

hepc . bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEP C IN THE NEWS

INFECTION RISK AT U of REGINA

The University of Regina has sent warnings to over 260 people—students, volunteers and fee-for-service clients, who took kinesiology or health studies and had “blood lactate level testing” there between 2006 and 2012. Not all the names of the 267 people were filed, so 644 letters are being sent out, just in case. The lancet used was replaced but the holder part was reused after being wiped with alcohol. The risk of infection is VERY low.

Source:

<http://ca.news.yahoo.com/university-regina-says-improper-blood-testing-puts-100s-193321243.html>
9 Oct, 2013

SIMEPREVIR & SOFOSBUVIR APPROVED IN US

The US FDA has just voted unanimously to approve the use of Janssen's simeprevir together with PR (pegIFN/RBV) for 24 weeks, and sofosbuvir + PR for 12 weeks. This decision is the prequel to two IFN-less treatments, to be approved early next year: sofosbuvir + ledipasvir by Gilead, and ABT450+267+333 by Abbvie—both treatments with or without RBV. Those trials have shown SVRs of 95-100% after 12 weeks of treatment. Sofosbuvir + simeprevir SVRs were 96% in hard-to-treat patients. Sofosbuvir + daclatasvir resulted in 100% SVR in treatment-naïve or previous NR patients (non-responders) to telaprevir or boceprevir. BMS, Merck, Boehringer Ingelheim and Presidio also have oral drug combos with 90-100% SVRs, and Vertex, Janssen and Roche are also in the running with all-oral combos. More data will be released at the 2013 AASLD conference in November.

Source: natap.org

GENOTYPE 1A & Q80K

Scientists have been investigating why GT 1a's haven't been responding so well to the new treatments as GT 1b's. A variant called

(Continued on page 5)

LOU REED

March 2, 1942 -
October 27, 2013



The music world is mourning the loss of Lou Reed, co-founder of the Velvet Underground—a vital part of Andy Warhol's Exploding Plastic Inevitable—who were very popular in the 1980s. He was considered to be a poet among his followers, and has been immortalized in his many albums and on YouTube. His hepatitis C made it necessary for him to have a liver transplant last year, and liver problems seem to have been the cause of his death.

Lou was from Long Island, NY, and dropped out of high-school to pursue his career. He is especially known for his “Walk on the Wild Side”, “Transformer”, “Metal Machine Music”, and “Sally Can't Dance”

“He defiantly always followed his own dark muse and mercurial instincts...” His passion and commitment to his art will be greatly missed.

Sources:

<http://lafiga.firedoglake.com/2013/10/27/rip-lou-reed/>

<http://globalnews.ca/news/918364/flu-shot-halves-risk-of-heart-attack-or-stroke-in-heart-disease-patients-canadian-study-suggests/>

MY STORY

Sept. 2013

by Andrew Cumming

My adventures as a hemophiliac started when I tried to walk at nine months of age in early 1960 and my ankle blew up like a balloon. I was living in Gravenhurst at the time with my mom and dad. Dr. Bill Cumming, my father, was a young general practitioner in town at that time. He drove me to Sick Kids Hospital in Toronto to see if the problem could be diagnosed, but he had a pretty good idea what it was. Turned out I was a severe Factor VIII hemophiliac. And so it started. He brought me back up to Gravenhurst where I proceeded to wait another nine months before trying to walk again. I guess that bleeding ankle must have hurt quite a bit. Once or twice a week my mom or my dad would take me up to the nearest hospital, which was in Bracebridge, where I would get a unit or two of fresh frozen plasma in an attempt to treat my bleeds. Cryoprecipitate wouldn't come along for another five years, and freeze-dried factor concentrates were in the far distant future at this time.

