

hepc . bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

CHERYL'S JOURNEY THROUGH BC: Part 2

(Summary of Part 1, published in the March, 2013 hepc.bull: Cheryl Reitz, HepCBC Volunteer, recently took a bus trip to visit old friends in Northern and Interior BC. She took with her a suitcase of hepatitis C pamphlets and 12 pamphlet holders, and distributed them in Friendship Centres, nursing stations, AIDS and community organizations, etc. She started in Smithers, then went to Terrace. Details of her trip continue here...)

On February 19th, I arrived in Prince George for a day, where I had great conversations with Bobby Koll of the Prince George Native Friendship Centre (to whom I presented a pamphlet holder), Sandra Sasaki (HIV/AIDS Education Manager and AIDS Walk Coordinator) of Positive Living North, and the very friendly nurses and staff of Dr. A.A. Hamour's infectious disease and liver clinic. I hope to meet with Northern Health's Blood Borne Pathogen team members Bareilly Sweet and Trish Howard, Ilse Kuepper of HepC Support, and Mary Proudfoot of Northern Health on a future trip.



Bobby Koll, 'Director of First Impressions' accepts pamphlets at Prince George, BC Native Friendship Centre

Williams Lake, my next stop, was a very inspiring place for me! Ironically, I was unable to meet the only two people with whom I had made initial contact by phone: Patti the Public Health street nurse and Sally Errey, who works with at-risk youth at the Boys & Girls Club. However, by following their helpful advice, I met an amazing array of knowledgeable and dedicated local people. Stephanie of the Boys & Girls Club spoke about the club's safe tattooing trainings and other harm-reduction work. I spoke with Denise Deschene of Interior Health's Mental Health & Substance Abuse Services (school-based Prevention & Outreach program) for over an

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A LIVING MIRACLE



J.A.K.: A LIVING MIRACLE

Back in 1992, JAK was diagnosed with the Hep C virus. She tried different variations of "the chemo from hell," as she would call it. "After the third round, I was done," she re-

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WORLD HEPATITIS DAY

World Hepatitis Day is a global event that takes place annually on **July 28th** to bring attention to chronic viral hepatitis worldwide, and stands in solidarity with persons who have hepatitis B or C. Every year, events are organized around the world to help bring attention to hepatitis.

The Canadian Society for International Health (CSIH) is a non-profit, non-governmental organization based in Ottawa, and through funding from the Public Health Agency of Canada, is responsible (for the 5th consecutive year) for chairing the National World Hepatitis Day Planning Committee. Members of the committee include individuals and organizations from across Canada. Through monthly teleconferences, we discuss ideas for events, media outreach, and promotional materials. Anyone interested in planning an event is eligible to receive free promotional materials. Contact Alison at amarshall@csih.org for access to the Event Proposal, which is due by April 30th.

CSIH also organizes an annual **World Hepatitis Day National Art Contest** for youth (ages 13-29) to further increase awareness. This year, youth artwork categories include written submissions, such as poems and short stories, and video entries, in addition to posters. Winners of the youth contest will be awarded a \$200 Apple™ gift card!

For access to poster contest guidelines and more information regarding World Hepatitis Day in Canada, please visit our website at www.whdcanada.org. Also, follow us on Twitter at [globalhepcnet](https://twitter.com/globalhepcnet). We look forward to your participation and support!



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(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 jkling2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

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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.

NEW!! FAQ version 9.0



Peppermint Patti's **FAQ Version 9.0 is NOW AVAILABLE.** Version 8 is available in FRENCH and SPANISH. The ENGLISH version includes treatment information and research from 2012. Place your orders now. It contains 169 pages of information for only \$15 each. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2012, the FAQ V9.0, the slide presentations developed by Alan Franciscus, and all of HepCBC's pamphlets. The Resource CD costs \$10 including S&H. Please send cheque or money order to the address on the subscription/order form: www.hepcbc.ca/orderform.htm

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REPRINTS

Past articles are available at a low cost in hard copy and on CD ROM. For a list of articles and prices, write to info@hepcbc.ca.

THANKS!!

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

Please patronize the following businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, VanCity, Shoppers Drug Mart, Market on Yates, Country Grocer, and Safeway.

