count. Hemoglobin transports oxygen to the vital areas, and a normal value of hemoglobin for a healthy person is about 16 g/dL. At one point I came down drastically to 8.5 g/dL and I had to take epoetin to increase the same.

When the liver does not function efficiently and metabolize toxins put into the body it passes them on through the bloodstream to various parts i.e. the muscles, joints or skin. Feeling tired and irritable with malaise, body aches, fever, mouth sores, skin rash, joint pains, itching, changes in appetite, insomnia, shortness of breath, mood swings, being disoriented, experiencing blurred vision, nausea, fever, headaches, swallowing difficulties, constipation, are just some of the side effects of liver disease and treatment management. The intensity and range of side effects also depends upon the extent of liver damage. It is hard to generalize and sometimes explain this experi-

ence because of the fatigue and the related mood swings that hepatitis C and its therapy brings. During this period many a time I have felt like an eighty year old man – slowed down, breathless, needing a nap, preoccupied with my body and internal workings, tired and grouchy. The interferon treatment is strange; it does odd things to us emotionally, psychologically and physically. Sometimes we can rise above and observe what is going on with us, at other times we are swept along and sometimes we just need to sit around, go with how we feel and relax in the knowledge that it is fine – it is a part of the process. There were days when I was irritable, aggressive, and aware that this was chemically induced, like feeling the sensation of alertness when I could not sleep or when I would wake up at 2 am in the morning or at times being irrational or temperamental. There were times I didn't want to talk, eat or be bothered; I labeled it "downtime." But my chin stays up and I know that I will make it through one day.

Living with the ongoing assault of therapy, having had multiple medical procedures makes me feel as though I have been run over by a bull dozer and thrown into an abattoir for 8 long years. Moreover, I have the physical scars and surgical masterpieces which run from various parts of my body: a scar that stretches from the left side of my groin to my left ankle, another scar that runs from the right ankle to my right knee, a third from left wrist to the elbow; but the real jewels are two deep scars that run down my chest (from the collar to the middle of my chest) which allowed the surgeons to gain access to my heart by cutting open my sternum during the two coronary bypass surgeries. The combined effects of therapy, surgical interventions, and a damaged liver has left me physically and mentally depleted.

During this period, my work (I manage a financial services company in India) has required major adjustments. During this period I also moved away from my social life. I was just too tired and with limited energy reserves each day, and I wanted to make sure that I was not spreading myself too thin. My priorities were on the home front. My daily routine and the lifestyle changes I made after my first coronary bypass surgery have been invaluable in helping me deal with the treatment side effects. I begin each day with a morning walk and retire to bed early; in addition I practice yoga. I also

have a masseuse who helps me relax. I eat a simple, primarily vegetarian, very low fat diet. A 20 minute meditation routine each morning helps me accept my circumstances and face each day with a level of zest, hope and joy! Staying deeply involved and disciplined with a routine of healthy habits practiced for over two decades has helped me tremendously and has gotten me this far.

Hope & Support

As I reflect on my life, I believe that I am truly blessed in that I have been saved every time before disaster has struck. At age 30, I was diagnosed and treated for heart disease before I could actually become the victim of a fatal heart attack, the probability of which was high since I had "triple vessel" disease. Then while going through HCV therapy I was diagnosed with the need for a repeat heart surgery and was operated upon before actually suffering a heart attack which would have left me too weak to undertake the aggressive therapy. Moreover, when I was diagnosed with HCV in 2005 my prognosis would have been disastrous if I had been discovered to be co-infected with HBV or HIV or if HCC (liver cancer) had set in my liver. I consider myself very fortunate that today I am in a position to be hopeful and am able to participate and gain from my journey.

I have a fantastic family comprised of my lovely life partner Kavita, my mother, my two sons, Rohan and Raghav, my new daughter-in-law Aradhana and the many friends and well-wishers in my life. I have imbibed the attributes of a positive attitude from my late father, the virtues of believing in God and spirituality from my mother and that of true compassion from Kavita.

My Innumerable Gains

The years after my diagnosis with HCV have provided me with a phenomenal opportunity to grow, to get to know myself much better and to reach a higher spiritual platform. This experience has taught me many valuable things about medicine, my overall health and my view of life. This period has helped me cultivate a strong sense of discipline and the will to fight and persevere endlessly. It has made me positive and proactive in my approach and stronger mentally and spiritually. Each setback may have initially shaken me up but in hindsight it has also provided me with an opportunity to introspect, take positive action and do my best in situations within my control. Moreover, it has al-

(Continued on page 4)

(Sanjiv's Story—Continued from page 3)

lowed me to share my learnings and give hope that I have travelled the path many may be travelling. If you look for the good in every experience, however bad a situation may appear, there is always something to be gained.