Mine has been a life of close calls and very fortunate timing. The fact that cryoprecipitate came out just as I started to get active and go to school, and the fact that my dad was a doctor, meant that we kept supplies of the stuff on hand at home and both mom and dad could infuse me at the first sign of trouble. This meant that I was on the vanguard of the first wave of hemophiliacs to lead relatively “normal” lives. By the time I was in grade one our family had moved to Toronto. I was able to participate in most gym and schoolyard games, and when I did have a bleed I was infused and sent off to school on crutches for a few days. I started to self-infuse at the age of eight. The remainder of my school days were uneventful. I ran cross country, joined the swim team, snow-skied, water-skied, played in the band, and in high school, be-

(Continued on page 2)

INSIDE THIS ISSUE:

| | |
|-------------------------------|---|
| HCV in the News / Lou Reed | 1 |
| Andrew Cumming: My Story | 1 |
| Marathon | 3 |
| Info Tables: Why? | 4 |
| Allison Crowe | 5 |
| Honour Roll | 6 |
| MerckCARE/PegAssist/Neupogen/ | 7 |
| Coming Up | 8 |

SUBSCRIPTION/ORDER FORM

Please fill out & include a cheque made out to
HepCBC - Send to our NEW address:

HepCBC
2642 Quadra Street
PO Box 46009
Victoria, BC V8T 5G7

Name: _____

Address: _____

City: _____ Prov. ____ PC _____

Home (____) _____ Work (____) _____

Email: _____

Please email me a PDF copy, free of charge.

Membership + Subscription (1 year)\$20.00

Membership Only\$10.00
(Doesn't include the *hepc.bull*)

Subscription Only\$10.00
(Doesn't include membership privileges)

Peppermint Patti's FAQ\$15.00

Resource CD\$10.00

Donation enclosed.....\$ _____

TOTAL: \$ _____

"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.)

You may also subscribe or donate on line via

PayPal at www.hepcbc.ca/orderform.htm

Download the *hepc.bull* free at

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

SUBMISSIONS: The deadline for any
contributions to the *hepc.bull*® is the 15th of each
month. Please contact the editors at
jkking2005@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:

EDITOR: Joan King
PHONE: (250) 595-3892
FAX: (250) 595-3865
EMAIL: info@hepcbc.ca
WEBSITE: www.hepcbc.ca

HepCBC
2642 Quadra Street, PO Box 46009
Victoria, BC V8T 5G7

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.

(MY STORY—Continued from page 1)

came a competitive sailor, winning a number of regional and national championships. Many of you reading this will find all of this unremarkable. Most hemophiliacs today participate in a full complement of sports, recreational and social activities. Forty or fifty years ago this was not the case for most of us. No sports, poor academics due to lengthy absences from school and crippled bodies led many hemophiliacs raised in the '60s and before to lead unproductive lives, professionally and socially. It is in this sense that I was so very lucky to benefit, at an early age, from the miracle of cryoprecipitate.

In 1978, after a year of university I decided that I wanted to take a run at the 1980 Olympics in sailing. My dad helped me buy a Flying Dutchman-class sailboat, and I started dragging it around the continent, going to regattas to train for the Olympic Trials to be run in the spring of 1980. Half way through those trials to see who would be on the Canadian Olympic Sailing Team, the Americans and most of their allies announced that they would be boycotting the Moscow games because of Soviet military involvement in Afghanistan, and so ended my Olympic dreams. Ironically, we and the Americans engaged in pretty much exactly the same sort of military intervention in that same country some 30 years later.

As I was preparing to go back to university in the fall of 1980, I noticed an enlarged and hypersensitive testicle. Thinking this must be somehow related to my hemophilia I treated it with the then novel product known as freeze-dried Factor VIII concentrate. After a few weeks I was cajoled by my girlfriend to go see an urologist. I never made it back from the hospital. They whisked me into surgery to excise the offending organ and biopsy it. I was diagnosed with Embryonal Cell Carcinoma, an incredibly aggressive cancer that kills 95% of patients within a month. Cancer was on everybody's minds and tongues at that time. Terry Fox was halfway through his historic run across the country and had visited Toronto a scant few weeks before. My dad told me that I probably had a couple of weeks to live. Luckily, my oncologist knew better. There was a new drug, cis-platinum, which was barely a few months old, and indications were that it was effective in a chemotherapeutic cocktail on this type of tumour. This is the second instance of extraordinarily fortunate timing in my

life. Needless to say, the new therapy saved me, as it now saves some 70% of patients with the tumour I had.

The next few years went by without incident. The fact that I survived cancer gave me an entirely new outlook on life. Whereas, up to that point, I had more or less cruised through school and most of my activities, after the close call with death (and constantly living with the threat of relapse hanging over me), I attacked life and all of its aspects with increased determination and verve. I went back to university, determined to be the best student in the class (which didn't happen, but I tried). I became intent on going to a top-flight school to do a Ph.D. and worked single-mindedly to that end. I spent my summers working in professors' labs, and nights studying harder and harder to bring my marks to the highest level of which I was capable. I was rewarded for this effort with a spot in the physics Ph.D. program at M.I.T.