Special thanks to Thrifty Foods for putting our donation tins at their tills and to Sooke Shoppers Drug Mart, for donating the water for sale at the Christmas concert and for having donated the water for our CASL Forum. Thanks, Allison Crowe and Billie Wood for giving your 110% at the Christmas concert. What a great way to start the most beautiful time of the year. Thanks also to Adrian for his continuous support.

CUPID'S CORNER



This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad, write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send a cheque payable to HepCBC, and mail to HepCBC, Attn. Joan, 2642 Quadra Street, PO Box 46009, Victoria, BC V8T 5G7 (250) 595-3892. Give us your name, telephone number, and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

Disclaimer: The hepc.bull and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.

AD 30

Youthful, early 50's single Caucasian male. 5'11", 200 lb non-smoker, outdoors, nature walks, camera, musical, science educ. Half life on hold since diagnosed. Time to break-out.

Searching intelligent, young at heart woman to share some time, hobbies, activities, friendship leading to...? Maybe just friends, maybe a family. Life rarely turns out as you wish or imagine.

Tell me about yourself—hobbies, website, photo?

Got Hep C? Single? Visit:

<http://forums.delphiforums.com/hepatitis/en1/chat>
<http://groups.yahoo.com/group/HepCingles2>
www.hcvanonymous.com/singles.html
www.hepc-match.com/

NOTE: Before paying for full service HepC Match, be aware that the site is not kept up-to-date. We have been advised that there are members there who are no longer active, and at least one who is no longer alive, and his listing remains, even though the owners have been notified.

TIP OF THE MONTH

Please get an ultrasound and an AFP (Alpha-Fetoprotein test) done every year, especially if you have cirrhosis. These are tests for liver cancer.

AUTOIMMUNE DISEASE & HEP C

What do cryoglobulinemia, lymphoma, thyroid disease, rheumatoid arthritis, Sjögren's syndrome and lichen planus have in common?

According to our source article, the answer is hepatitis C. The above are all autoimmune diseases. Hep C can affect any organ. It can take over our immune system and cause it to attack our own body by expanding certain B cells and by affecting T cells so they don't kill off old cells when they are supposed to, creating autoimmune disorders. (There is still some debate.)

The first Hep C-related health problem found was cryoglobulinemia, an autoimmune disease which can progress to lymphoma.

HCV alone can trigger thyroid problems. In some people the condition may be hereditary. Interferon (IFN) treatment can be hard on the thyroid, apparently creating changes in the signalling pathways and making changes in what is called the estrogen receptor- α . The risk of thyroid disease in people taking IFN is more common in those with genotype 1. In about 1/3 of cases, thyroid disease disappears after treatment. The researchers think that HCV envelope proteins can cause thyroid inflammation. Some HCV receptors found on thyroid cells had activated interleukin-8. Those thyroid cells kept growing and didn't die off as they were supposed to (apoptosis). "The HCV envelope glycoprotein E2 can bind to CD81 receptors expressed on thyroid cells" causing a flurry of signals, possibly triggering thyroiditis in genetically susceptible patients. Those with Hep C should have our thyroid tested regularly, especially while taking IFN.

Sjögren's syndrome, another autoimmune disease, mainly affects the saliva and tear glands, sometimes causing arthritis, and sometimes symptoms like weakness. Lab tests show SSA and/or SSB autoantibodies, sometimes with rheumatoid factor. Sjögren's may be linked to rheumatoid arthritis or lupus, but we don't know yet that HCV can cause Sjögren's syndrome. More studies are needed.

Glomerulonephritis, a kidney disease, may be linked to HCV, as are oral lichen planus and other skin problems. Neurologic diseases—myelitis, polychondritis, encephalomyelitis and poor blood clotting—may be linked to Hep C. Polyarthritis, common with HCV, is sometimes found with cryoglobulinemia. The investigators took 45 HCV+ patients and 30 without HCV who had rheumatoid arthri-

(Continued on page 6)

(MIRACLE—Continued from page 1)

ported. None of the treatments had worked.

Then in 2007, JAK was given the devastating news that she had liver cancer, both on and inside the liver. But she is a fighter.

She was sent to an oncologist, who wanted her to try something just recently approved in Canada, called Radiofrequency Ablation (RFA). The first time, the treatment was injected surgically, so the surgeon and his team could actually see the tumours. The treatment worked, and got rid of the tumours...until they came back. A second attempt was done with RFA. That was an easier procedure. It was done by an injection into the liver through the femoral artery. There were a total of 4 attempts. Unfortunately, there was no improvement. Some people would have given up.