Changes and opportunities are not only about getting cured – they are about finding a whole new perspective and a view on what is truly important. I was compelled to get down to taking my fears head on - my fear that my medical challenges would kill me sooner than later, my fear that the treatment wouldn't work, or the side-effects could permanently damage me, and so on. A patient will engage in and process feelings, and then come back to a position of acceptance, which is one of the hardest things for any patient. I understand this today; there are no shortcuts in life, you have to put in the effort, stand upright and fight.

How has all this changed me? During every setback, I've encountered many questions and thoughts of self-pity, but you learn to embrace the challenges. When life presents you challenges, it also presents you clues of strength. You may choose to pick the easy route which requires you to do nothing but surrender, but I was fortunate that I took what was offered and decided to fight and this, I believe, makes all the difference! Experiences shape us and each experience has its own effect.

Emotions

My journey has been a grueling marathon with the distance constantly changing, the bar being reset to a higher level, and the climb becoming steeper. Every time I feel that I am close to the finishing line, it seems to be taken further away and out of sight; it is unsettling and catches me unprepared. I am used to running low on my body condition and have had many bumps and grinds on the way. I get progress reports from routine medical tests every few months, some good and some not so good. However, the big difference between the day I started and the present day is that now I try harder than I ever did in the past. During the course of my marathon, I think about my occupation, my livelihood, my responsibilities, and just making it through. The idea pumps me up; winning my health back and enjoying 20 healthy years of my life with Kavita will be my biggest victory! I am focused on getting on with it; as long as I follow what I have programmed myself to be and do, I am in control and healthy!

Knowledge & Education

I read extensively on the subjects I deal with – the heart, liver, on coping emotionally, spirituality, about human traits, behavior, motivation, attitude, and perseverance. I have learnt about diet and lifestyle choices, about milk thistle, flaxseed oil, wheatgrass, soy, garlic, COQ 10, vitamin D, selenium, alpha lipoic acid, NAC, turmeric, a host of other antioxidants, yoga, meditation, aura healing, massage, exercise, lifestyle, and so on. I follow clinical trials and their outcomes. The more research I do the better conditioned I get. Knowledge is always more reassuring than ignorance; at least you know what you are dealing with! Knowledge and adherence to discipline helps me avoid that feeling that I am just a passive observer helpless in regard to what has happened to me. I feel that I am at the helm and in control and I play an active role in my own healing. Knowledge is power and understanding medical information and myself “empowers” me to take responsibility for my health and my treatment.

Encore

Sharing helps people come together and support one another. The crux of my sharing is not about disease but is about taking control over challenges that life thrusts on us and doing your best in situations that may be life threatening. It is about conditioning the mind, making a mental resolve and following it up with determined action on a daily basis. It is about optimism, discipline, perseverance, attitude and keeping your chin up through times of adversity. It is about working on the belief that the human body is resilient with an incredible capacity to heal and that the mind has the power to drive it and overcome adversities. Above all it is about living in the present! I am consistently inspired by Mahatma Gandhi's quote, "I do not want to see the future. I am concerned with taking care of the present, as God has given me no control over the moment following." Moreover, I do not want the epitaph on my tomb to read, "The sick guy, who succumbed to disease," but rather, "He who did his best in every situation." Good health, a good frame of mind, and life itself is not to be taken for granted.. being alive is glorious and therefore “*Carpe diem.*” I hope that each of you will enjoy your journey, find the positives, and make your experience the

best it can be for you and your loved ones. Good luck and God Bless!!

Gratitude & Acknowledgements

I am extremely grateful to the long list of medical professionals who have patiently addressed my questions and provided me with the best advice: Dr Mitchell L Shiffman, Dr S. K Sarin, Dr Bennet Cecil, Dr Samir Shah, Dr Sanjiv Saigal, Dr Subhash Gupta, Dr Navin Dang, Dr Ravendhran & Dr Naresh Trehan. I am grateful to the management and medical team at Sir Gangaram Hospital, New Delhi, The Institute of Liver and Biliary Sciences and the Liver Institute of Virginia, USA (especially Suzette Tips) for taking excellent care of me. I am grateful to the healers Gurbax and Gunvir Arora and my yoga guru Vijay. I am grateful to the websites HCV Advocate, Heart disease - About, Clinical Care Options and Janis for enriching my knowledge on the subjects and the work they do for the community. I am grateful to my dearest friends and my family for being around me and having seen me through the worst, and above all, I am eternally grateful to God! I am reachable at sanjivsyal@ablindia.com

“You have to have the mentality of executing your game when you don't feel like there's a lot of hope. I think the best feeling is when somebody pushes you to the limit and you dig down a little bit extra. By the same token, you also need a little luck. Sometimes they come together.”—Andre Agassi

Editor: I think many of us feel like we know Sanjiv personally, and I'm sure you are all in suspense... Sanjiv wrote back to reassure me: “I did achieve SVR 24!” These words always bring happy tears to my eyes. I can't think of anyone who has tried harder.