Now we get to the part of the story that is common ground for all the severe hemophiliacs in Ontario and indeed, most of North America and Europe. In my case, D-Day was December 20th, 1985. I was in Toronto for Christmas break at the end of the first term of the second year of my Ph.D. studies. I had just had a tumour marker assay and a final visit with my oncologist, and was declared cured of the terrible cancer I had contracted five years earlier. On that basis, and with that great news in hand, I proposed that morning to my then girlfriend. We had both been a little trepidatious about proceeding with marriage if the cancer issue was unresolved. Now that was behind us. She accepted my ring! Later that same day, I had what I thought was going to be a routine checkup at St. Mikes with the hemophilia team there. Then the bomb dropped. I (and indeed virtually all of the patients of the clinic) had been infected with HIV. As many of you reading this will recall, at that time HIV was probably the most feared and loathed illness on earth. People routinely killed themselves when they found out they had it. It was universally assumed to be highly contagious and lethal in all cases. The people who had it became social pariahs, often ostracized by their communities. Young hemophiliacs all over the world were asked not to come to school. In extreme cases violence was perpetrated on HIV-positive people, including children. People's houses were burnt down (I happened to be friends with Ricky, Robert and Randy Ray, who were all campers at a hemophilia camp I volunteered at in central Florida during the eighties, and whose house

(Continued on page 4)

VICTORIA MARATHON REPORT FROM THE LIVER WARRIORS

There were 12 of us on the “HepCBC Liver Warriors” team this year at the October 13, 2013 Victoria marathon. Half of us were hepatitis C-positive (HCV+). We came in #25 in the Half-Marathon teams. Special thanks go to Doug T., Sarah S., Steve F., and Douglas L., who had the four best times that got our team that great placement!

Four intrepid Liver Warriors: Douglas, Steve, Anita, and Cheryl gather behind HepCBC's Victoria Marathon info table.



Rosemary P., Ethan R., and Cheryl R. were the last ones from the team onto the finish line, but hey! WE got the news coverage. A CHEK News cameraman met us as we crossed the finish line and interviewed us!



Ethan Reitz, his mom Cheryl, and HepCBC President Rosemary Plummer, RN, at the Half-Marathon finish line. 2nd year in a row for Ethan, 3rd straight year for the two ladies, who get a little faster each year.

The goals of the team are to fight stigma against HCV+ people, to raise awareness about hepatitis C and encourage testing, to raise funds for HepCBC's education, preven-

tion, and support programs, to demonstrate the benefits of exercise for those with liver disease, and of course to improve our own health, meet new friends, and have fun!



Sarah Sullivan, Social Worker at AIDS Vancouver Island, Courtenay, after completing her second race with the HepCBC Liver Warriors team, in front of our team tent in front of the Empress Hotel. Go, Sarah!!

We raised approximately \$3500, mostly from our sponsor, pharmaceutical company Janssen, Inc. Several of us manned a large hepatitis C information booth at the 2-day pre-race exposition where we handed out pamphlets, red and yellow ribbons, and had many great discussions with the other (more serious!) athletes and their families.

Many were supportive, but some were a little surprised to see a hepatitis C booth in this exposition. They took a red/yellow ribbon and wore it, anyway, because we told them if they did, they'd run faster (Anita's idea!)

To support the Liver Warriors, consider sending a “2013 Post-Race” donation to

Haixia and Anita (back) with Cheryl and Wally, having fun manning the info booth.



HepCBC through this site:

www.canadahelps.org/GivingPages/GivingPage.aspx?gpID=19683, joining our team next year, or

starting a Liver Warriors team at your local marathon. If you need ideas, go to

www.hepcbc.ca/exercise/

or www.hepcbc.ca/marathons-walks/.

Watch our video on You Tube:

www.youtube.com/watch?v=-FKC39ChTes.

Liver Warrior Sarah Sullivan and Board Member Chaim-David Mazoff, PhD, sharing a funny story.



Wally and Haixia were both trying to make red/yellow ribbons, but people wanted more than we could make! We'll have to start right away for NEXT year!