The next treatment was chemoembolization, which was administered 3 times. This was more successful. But at the end, there was still one bothersome tumour left—and it was growing, according to CT scans. She was scheduled once again for surgery. The surgical team did a right lobe resection, using the previous incision site. They took a lot of the liver in the process.

A month later, another CT scan was done. Unfortunately, another tumour was spotted. It had been hiding behind the liver. Worse still, there were tumours on her lungs. The doctor was as devastated as JAK was. He shook her hand and apologized. But he referred her to Dr. Alan Weiss, a gastroentero-oncologist in Vancouver.

Dr. Weiss and his cohorts at the hospital discussed her during rounds, and they chose her to receive a new treatment known as sorafenib—a multikinase inhibitor. It had made its way to Canada from the US about 2 years ago. Worried, JAK went to her dear, retired gastroenterologist, Dr. Frank Anderson, who told her, "Go for it!"

Luckily she didn't have bad side-effects. After she had been taking sorafenib, 200 mg twice daily, for a year and a half, JAK steeled herself, ready for the truth, and went to Dr. Alan Weiss. "How much time do I have to live? Can I travel?" were her questions. He gave her a straight answer. He gave her 2 years, if she took no more treatment.

Just recently, she returned for a check-up. Dr. Weiss greeted her with the precious words: "You are a miracle!" The latest CT scan showed nothing—not on her liver, nor on her lungs. She had also been diagnosed with deep vein thrombosis, and that, too, was gone.

JAK is taking warfarin, a blood thinner, and her INR (clotting time) is being kept high on purpose. She has had to have blood and iron infusions—but now she has been

given the OK to travel. She is poring over travel journals, dreaming of sunny days in Cancun or some other warm spot. JAK is still taking sorafenib

Editor: JAK is my hero. I have known for a while that she had liver cancer, and was overjoyed when I read a post, from her on the hepcan list, which resulted in the interview above. Here is that post:

"Greetings family & friends,

I have amazing news to tell you. The tumours in my liver & on my lungs, and the blood clot in my liver have disappeared, gone into remission. My oncologist said it's a miracle! My oncologist gave me 2 years to live before I started this chemo and he is totally blown away by my results.

I am getting ready to die and now I have been given a second chance to live. I have never been a religious woman, but I did pray about one month ago to a higher power for help. I believe my prayers were answered. I love you all!!!"

More info:

THE CURE?

Hepatitis C: the cure? FT Magazine

www.ft.com/cms/s/2/542ad524-8b77-11e2-b1a4-00144feabdc0.html#axzz2Nf6ZTp7F

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EGGS FLORENTINE

1/2 C plain low fat yogurt
2 T fat-free mayonnaise
1 t Dijon mustard
2 English muffins, split
1 C baby spinach leaves
1 T vinegar
Pinch of salt
4 eggs
Black pepper
Chopped parsley to garnish

In a small pan, combine yogurt, mayo and mustard. Warm. Microwave spinach sprinkled with a bit of water for 20-30 seconds. Toast muffins. Put 1/2 on 4 plates. Top each with 1 T warm sauce, then 1/4 of the spinach. Put 2 in. of water + 1 T vinegar + pinch of salt in a skillet. Boil, then simmer. Put eggs in shallow bowl; slide into skillet. Simmer 3-5 min. Remove with slotted spoon. Place on spinach. Drip sauce over eggs. Garnish with pepper & parsley. Serve immediately.

CONFERENCES

EASL 2013 - 48th Annual Meeting of the European Association for the study of the Liver
24-28 April 2013
Amsterdam, Netherlands

www2.kenes.com/liver-congress/pages/home.aspx

DDW - Digestive Disease Week
18-21 May 2013
Orlando, FL
www.ddw.org/

2nd Latin American Meeting on Treatment of Viral Hepatitis
24-25 May 2013
Sheraton Hotel WTC Convention Center
São Paulo, Brazil
www.virology-education.com/index.cfm/t/2nd+Latin+American+Meeting+on+Treatment+of+Viral+Hepatitis/vid/79A8744A-B1E1-0C58-45D30F3960DA4D3D

23rd Conference of the Asian Pacific Association for the Study of the Liver (APASL)
6-10 June 2013
Singapore
www.apaslconference.org/

8th International Workshop on Hepatitis C Resistance & New Compounds
27-28 June 2013
Cambridge, MA
www.virtualmedicalcentre.com/conferences/2013-8th-international-workshop-on-hepatitis-c/2540

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

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



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DIGESTIVE DISEASES WEEK

hit Victoria this year!