CANADIAN DIGESTIVE DISEASES WEEK

Attended by 3 HepCBC Volunteers

Between February 5–11, 2014, three



HepCBC volunteers attended many meetings in Toronto to get the latest HCV and liver disease research and treatment news from top Canadian and international specialists. First, Cheryl Reitz attended meetings of Canadian Aids Treatment Information Exchange (CATIE) and Action Hepatitis Canada, while Fran Falconer attended meetings of the Canadian Association of Hepatology Nurses (CAHN). The two were joined by Douglas Laird at the one-day Canadian Institutes of Health Research (CIHR) HCV Symposium, followed by four intense days at the Canadian Association for the Study of the Liver (CASL). The final day of CASL was totally devoted to hepatocellular carcinoma (HCC or liver cancer). In upcoming issues we will do our best to share highlights of this vast body of information with *hepc.bull* readers.

HCV MANIFESTO UPDATE

As of February 28, 2014, the HCV MANIFESTO (www.hepcbc.ca/hcv-manifesto/) has been signed online by 53 individuals and 10 organizations, getting us to about 5% of our goal of 1000 individuals and 200 organizations! Please share this document with your friends, family, community groups, and Social Media. Encourage them to sign it online in support of people with HCV. Thanks so much!

ANTIDEPRESSANTS + HCV

January 6, 2014: Some French researchers believe that antidepressants are more toxic than thought, especially for those with Hep C. The new info came from 88 case reports, 38 articles and 32 literature reviews. The liver can sometimes regenerate, so the researchers recommend watching ALT levels regularly, and stopping the drug if they rise. Most risky are the MAO inhibitors, tricyclic/tetracyclic antidepressants, nefazodone, bupropion, duloxetine and agomelatine. A bit safer are citalopram, escitalopram, paroxetine and fluvoxamine.

(<http://ajp.psychiatryonline.org/article.aspx?articleID=1795083>)

(http://www.hepmag.com/articles/antidepressants_liver_2501_25000.shtml)

NEWS FLASHES

SOFOSBUVIR PRICING IN CANADA

Feb. 24, 2014: Gilead announces \$55,000 Canadian pricing for its sofosbuvir (SOVALDI™) treatment which is significantly lower than the \$84,000 that is being quoted for the USA, and actively opposed by patient advocacy groups there:

"Gilead Sciences Canada Inc. is committed to ensuring the best possible market access for HCV patients who would benefit from treatment with Sovaldi. As such, a 12-week course of treatment with Sovaldi will be \$55,000 CDN reflecting overall regimen parity with currently-approved protease inhibitor-based triple therapy."

Note this amount does not include the cost of other HCV medications such as interferon, ribavirin, or simeprevir with which it is currently being combined, depending on patient's genotype or other factors. This treatment is currently only available to Canadians who are able to purchase it with private insurance or their own funding, pending provincial approvals which may take another year or more. HepCBC is working with other groups to press for expediting approval of this and other life-saving HCV drugs in Canada.

NEW FDA SUBMISSIONS

A flurry of interferon-free, ribavirin-free submissions are coming to the FDA. Will the intensely competitive atmosphere – seen to pervade the regulatory reviews of three new interferon-free, ribavirin-free hepatitis C treatments in the US – result in a lowering of the price of HCV treatment in Canada as well? Here are three recently-announced developments we are monitoring:

Gilead Sciences - First Interferon and Ribavirin-Free Submission for Genotypes 1A/1B to FDA

Feb. 10, 2014: Gilead submitted a New Drug Application (NDA) to the FDA for the first interferon-free and ribavirin-free oral treatment, a two drug combination for HCV Genotypes 1a and 1b patients; this drug combination was awarded "breakthrough status" by the FDA, which should speed up approval. The treatment is "a once-daily fixed-dose combination of the NS5A inhibitor ledipasvir (LDV) 90 mg and the nucleotide analog polymerase inhibitor sofosbuvir (SOF) 400 mg for the treatment of chronic hepatitis C genotype 1 infection in adults. The data submitted in the NDA support the use of LDV/SOF in patients with genotype 1 hepatitis C virus

(HCV) infection, with a treatment duration of eight or 12 weeks depending on prior treatment history and whether they have cirrhosis."