Pamphlets, signs, red and yellow ribbons pinned to info cards all helped to inform this health-conscious group (12,000 runners!) about hepatitis C, fight stigma, and promote the importance of testing.

INFO TABLES: WHY?

HepCBC Information Tables: A Powerful Way to Educate and Fight Stigma

HepCBC has been using information tables a lot recently to educate people about the hepatitis C virus (HCV) and fight stigma, at the same time. The tables are customized for the audience at each special event, but all the tables have a variety of pamphlets (from CATIE, Canadian Liver Foundation, PHAC, BCCDC, and HepCBC), and a large information display, with one to three HCV+ volunteers manning the table.

One of the major barriers to people getting tested is ignorance—about the way HCV is spread, the many decades it normally takes for symptoms to develop, the severe organ damage that can occur during this ‘silent’ phase of the disease, the greatly increased chance of liver cancer or liver failure or the need for transplant, and that, while there is no vaccine, there is actually a good chance they can get cured if they are treated in time. A lot of people know they have the disease, but have decided nothing can be done about it, or have decided they’ll wait until they have debilitating symptoms before they go for treatment. We encourage these people to look into upcoming treatments, and we point out the advantages of getting treated before major damage has occurred.

Another major barrier to testing is stigma: “Bad people get hepatitis C. I’m not a bad person, so I couldn’t have hepatitis C, therefore I don’t need to get tested.” OR “I might have hepatitis C, but if I actually find out I have it, I’ll have to tell my family/partner(s)/ employer, and if they find out, I may lose my family or job, therefore I’ll take my chances and not get tested.” An openly HCV+ person behind the info table can help people see that HCV is nothing to be ashamed of, that getting tested is a responsible thing to do, and that a diagnosis of HCV does not have to be “a death sentence.”

With HepCBC information tables, we give the information with a smile and an accepting, understanding attitude that can change people’s minds and hearts – and hopefully encourage some of them to get tested, as well. In 2012, we had information tables at our March Educational Forum in Victoria, the Victoria marathon, and the Victoria Immigrant/Refugee Centre health fair in Victoria. This year we’ve had tables at the marathon and immigrant/refugee health fair, once again. We will also have a table at the October 22-24 First Nations “Gathering Wisdom” Health Fair in Vancouver, and at the November 8-9 forum for infectious disease physicians and nurses in Victoria. If you

(MARATHON—Continued from page 3)



*If you can read the fine print on their ID tags, Wally and Haixia, in their second year in the half-marathon, ran under the same name, “SPEED”!
They definitely ran much faster than several other Liver Warriors.*



HepCBC Board Member Wally's supportive family included his sister Shelly and brother-in-law Doug, seasoned marathoners who helped the Liver Warriors team to place in the top 25 for the half marathon!

want to have a hepatitis C info table at a local event, we advise looking at CATIE’s website www.catie.org and ordering their free pamphlets several weeks in advance. HepCBC also has peer support pamphlets we can send to you. While this is a free service, if you can afford to send a donation to cover printing and postage, that really helps. We’d love to hear about your HCV information table experiences. (Good or bad. Any tips?)

H
E
P
C
B
C

(MY STORY—Continued from page 2)

was burned in an attempt to drive them out of town). People lost their jobs. People lost their lovers and spouses, and couldn’t find new ones. It was a truly horrible time, as those of us who lived through it remember so well.

My fiancée decided to stay with me, which was a great relief, and we were married a year and a-half later in June, 1987. As the eighties wore on and many hemophiliacs around the country started to show the signs of full blown AIDS, I carried on with my studies, a post-doctorate, and finally landed a professor position at a major university, all the while waiting for what seemed to be the inevitable. Probably the most challenging aspect of this illness, at least for me as a seemingly healthy victim, was the necessity to keep confidential the information that I was HIV-positive. The prejudice and hysteria surrounding this disease was intense, and took literally decades to subside, even with the massive educational efforts by both governments and NGOs, followed by legislation concerning the human rights of HIV sufferers. With all the work I had put into my education and career since surviving cancer, there was no way I was willing to have my dreams and aspirations sidelined by a bigoted and ignorant public.