During the last few days of February and the first few days of March this year, Victoria welcomed the top hepatitis C researchers and practitioners to Digestive Diseases Week.

This year included high-level meetings of the Canadian Association for the Study of the Liver (CASL), the Canadian Association of Hepatology Nurses (CAHN), the Canadian Association of Gastroenterologists (CAG), the 2nd Canadian Symposium on Hepatitis C Virus (Sponsored by the National Canadian Research Training Program in Hepatitis C; this is also known as CRTP-HepC of the CIHR), and the Canadian Coalition of Organizations Responding to Hepatitis B & C. HepCBC is a long time participant in the last-named organization, and serves on its Steering Committee. We also participated in the 2nd Canadian Symposium on Hepatitis C on March 4th (see photo). The next few issues of the *hepc.bull* will include short reports of some of the more interesting things gleaned from these meetings. Stay tuned!



Above: A group who attended Canadian Digestive Diseases Week 2013 in Victoria, BC from national and provincial-level HCV-involved organizations: top, from left: Anika Ollner of Prisoners AIDS Support Action Network (PASAN), Billie Potkonjak of Canadian Liver Foundation, Deb Schmitz of Pacific Hepatitis C Network, Colin Green of Hepatitis Outreach Society of Nova Scotia, Patricia Bacon of Blood Ties Four Directions, & Paul Sutton of Canadian Treatment Action Council (CTAC). Bottom from left: Jeff Rice of CATIE, Alex La Porte of Hepatitis Ressources (Quebec), Cheryl Reitz of HepCBC, and Douglas Laird, independent rapporteur. (Missing: Michel Long of Canadian Hemophilia Society.)

J. Lemmon

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HEP C CLINIC AT PERCURO



Did you know that the Hepatology Clinic at PerCuro 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



HEPATITIS C CONNECTIONS

www.facebook.com/groups/222751877843182/

I have two groups:

Hepatitis C Connections on Facebook is a group for discussion & support for people living with Hepatitis C and their caregivers.

I also have my volunteer website, a safe place to get together and blog about Hep C health. I hope to connect with anyone interested in sharing how we cope and manage our health challenges. Please pass this along to anyone out there who needs this info.



COME VISIT OUR RE-DESIGNED WEBSITE!!

(**CHERYL'S JOURNEY**—Continued from page 1)

hour, sharing experiences and new HCV research. Jessica Doerner of the Denisiqi Services Society Aboriginal Child and Youth Wellness Program told me where various nearby First Nations got their health information, and took a pamphlet holder for the Anahim Lake Reserve Health Unit.

Denise Deschene, School Based Prevention & Outreach of Interior Health, Williams Lake, BC, meets with Cheryl Reitz, HepCBC Volunteer



I also met with Wayne Lucier of Canadian Mental Health Association's Homeless Outreach and Transition Home as well as Heather Burnett of the Cariboo Friendship Society (Shelter Coordinator, also involved with mental health, youth, and social programs).



Heather Burnett (right), Shelter Manager, with Martina Evans, both with Cariboo Friendship Society, Williams Lake, BC accepting pamphlets to be placed in the shelter, some of whose residents may be living with HCV.

Pamphlets, professional development meetings, and visits to community and support groups were urgently requested (in person or by phone) by Ada Phillips of the Northern Shuswap Tribal Council, Shawna Sellars of the Women's Contact Society, Norma Myers of the Tsilhqotin National Government, Lana Squinas (family support worker) of the Carrier Chilcotin Tribal Council, Nora Gregor of Nenqayni Wellness Centre, and Erin Friesen, Director of Nursing at the Three Corners Health Services Society. From them I learned that the many small communities between Quesnel and Williams Lake, and between Williams Lake and Bella Coola are in particular need of HCV awareness and support.

