

hepc . bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

MOVING TO ACHIEVE EQUITY IN HEPATITIS FUNDING AND CARE ON THE NATIONAL LEVEL: A PLACE FOR POSITIVE VOICES

The lack of HCV+ peoples' participation in HIV/AIDS organizations which serve the needs of the HCV+ population, and speak on our behalf (to the media, to government, etc.) is something we as HCV+ people should be very concerned about. HIV/AIDS organizations have received many times greater funding at all levels, and have developed an extensive infrastructure over time. Because of this historical advantage, the Public Health Agency of Canada and other funders have decided that AIDS service organizations (ASOs) should take on HCV (as well as other blood-borne and sexually-transmitted diseases, even TB). The lack of HCV+ voices in ASOs has recently become of critical importance at the national level. As I am the only HCV+ individual on a national committee now dealing with this question, I am seeking HepCBC's and the HCV+ community's feedback and creative suggestions on how to deal with it.

For several years, HepCBC has been actively involved on the steering committee of the only national-level hepatitis B and C organization (which recently changed its name to Action Hepatitis Canada / Action Hépatites Canada—or "AHC"—now online at www.actionhepatitiscanada.ca). AHC is an unincorporated umbrella group made up of Canadian organizations responding to hepatitis B and C.

Its steering committee is like the board of directors of a society, and it is now determining the membership, policies, and procedures of the group. This founding steering committee consists of representatives from the following organizations (followed by their reach and the diseases they deal with):

- Canadian AIDS Treatment Information Exchange (CATIE)— national, HIV, HBV, HCV;
- Canadian Treatment Action Council (CTAC)—national, HIV, HCV-focus on co-

- infection;
 - Canadian Liver Foundation (CLF)— national, HAV, HBV, HCV, any disease which affects the liver;
 - Prisoners AIDS Support Action Network (PASAN)— national, HIV, HCV;
 - Canadian Hemophilia Society— national, HIV, HBV, HCV, and any other blood-borne infections;
 - Blood Ties-Four Directions Centre— regional, HIV, HCV;
 - Hepatitis Outreach Society of Nova Scotia— provincial, HBV, HCV;
 - Pacific Hepatitis C Network— provincial, HCV;
 - HepCBC Hepatitis C Education and Prevention Society— provincial, HCV;
 - Hépatites Ressources— provincial, HCV.
- AHC itself is open to membership to any organization in Canada committed to addressing hepatitis B or C, contingent on their support of the umbrella group's mandate and policies. AHC is not open to individual membership, though individuals can sign up to receive news/updates via email. Presently,

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ALANA HARDY

January 22, 1947– May 13, 2013

Alana, daughter of the late Phyllis and Alan Hardy, was predeceased by her brother Richard and her first husband, Joel Smith, and survived by her sister Lisa Morrow, and her children Joel and Jennifer, her second husband, John Montgomerie, and their daughter Johanna. She attended Huberside College and York University. Alana's first job was at the *Globe and Mail*. After that, she worked at *The News* and *The Review* in Richmond, promoting women in the community through her Ethel Tibbits Woman of Distinction Award and the insert "Women in Business." Although she lived in Toronto for half her life, her home was the West Coast.

Alana stopped working after her Hep C diagnosis and began writing in earnest. She published several short stories. She got her Creative Writing Certificate from Humber College. Some of her stories were featured on CoOp Radio on May 22nd.

She dedicated many years to the disadvantaged, and many remember her on the corner of Main and Hastings, giving Christmas toys to random children or serving countless Christmas and Thanksgiving meals in conjunction with churches, AIDS Vancouver, Crabtree Corner and the Salvation Army.

Alana's grandchildren, Jackson, Ronan, Sofia and Axel, Joshua, Alexandra, and Noah, Elias and Athena, are missing her games, stories, and expeditions. Alana also had step-children—her "Toronto Family"—including another 6 grandchildren.

The family suggests donations to the Chatamilu Project Scholarship Fund. Make

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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.

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(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 jkling2005@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: _____
PHONE: _____
FAX: _____
EMAIL: _____
WEBSITE: _____

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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.

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

DISCLAIMER: The *hepc.bull*® cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the editors, of HepCBC or of any other group.

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 31

Old-fashioned lady, 71 yrs old, European background, seeks solvent, faithful, age-appropriate gentleman in Victoria, BC, for companionship: movies, walks, cooking. Let's grow old together happily.

Got Hep C? Single? Visit:

<http://forums.delphiforums.com/hepatitiscen1/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.



DIAL-A-DIETITIAN

(604) 732-9191 or
1 (800) 667-3438

Dietitians of Canada: www.dietitians.ca
HealthLink: www.dialadietitian.org



NEED A BETTER RESUME?