More and more was being learned about the virus by the researchers, and we patients who were still not sick carried on with life, monitoring CD4 levels and viral loads, and watching the newspaper obituary page for death notices of our friends. And there were many. I was lucky, in that, despite astronomical viral counts, my CD4’s stayed in the 300s up until the presentation of the therapeutic alternative of AZT to the general HIV population. I stayed away from AZT for a year or so because I was still feeling very healthy and the side effects of this potent and toxic medicine were far from well understood. I eventually started taking it when I realized that the key to survival was getting the viral loads down, reducing the rate of mutation, which if left unchecked would eventually yield up a strain that was able to overcome what was left of my immune system and maybe even drug therapy in the future.

By the early 1990s, with virtually all of the severe hemophiliacs infected with HIV, and more than 75% of them dead, dying or showing signs of AIDS-related illnesses, many professionals in the field started looking to new areas in which to practice. It

(Continued on page 5)

(MY STORY—Continued from page 4)

truly seemed that within a few more years there wouldn't be enough hemophiliacs left to support the clinics. Some giants in the field, like Dr. Peter Levine, who was a pioneer in the creation of comprehensive care clinics for the treatment of hemophilia, abruptly abandoned their posts when their clinical patient cohort, their own lives' work, were eviscerated by this horrible "hemophilia holocaust," as I call it. At the St. Michael's Hospital clinic where I was a patient, we were luckier. Drs. Teitel and Garvey and, most importantly for me personally, Ann Harrington, stayed on station, treating, consoling, commiserating with and supporting their flocks as they shepherded them through the fires.

As for me, my life of close calls and fortunate timing continues. It is an unhappy fact that the woman I married in 1987 left me in 1994. I didn't really know why at the time, but in retrospect I think it is because she didn't want to have children with somebody who was sure to die before they grew up. Ironically, by the time this happened I was responding very well to the cocktails of drugs they were serving up, and my viral load had become undetectable. I had never had an HIV-related opportunistic infection. I was maintaining my CD4 levels. But I admit that there was a huge element of uncertainty as to what the future would hold for me. I was devastated, of course. I knew that it would be impossible to marry anyone else. Who, in her right mind, would even go on a date with a crippled HIV-positive divorced man? But I was wrong. I am always amazed at the capacity for courage and compassion that some human beings possess. I was able to start dating again, and met my soul mate, Hillary, in 1996. By this time I had abandoned my career as a physics professor, and had become a financial derivatives trader (that's another whole story) at a major bank. Hillary worked there. We were married in 1998 and were blessed with children in 2000, 2001 and 2010! I continued my work on Bay Street for another few years before the "other virus" (hepatitis C) started to work its spell on my liver. By 2003 I had had several hospitalizations for bleeding from esophageal varices, which for hemophiliacs are extremely dangerous. I knew it was only a matter of time before one of these bleeding episodes killed me. By late 2004 I had a fully decompensated cirrhotic liver and was in danger of dying from the complications of advanced liver disease directly, even if I managed to continue to dodge

the internal bleeding for a while longer. I was lucky enough (and wealthy enough, something that was a direct outcome of moving from academia to finance, although that was not why I made the move originally) to get onto the liver transplant list at the University of Miami in Florida, and in May of 2005, managed to get a transplant. Curing my Hep C infection turned out to be a struggle. I was on a double dose of interferon for 18 months because the standard interferon/ribavirin therapy had failed to clear the virus in an earlier attempt in 1999. Those of you who have endured that particularly sinister form of chemotherapy know the hell that I was to live through. The only good thing I can say about it was that it worked.

I am now clear of Hep C, my HIV is totally under control (still undetectable viral loads and CD4s in the 400s), and wonder of wonders, my hemophilia is cured. The liver is where Factor VIII is manufactured, so when you get a new liver, you get a clotting factor factory at the same time. Too bad my poor old knee, ankle and elbow are so messed up from a lifetime of hemarthroses, or I would be perfect (lol). As my son, now 13, and older daughter, 12, settle into the monumental struggle that is adolescence, and my baby, 3, develops her full measure of toddler sass, my wife and I embrace the mundane reality of simply trying to do the best job we can at bringing up a family. Life goes on.

*Reprinted from the HCV Advocate
Sep 20 2013 with their kind permission.*

(Hep C in the News—Continued from page 1)

the Q80K polymorphism has been discovered in 48% of genotype 1a patients in the US, but in only 19% in Europe. It is rarely if ever found in GT 1b's. In clinical trials with Gilead's sofosbuvir and Janssen's simeprevir, the Q80K variant apparently weakened the effects of simeprevir. Ideally, GT 1a patients would be tested for Q80K before treating them.