Then I went on to Lac La Hache, where I met an old family friend and relaxed for the weekend at her church's Ladies Retreat, playing with puppies, photographing her horses—a refreshing break from talking nonstop about hepatitis C!

Kamloops was the next destination. I met first for interesting discussions at the Aboriginal Friendship Centre with Barry James, Program Director/HIV Liaison, and Cherri Fitzsimmons, Blood-Borne Infections Counselor. Next, I had a very fruitful talk with Larry Loranger, Coordinator of Health Navigation Services at the ASK Wellness Centre. They want to work with us any way we can figure out. Larry also directed me on to another

agency, Kamloops Immigrant Services, whose Executive Director Paul Lagacé, C.D., and Christopher Buchner, ELSA Coordinator, spoke with me about translation of hepatitis C materials. There are several groups I know of who are currently doing this, and we discussed the developing need to coordinate these translations in an efficient manner, ensuring that the same materials were not being translated into the same languages, but rather getting a broad coverage of topics and languages, then widely publicizing this list of materials within the hepatitis C community. I decided to leave a pamphlet holder at this Immigrant Services society. The other societies in town had some HCV materials on hand, while this one had none, and the prevalence of HCV is very high within certain immigrant groups due to unsafe medical practices in their home countries. By then it was the end of my day in Kamloops. I wish I'd had one more day there as I'd been told "I really must visit" Public Health street nurses Gaudenza and Erin, the nurses in the Kamloops Urban Aboriginal Primary Healthcare facility, and Marilyn Triggs of the Liver Clinic. It looks like another trip is called for!

The next stop was Vernon. There, I had a 90 minute (frequently interrupted!) introduction to the work of Jessica Bridgeman, street nurse with North Okanagan Youth & Family Services. I have invited her to share some of her incredible experiences and insights with this newsletter. I also was warmly welcomed by Dolly Tweed of the First Nations Friendship Centre, where I dropped off pamphlets.



Dolly Tweed, Executive Secretary at First Nations Friendship Centre, Vernon, BC, with HCV awareness materials

The last two visits were with Jean Elliott at the Interior Health Clinic, an extremely busy place(!), and Judy Goplen, the lead hepatology nurse at Dr. Brian Chai's Liver Clinic.

My next stop was Kelowna, where I stayed with long-time friends. This segment of my trip was a little frustrating, as most of the people I was hoping to talk to were either very busy or ill that day, or the offices were closed for the day or too far for me to get to (via walking or bus) before they closed! I was fortunate enough to meet with Erika Schrank, Kelowna administrative coordinator of the street outreach program of Interior Health. I met Lisa Mortel, a long-time HCV

awareness educator, for lunch, and she agreed to present a pamphlet holder on HepCBC's behalf to Molly Brewer, the Mental Health Coordinator at the Ki-Low-Na Friendship Society. I met shortly with Lisa Binnie, ED of the Kelowna Family Centre. A visit with Shelia Kerr from Living Positive Resource Centre will have to await another journey!

LAST STOP (Feb. 28th): Merritt! I presented a pamphlet holder to Barbara Sobaszkievicz at the Conayt Friendship Centre, then quickly continued on to the office of Stacy Wormell and Chelsea Morrey, rural street outreach workers at ASK Wellness Centre. They had arranged with the local high school for me to speak to about 100 Grade 10 students about hepatitis C. It was very exciting, and the students seemed engaged most of the time. However after feedback, I felt it would have been helpful to coordinate with the Health Class teachers more in advance, rather than just jumping in, not entirely clear on what the students already knew, or what they were going to learn in class the following year. It was really wonderful to end this tour in a classroom of young people who (hopefully!) do not have hepatitis C, and will never have to suffer from this terrible disease.

This was a trip of a lifetime, and I wish to honour the kindness, insights, and dedication of the people I was so privileged to meet along this journey. The communities of British Columbia's North and Interior are blessed by their presence. I regret having been unable to visit the northern communities of the far NW and Peace River, the many small communities west of Williams Lake, or the Kootenays. In the future perhaps this can be arranged. I really hope HepCBC will be able to take a more active role in supporting their important work. In particular there is a great need to provide positive models for fighting stigma in small communities (where anonymity is difficult if not impossible), to encourage people in remote areas to access HCV testing and treatment, and to ensure local health providers have access to the most current HCV research, tests, and treatment protocols.