(<http://hepatitisnewdrugs.blogspot.ca/2014/02/gilead-files-for-us-approvalledipasvirs.html> and <http://www.hcvadvocate.org/news/newsLetter/2014/advocate0314.html#1>)

Bristol-Myers Squibb Awarded FDA Breakthrough Status for Genotype 1B Treatment

Feb. 24, 2014: BMS was awarded "breakthrough status" from the FDA for its all-oral, interferon-free, ribavirin-free treatment for HCV patients with genotype 1b only. This treatment combines daclatasvir (DCV) and asunaprevir (ASV). This 'breakthrough' designation "is based on data from the company's ongoing Phase III clinical trial program evaluating the all-oral combination regimen of DCV, an investigational NS5A replication complex inhibitor, and ASV, an investigational NS3 protease inhibitor, without ribavirin... Breakthrough Therapy Designation is intended to expedite the development and review of drugs for serious or life-threatening conditions."

(<http://news.bms.com/press-release/bristol-myers-squibb-receives-us-fda-breakthrough-therapy-designation-all-oral-daclata&t=635288455840568400>)

AbbVie Completes Interferon-Free (some Ribavirin-Free) Trials for GT1

Jan. 31, 2014: AbbVie completed Phase III of its all-oral, interferon-free trial for genotype 1a & 1b patients, which included those with cirrhosis. Treatments with and without ribavirin were tested for each 'treatment arm'. SVR results were between 90 and 100% for ALL of the treatment arms: "The AbbVie investigational regimen consists of the fixed-dose combination of ABT-450/ritonavir (150/100mg) co-formulated with ABT-267 (25mg), dosed once daily, and ABT-333 (250mg) with or without ribavirin (weight-based), dosed twice daily. The combination of three different mechanisms of action interrupts the HCV replication process with the goal of optimizing SVR rates across different patient populations. In May of 2013, AbbVie's regimen with and without ribavirin for HCV GT1 was designated as a Breakthrough Therapy by the U.S. Food and Drug Administration (FDA). AbbVie is on track to begin major regulatory submissions early in the second quarter of 2014."

(<http://abbvie.mediaroom.com/2014-01-31-AbbVie-Completes-Largest-Phase-III-Program-of-an-All-Oral-Interferon-Free-Therapy-for-the-Treatment-of-Hepatitis-C-Genotype-1>)

I am a liaison worker for the STRIDE Program at the Lower Mainland Purpose Society here in New Westminster- which is a multi-service organization with programs including youth, family therapy, HIV/Hep C (Stride) support and we also run an alternative high school. In terms of changes to the Stride (HIV/Hep C) Program, we have recently received the STOP HIV funding for the Fraser North Region, which means our service area now includes New Westminster, Burnaby, the Tri-Cities, Pitt Meadows and Maple Ridge, and we provide in house and outreach support, referrals and advocacy services to individuals who are Hep C and/or HIV positive. Here is a quick synopsis of our services at Stride:

- Mobile needle exchange/harm reduction distribution Van (safer sex, safer smoking, safer injecting) – 6 days a week (Locations beyond Maple Ridge – once every 2 weeks). We also have a needle-exchange at the Purpose front desk, which is open Monday to Friday 9am-5pm. Individuals in our service area can call during our Health Van hours and we will deliver/collect supplies.

- FREE Educational workshops- HIV 101, as well as Hep C and safer sex workshops and Harm reduction training. Available to service providers, organizations, clients and schools. To be booked with me (Tatiana) 604 562 5106

- Support for HIV+ and Hep C+ clients (e.g. one on one support, advocacy, referrals, transportation to and from doctor's office) – available 5 days a week (Mon-Fri), scheduled with outreach/support workers. Drop in days are Mondays, Wednesdays and Fridays.

- Point of Care (POC) (HIV) testing events involving the nurses from BBP team at the New Westminster Public Health Unit

- Free Adult Clinic (testing, vaccines, etc.) on Fridays 10am-1pm. We used to have a NP (nurse practitioner) on staff but she has taken another position, so our clinic is currently staffed by a Public Health Nurse from the BBP (Blood-Borne Pathogens) Team in New West. We are currently in negotiations to get a new NP. Services provided are currently limited to urine, STI (Sexually Transmitted Infection), POC testing, and vaccines.