Source:
www.natap.org/2013/HCV/102313_02.htm

RESEARCH: VECOYS

Viruses are sneaky. They take over living cells, where they can replicate. It's hard to destroy the virus without destroying the cell. And they mutate! So Erez Livneh of Vecoy Nanomedicines and his team are working on a way to make nanotraps for the viruses, to trick them into taking up residence in the traps instead of in human cells. Today's



Allison Crowe

ALLISON CROWE'S VICTORIA TIDINGS

Saturday, December 7, 2013
Fairfield United Church
1303 Fairfield Road, Victoria, BC,
Canada V8S 1E3

Music 8:00 pm
(Doors 7 pm)

Good Parking Available
To aid Artemis Place

www.artemisplace.org/
(Girls' educational and life-skills),
and HepCBC
www.hepcbc.ca

Tickets now online at
www.allisoncrowe.com/shoptickets.html

Tickets will also be available
at physical outlets.



treatments "penetrate cells that have been infected by viruses to keep them from multiplying." And this causes a lot of side-effects. Vecoy wants to trap the viruses while they're swimming around in the blood, before they reproduce, in teeny virus traps that look like human cells, but can capture and destroy them. Right now, he's having success rates of 97% in viral cultures in the lab. It wouldn't be a cure, but could reduce viral loads and give the immune system a rest. He plans to do 3 more years of lab trials, and hopes to start clinical trials after that.

Source:
<http://medcitynews.com/2013/09/anti-viral-technology-baits-hooks-viruses-nanoparticle-traps-camouflaged-human-cells/>





UPDATE on "Dale" and the Liver Transplant Situation for Patients from outside Vancouver Area:

The latest update on our friend awaiting a liver transplant in Kamloops indicates that Dale has come out of his long hepatic coma, and is working with the Vancouver Transplant Assessment Team. His social worker says he continues to ready himself for his transplant. This includes meeting with local (Kamloops) specialists to monitor his medical and psychological condition. He still faces an uphill battle once his "beeper" signals news of an available liver. At that point he will be rushed to Vancouver for a long and risky emergency operation. But that's not the last of the hurdles he and his family will face.

His relatives and support team in Kamloops will want to be with him, but it will be extremely difficult for them to leave their jobs and families in Kamloops to support Dale for the 2-3 month "post-transplant period" in which he must remain in Vancouver. The Transplant Assessment Team requires proof that such social support will be available locally (in Vancouver) before it will put someone on the transplant list. It will be quite expensive for him and his support team to find somewhere near the hospital to live during that time. The Transplant Assessment Team also requires proof that transplant patients and their support person or team will have a place to stay during the post-transplant period. While entirely reasonable, these requirements obviously create huge challenges for liver transplant patients and their families from outside Vancouver!

That's where the Happy Liver Society (HLS) comes in. Karen Stacey, its founder, and a transplant survivor herself, has some amazing stories we hope to share in another issue. HLS owns a condo which it rents out for \$25 a day to liver transplant patients and their support person. HLS provides other support services, from doing laundry, grocery shopping and driving patients to appointments, to providing transplant peer support almost anywhere, 24/7 – all of this done by a tiny handful of devoted volunteers. \$25 is the same amount other transplant patients have been paying to sleep in their cars in the hospital parkade! For every patient who uses the HLS services, there are at least four others who need it. The waiting list is long and it's heartbreaking for Karen to have to say, "No, sorry!" so often to people who have already had to quit their jobs, see their spouses quit their jobs to care for them, sell their car and

get a second mortgage - or worse.

Karen and the HLS have a vision of expanding what they can offer liver transplant patients (60% of whom have hepatitis C). They want to provide more housing and other services. They hold really fun fundraisers! (Karen has been a professional 'event organizer'.) You can find out more about HLS, how to donate, and where their next fundraiser will be at

www.happyliversociety.org

or their Facebook page:

www.facebook.com/HappyLiverSociety

It is an inequitable and terrible situation for liver transplant patients from outside Vancouver. The government should address this regional inequity. Until then, the Happy Liver Society team is doing its best to fill a huge void, and the hepatitis C community should be doing everything we can to help them fulfill their mission.