Postscript: On March 12-13, 2013, I returned to Smithers, BC, where I gave a presentation about living with hepatitis C at a 2-day training there, sponsored by the Pacific AIDS Network (PAN). On this trip I was able to bring up 8 more pamphlet holders and pamphlets which will be distributed to 8 First Nations health units in Burns Lake, Houston, Hazelton, and New Hazelton areas by Shannon Froehlich of Positive Living North-Prince George office and Kia Beertema, RN, of the Gitxsan Health Society. Thanks PAN!!



IS HepCBC STILL NEEDED NOW THAT HEPATITIS C CAN BE CURED?

Some say that with the high success of new HCV treatments, there will soon be no need for HepCBC. We hope someday this will be true, but there are still many issues that HCV+ people are facing as they await treatment, during treatment, and after treatment—whether treatment is successful or not. These include legal, financial, and public policy issues such as the following:

DRUGS & TREATMENT:

Early treatment is more successful than later, but Pharmacare criteria for coverage of treatment requires proof of severe liver damage.

Is it easier for a citizen to get their treatment costs covered for HIV/AIDS or cancer than for HCV, and if so, why?

Financing treatment and medications to alleviate side-effects or chronic symptoms is difficult for HCV+ patients.

Applying for and qualifying for disability status during treatment or severe chronic illness is difficult for HCV+ individuals.

Is sufficient training, funding and support being provided to help doctors and nurses treat HCV with the new direct-acting antivirals?

Is enough attention being given to end-stage liver disease, chronic HCV and liver transplant issues?

Dental health is impaired by (and in turn exacerbates) liver disease and especially by treatment; dental care is often unavailable to HCV+ individuals.

Can/should the provincial Pharmacare approval process for new HCV drugs be expedited, and possibly be standardized for the entire country? There are no automatic HCV drug fast-tracks, such as those available for drugs against cancer or HIV/AIDS.

DISCLOSURE ISSUES:

What is a person's responsibility to disclose their HCV+ status on employment applications, mortgage applications, insurance forms (for extended health, mortgage, life, and even burial insurance), to intimate partners, colleagues, etc.?

— Job applications sometimes inquire if applicants have an "infectious disease".

— Life insurance plans often disqualify HCV+ people; this can disallow them for some loans and mortgages.

— Possible liability exists if HCV+ individual doesn't disclose HCV+ status to a sexual partner, or if partner becomes HCV+.

— If a person still shows antibodies for HCV, but cleared it on their own, or through

treatment, are they still considered HCV+ and to "have an infectious disease"?

PUBLIC HEALTH ISSUES:

Is HCV an infectious disease, a chronic disease, or a disability? What are the implications?

If a deceased person who was HIV+, HCV+ and cirrhotic dies of liver disease, what condition is listed as their cause of death? If a person dies of liver disease or liver cancer, is his/her blood automatically tested for HCV? Is HCV being listed adequately as the cause of death?

Is adequate HCV surveillance and treatment available in Canada's northern, rural and First Nations communities?

Is adequate HCV surveillance, language translation, and treatment provided for immigrants coming from high-risk countries?

Why are prisoners not routinely offered HCV testing and treatment, harm-reduction supplies, and methadone (or other drug treatment) therapies? Prisons are currently a breeding ground for HCV and a major source of infection into the public "blood pool". There is great potential in prisons for ending this cycle.

Why is there no routine HCV testing for at-risk cohorts such as baby boomers or veterans, but only for those currently engaging in risky behaviours? There is an emphasis on Incidence Prevention over Prevalence Testing. Both are important, and Prevalence Testing within a cohort can also be part of a Screen-Test-Treat program.

Why is there no "Centre for Excellence" for HCV research in BC? Compare this to cancer or HIV/AIDS.

Why is a disease like HIV/AIDS given much more federal and provincial funding than HCV, when HCV is actually causing more deaths?

This list of issues is not exhaustive, but is a good beginning. We hope it will result in further conversation, debate, and at some point that it will result in clarification or improvement of policy, more equitable laws and distribution of resources. HepCBC is here to provide the voice of HCV+ people in these discussions.