- Hep C Support Group every first and third Friday of each month. Open to all who are interested, although individuals should let us know prior to attending so that we can accommodate them.

- In house laundry/showers available during drop-in hours for clients

- Weekly client Friday food bank (with the exception of cheque-issue week), as well as weekly mobile food bank delivery to HIV+

members.

- Friday hot lunch for clients at 12pm (with the exception of cheque-issue week)

In the case that someone is interested in becoming a client, all that is required for membership is a doctor's confirmation of Hep C or HIV positive status and a quick in-take appointment, although individuals can still access the health van, educational services and the adult clinic without being a client, or being HIV or Hep C positive. If anyone is worried about their status and would like to get tested, they are welcome to come to our Friday Clinic (10am-1pm) and get tested free of charge. Individuals can self-refer to our program, or can be referred by other organizations/health care practitioners.

If you are interested, we can add you to our out-going email list for the monthly calendars. I hope you find this information useful.

Tatiana Pakhomova
STOP HIV Liaison
The Lower Mainland Purpose Society | Stride with Purpose
40 Begbie Street, New Westminster, B.C. V3M 3L9
C: 604-562-5106 | F: 604-526-6546
tatiana.pakhomova@purpose.society.org

CAPAHC: FRENCH SUPPORT GROUP

Are you are a French speaker infected with hepatitis C or co-infected with HIV? Do you need information, support, and interaction with people who are experiencing the same thing as you? Would you like meeting with patients on treatment, or others who have completed treatment?

CAPAHC welcomes you to its monthly French-language support group (5055 Rivard St., Montreal, QC), held every third Thursday of each month from 6 PM to 8 PM. For more information, you can contact us at 514-521-0444 or 1-866-522-0444.

www.capahc.com



Have you responded to treatment and remained undetectable for a minimum of 12 weeks after finishing treatment (i.e., SVR or Sustained Viral Responder)? Let us help you celebrate. You can give others hope. Please take a minute to send us your name, genotype, date of SVR, and type of treatment to post here, and we'll add your name (or initials). Congratulations to our friends:

1. **GJ** - Dec 1998 - IFN/RBV 52 wks - Dr Anderson /Natalie Rock, Vancouver, BC.
2. **Amberose** - 2000 (GT 2A/2C) - Schering IFN/RBV 24 wks
3. **Jeanie Villeneuve** - Oct 2000 - Schering IFN/RBV
4. **Kirk Leavesley** - (GT1) - 2004 - Roche
5. **Darlene Morrow** - (GT1 relapser) - Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.
6. **Beverly Atlas** - (GT1a) - 2006 - Albuferon/RBV 44 wks
7. **Steve Farmer** - 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
8. **Gloria Adams** - (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks - Drs Erb & Yoshida, Vancouver, BC.
9. **Don Crocock** - (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 weeks
10. **Daryl Luster** - (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
11. **Donna Krause** - (GT1 partial responder) SVR - Nov 2011- Pegasys/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks - Dr. Erb, Vancouver.
12. **Cheryl Reitz** - (GT1b partial responder) SVR12 Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
13. **Anita Thompson** - (GT1a treated 3 times) Cirrhosis - SVR April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
14. **Leon Anderson** - (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
15. **Joan King** - (GT1b treated 5 times) SVR24 June 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
16. **Sandy J.** (GT 1a treatment naïve) SVR12 Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island.
17. **Andrew P.** - (GT 1a treatment veteran - multiple previous attempts including Incevik over 10+ years.) SVR24 Jan 2014. GS-7977/GS-5885 (Sofosbuvir/Ledipasvir) + RBV 24 wks
18. **Diane Stoney** - Transfused 3/21/79 (GT 1a treatment naïve) SVR24 2/4/1014 - 12 wks placebo, then 12 wks on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC [NEW!]

We know there are many more of you. Please send your name and info to Joan at info@hepbc.ca and help raise the hope of those still infected.

CONFERENCES

12-15 March 2014

Asian Pacific Association for The Study of the Liver
Brisbane, Australia
<http://apasl2014.com/>

17-18 March 2014

International Conference on Viral Hepatitis
Fordham University – New York, NY
www.xcdsystem.com/icvh2014/

9-13 April 2014

EASL - The International Liver Congress 2014
International Convention Centre ExCeL
London, United Kingdom
www.easl.eu

1-3 May 2014

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

3-6 May 2014

DDW 2014
McCormick Place Chicago, IL
www.ddw.org

28 July 2014

World Hepatitis Day
www.worldhepatitisalliance.org/
WorldHepatitisDay.aspx

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

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/