DID YOU KNOW?

FLU VACCINES ARE LINKED TO A LOWER RISK OF DAMAGE FROM HEART ATTACKS

GET YOUR FLU SHOT!!

Need more info?

Click [HERE](#)

<http://globalnews.ca/news/918364/flu-shot-halves-risk-of-heart-attack-or-stroke-in-heart-disease-patients-canadian-study-suggests/>

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, VanCity, Shoppers Drug Mart, Market on Yates, Country Grocer, Safeway and Thrifty Foods.

We often hear only the stories of those who are suffering with Hep C. Our responders go back to "real life" and want to forget about their struggles with Hep C. Have you responded to treatment and remained undetectable for a minimum of 12 weeks* after finishing treatment (i.e., SVR or Sustained Viral Responder)? Let us help you celebrate. You can give others hope. Please take a minute and send us your name, genotype, date of SVR, and type of treatment to post here, and we'll add your name (or initials). Congratulations to our friends:

1. **GJ** - Dec 1998 - IFN/RBV 52 wks—Dr Anderson /Natalie Rock , Vancouver, BC.
2. **Amberose** - 2000 GT 2A/2C Schering IFN/RBV 24 wks [NEW ADDITION]
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, Daprovir/Ritonavir/R05024048 24 wks - Dr. Erb, Vancouver.
12. **Cheryl Reitz** (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
13. **Anita Thompson** (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
14. **Joan King** (GT1b treated 5 times) SVR12 Apr 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC.
15. **Leon Anderson** (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
16. This could be **YOU!**

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



CONFERENCES

AASLD - the 64th Annual Meeting of the American Association for the Study of Liver Diseases
1-5 Nov 2013
Washington DC
www.aasld.org/Pages/Default.aspx

EASL Masterclass on Hot Topics in Hepatology
14-16 Nov 2013
Bordeaux, France
<http://bit.ly/1447ti1>

EASL Translational Research in Chronic Viral Hepatitis - Bridging Basic Science and Clinical Research
29-30 Nov 2013
Lyon, France
www.easl.eu/events

HEP DART 2013
frontiers in drug development for viral hepatitis
8-12 Dec 2013
The Fairmont Orchid -Big Island, Hawaii
www.informedhorizons.com/hepdart2013/

3rd Global Workshop on HCV Therapy Advances
New Antivirals in Clinical Practice
13-14 December 2013
Rome, Italy (t.b.c.)
www.virology-education.com/index.cfm/

2013 International Conference on Viral Hepatitis
24-25 December 2013
Bangkok, Thailand
www.waset.org/conferences/2013/bangkok/icvh/

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

3rd Canadian Symposium on Hep C Virus
7 February 2014
Toronto, ON, Canada

EASL - The International Liver Congress 2014
Wednesday, 9-13 April 2014
International Convention Centre ExCeL
London, United Kingdom
www.easl.eu
DDW 2014
3-6 May 2014
McCormick Place -Chicago, IL
www.gastro.org/education-meetings/live-meetings/digestive-disease-week-ddw

INCIVEK CARE

Vertex's Incivek Care Patient Assistance Program supports patients with the reimbursement process for Incivek (telaprevir) treatment (Incivek, pegIFN, ribavirin). It will give you an efficient assessment of your options and eligibility. You may qualify to receive co-payment and other financial assistance to supplement your private and provincial drug program coverage. The program also provides dispensing and home delivery options, and expert treatment advice. Call the Support Line at 1-877-574-4298. (Select option 2 for English, then 2 for Incivek Care.)

MERCK 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.

NEUPOGEN VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependent on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge. Please note that Amgen will only provide Neupogen to patients on a compassionate basis **as long as it is prescribed and dosed in accordance with the approved product monograph**. This service is accessed through the Victory Program: 1-888-706-4717.

COMPENSATION

LAW FIRMS

1986-1990

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



Pre-1986/ Post-1990

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/class/settled/hepc/
Lauzon Belanger S.E.N.C. (Quebec)
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204
<http://lavlavocats.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/

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, needle exchange, advocacy. 1371 C - Cedar St. Contact leanne.cunningham@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 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 Tom, 250-949-0432 tom.fenton@avi.org.