Statins Are Associated With a Reduced Risk of Hepatocellular Cancer: A Systematic Review and Meta-analysis
Gastroenterology February 2013

www.natap.org/2013/HBV/021913_01.htm

COMMON MEDICAL QUESTIONS ASKED BY CALLERS TO HepCBC's PEER-SUPPORT PHONE

HepCBC's peer-volunteers report these are the most common medical concerns of callers to our telephone helpline:

- New Treatments, Clinical Trials & Pipeline.
- Should I get treated NOW or LATER?
- Treatment Side Effects and how to alleviate.
- Transmission, How to avoid infecting others. Can I get Hep C from my partner?
- Depression & Mental Health – on and off treatment.
- Meaning of Test Results including blood panel, ALT and Liver Biopsy.
- Non-Invasive Tests such as FibroScan, UltraSound, APRI, etc.
- Genetic Testing for IL28B allele.
- Chronic HCV Symptoms vs. Aging, and how to handle them.
- Diet, Exercise, & Supplements.
- Alternative and Non-Western Treatments.

If we cannot answer the queries, we try to find another peer who can, or refer the caller to another person or agency who will probably be able to help. Our number: 250-595-3865. Leave a short message and a peer-volunteer will phone you back ASAP (usually within one to two days).

(AUTOIMMUNITY—Continued from page 3)

tis, and found a condition called HCV arthropathy that resembles rheumatoid arthritis. You can tell them apart with anti-CCP. Real rheumatoid arthritis is rarely seen in Hep C. The arthritis found is usually a "nonerosive intermittent oligoarticular arthritis."

It's too bad. IFN, the most successful approved treatment, can cause autoimmune diseases provoked by the virus. And the best way to treat HCV-related autoimmune disorders is IFN. Luckily, many treatments being developed may replace IFN in the treatment of Hep C. In the meantime, hopefully researchers will find out how HCV can cause autoimmunity, and our government will be ready to approve the new treatments that prove effective.

Source: 10-23-2012
www.ncbi.nlm.nih.gov/pmc/articles/PMC3484639/



SVR HONOUR ROLL

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
2. **Jeanie Villeneuve** - Oct 2000 -Schering IFN/RBV
3. **Kirk Leavesley** (GT1) – 2004 – Roche
4. **Darlene Morrow** (GT1 relapser) Mar 2004 -Hyperthermia/Induction + pegIFN/RBV
5. **Beverly Atlas** (GT1a) - 2006 - Albuferon/RBV 44 wks
6. **Daryl Luster** (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks
7. **Cheryl Reitz** (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre.

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

* "Recently, the U.S. Food and Drug Administration (FDA) regulators revised this time point from SVR-24 to SVR-12, since most post-treatment relapses (when HCV RNA becomes detectable after treatment completion) occur within 12 weeks. Thus, SVR-12 became the new primary outcome for clinical trials studying peginterferon-based regimens."

Source: <http://i-base.info/htb/20643>



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 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. Dependant 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/Grant Kovacs Norell
Vancouver, BC
Phone: 1-604-609-6699
Fax: 1-604-609-6688

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
www.lauzonbelanger.qc.ca/cms/index.php?page=108

Roy Elliot

Roy Elliott Kim O'Connor LLP.
hepc@reko.ca www.reko.ca/html/hepatitis.html

Kolthammer Batchelor & Laidlaw LLP
#208, 11062 – 156 Street,
Edmonton, AB T5P-4M8
Tel: 780-489-5003 Fax: 780-486-2107
kkoltham@telusplanet.net

Other:

William Dermody/Dempster, Dermody, Riley & Buntain
Hamilton, ON L8N 3Z1 1-905-572-6688

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
www.phac-aspc.gc.ca/hepc/comp-indem_e.html

CLAIMS ADMINISTRATOR

1986-1990

Administrator 1-877- 434-0944
www.hepc8690.com info@hepc8690.com
www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf

Pre-86/Post-90

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

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



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, counseling, 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 Shorncliffe 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

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 mid-islandhepc@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, 330 Ellis Street, Penticton. Contact: 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 ADDRESS:** 31943 S. Fraser Way Suite 200, 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.herczeg@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 stew-arc@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 hepccommcoord@gmail.com, www.aidsnorthbay.com

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

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

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

healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194

Sudbury Circle C Support Group 1st Tues. monthly. Contact Ernie 705-522-5156, hepc.support@persona.ca or Monique 705-691-4507.

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 reneeaurio@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@hepcns.ca www.hepcns.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!