♦ Victoria Access Health Centre, drop in, disability applications, peer training. Support group Tues 12:30 PM, 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jeffers@avi.org

Boundary HCV Support and Education Contact Ken 250-442-1280 ksthomson@direct.ca

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

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

Chilliwack PCRS Hep C Prevention, peer support, harm reduction. Meetings 3rd Mon monthly, 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416. lbirdsall@pcrs.ca www.pcrs.ca

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

CoolAid Community Health Centre, Victoria. Meetings each Wed 10 AM and Thu 1:30 PM. 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Roz rmilne@coolaid.org for treatment or group info.

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231 dggrimstad@shaw.ca

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

HepCBC info@hepcbc.ca, www.hepcbc.ca

♦ Victoria Peer Support: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-3891

♦ Fraser Valley Support/Info: 604-576-2022

Kamloops ASK Wellness Centre. Chronic illness health navigation/support. info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098 www.askwellness.ca

Kamloops Hep C support group, 2nd and 4th Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cheri 250-376-1296 Fax 250-376-2275

Kelowna Hepkop: Phone support, meeting info. Contact Lisa 1-866-637-5144 ljmortell@shaw.ca

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

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

Nelson Info & support for prevention, testing, treatment and living well with hepatitis C. Women's gathering monthly. Contact Laura 1-800-421-2437, 250-505-5506, ankorshepc@ankors.bc.ca

New Westminster Stride "HepC" Support Group each Fri 10 AM *except* 4th Fri. of the month. Nurse Practitioner, refreshments. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

Positive Wellness North Island-North Island Liver Service Info, support, treatment. 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: 2nd Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

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 **NEW: #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 Melinda.herceg@vch.ca 604-485-3310

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

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-2487, 1-888-557-2487, <http://health.groups.yahoo.com/group/Network-BC/> wendy@wendyswellness.ca www.wendyswellness.ca

Slocan Valley Support Group Contact Ken 250-355-2732, ken.forsythe@gmail.com

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 Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211, or call 604-522-1714 (Shelley), 604-454-1347 (Terry), to talk or meet for coffee.

Vernon telephone buddy, M-F 10-6 Contact Peter, pvanbo@gmail.com Tel. 250-309-1358.

YouthCO HIV/Hep C Society of BC. Drop-in T&W 12-3, Fri. 9-12. Call for appts M-F 10-6. 205-568 Seymour St, Vancouver 604-688-1441, 1-855-YOUTHCO Stewart stewartc@youthco.org, Briony brionym@youthco.org www.youthco.org

Whitehorse, Yukon—Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437 bloodties@klondiker.com

OTHER PROVINCES

ONTARIO:

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 hepcmmcoord@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 www.hars.ca hars@kingston.net

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room, 659 King St. East (Enter off King St) Kitchener. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Hep C Support 186 King St, London. For those infected as well as affected by Hep C. Contact: 519-434-1601, 1-866-920-1601, www.hivaidconnection.com

Niagara Region Hepatitis C Care Clinic Education, Counseling and Support - Individual / Group, Treatment, Community Outreach, harm reduction. Contact 905-378-4647 ext 32554 HCCC@niagarahealth.on.ca www.niagarahealth.on.ca/services/hepatitis-c-care

Oshawa Community Health Centre Hepatitis C Team Drop-in, lunch provided each Thurs. 12-1 PM, 79 McMillan St. www.ochc.ca Contact 1-855-808-6242

Owen Sound Info, support. Contact Debby Minielly dminielly@publichealthgreybruce.on.ca

a 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, www.publichealthgreybruce.on.ca/

Peel Region (Brampton, Mississauga, Caledon) 905-799-7700 healthline-peel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

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

bpotkonjak@liver.ca www.liver.ca

Thunder Bay Hep C support. Contact Sarah Tycholiz 807-345-1516 (or for 807 area only 1-800-488-5840)

Unified Networkers 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

ATLANTIC PROVINCES

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767

Online Peer Support: info@hepns.ca www.hepns.ca

PRAIRIE PROVINCES:

Manitoba Hepatitis C phone and email support and outreach. Info Line: 1-204-779-6464 or contact Kirk at info@mbhepc.org. Direct line: 1-204-389-5814

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E AB Assoc, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca



To list Canadian groups here, please send details to info@hepcbc.ca by the 15th of the month. It's free!