We need a volunteer Executive Director. Also needed: Board members, summarizing, telephone buddies, translation English to Spanish or French. Please contact us at (250) 595-3892 or info@hepcbc.ca



ANNUAL GENERAL MEETING

**Tuesday September 10, 2013
6:30 PM**

**1947 Cook Street,
Victoria, BC
(Victoria Health Unit, Activity Room)**

Schedule:

6:30-7:30pm Welcome and Main Speaker
7:30-8:30pm Annual General Meeting

AGENDA:

- Approve minutes of AGM 2012
- Set number of directors (We are looking for new directors)
- Election of those directors
- President's Report
- Coordinator and Staff Report
- Financial Report

Main Speaker & Topic: T.B.A.

Refreshments provided. Public welcome. No charge. Must be a member to vote. Hope to see you there.

A member is entitled to one vote at a meeting of members, and must become a member at least 30 days prior to the meeting to be able to vote.

CALENDAR: SAVE THESE IMPORTANT DATES!!

GOODLIFE FITNESS VICTORIA MARATHON



JULY 15, 2013: Last Day to Register for Victoria's (October) "Goodlife Fitness" Marathon at Early Bird Prices.

OCTOBER 13, 2013: GOODLIFE FITNESS VICTORIA MARATHON. If you are considering joining the HepCBC Liver Warriors team this year (our THIRD YEAR!) in the Goodlife Fitness Victoria Marathon to be held October 13, 2013, you should register very soon! The last day to register at Early Bird pricing is July 15th. You can WALK, WHEEL-CHAIR, or RUN 8k (road race), 21k (half marathon) or 42k (full marathon). If you're a serious racer, this is a Boston Marathon Qualifier. Other reasons to participate: Help fight stigma against hepatitis C, help publicize the benefits of exercise for those with liver disease, raise funds to help HepCBC continue its education, prevention, and support programs, and personally have fun, get healthy, and meet some great new friends! Register at <http://www.runvictoriamarathon.com/events/register.php>. Be sure to select us from the dropdown list of teams: "HepCBC Liver Warriors"!

We also need volunteers (to cheer on race day, to help at our info booth October 11/12, or to help with fundraising efforts). If you want to help in any way, or to donate, get information at our site: <http://hepcbc.ca/marathons-walks/>. SEE YOU AT THE RACE!

HEPCBC ANNUAL GENERAL MEETING

AUGUST 10, 2013:

-- DEADLINE TO BECOME A REGULAR MEMBER OF HepCBC (\$10/year) who can vote at our 2013 AGM. To become a member, go to www.hepcbc.ca/hepcbc-order-form/.

-- To become a BOARD MEMBER, you will also have to apply for a free police check (email us ASAP for personalized form to take to your local station) and sign a confidentiality pledge (at AGM). Prospective Board Members can start attending meetings as non-voting members at any time. Members must attend three consecutive meetings (before or after being elected as a Board Member) before being granted full voting rights on the Board.

SEPTEMBER 10, 2013: AGM (See details in the column on the left.)

(EQUITY—Continued from page 1)

the secretariat needs of the AHC are ensured by CATIE, a coalition member, who provides these services in-kind.

Though CATIE has recently been dealing very extensively and successfully with HCV awareness and projects the last few years, it still operates under a Board of Directors which is mandated to consist of at least 50% HIV+ individuals. Increasingly, HIV/AIDS in North America is becoming a chronic, rather than a fatal, disease. At the same time, aging HCV+ Baby Boomers are developing cirrhosis or liver cancer, contributing to a higher death rate due to complications of HCV than to complications of HIV. The lack of HCV+ voices at CATIE is typical of most ASOs serving the needs of the HCV+ population and speaking on our behalf; this is something these ASOs may need to change, in order to adapt to the altered morbidity figures and funding landscape.

ACTION HEPATITIS CANADA'S MANDATE

“Action Hepatitis Canada works to improve health outcomes for persons living with and at risk for hepatitis B and C by working on behalf of organizations with governments, policymakers and civil society to realize a commitment to hepatitis B and C prevention, care, treatment, support and research—with funding proportionate to the impact and burden of this health issue on quality of life.

By engaging government, policy makers, and civil society Action Hepatitis Canada seeks to achieve equitable policy and program implementation in the following areas:

- Prevention of both hepatitis B and C through expanded education, immunization and harm reduction programs across Canada.
- Access to comprehensive care and treatment programs across Canada.
- Increased knowledge and innovation through interdisciplinary research and surveillance that monitors and reduces the burden of both hepatitis B and C on Canadians.
- Awareness of risk factors, stigma and the need for testing among the at-risk groups, as well as the general population.
- Recruitment, training and capacity development of qualified service providers and health professionals.
- Support for communities and community-based groups to develop, deliver and evaluate peer-driven initiatives.”

With a mandate like that, it is clear to see why I am so excited that AHC is forming, that HepCBC is one of the founding members of AHC, and that I am HepCBC's representative on its first steering committee. However, as it turns out, I am also the only HCV+ individual on this committee, and there are no HBV+ individuals on it at all. **We are a marginalized and highly-stigmatized population, and I want to ensure that we do not get re-marginalized institutionally due to not speaking up at the founding of the only national-level “hepatitis” organization. AHC will be perceived by government(s), pharmaceuticals, the press, and the public as Canada's sole**

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WHY DON'T SOME PATIENTS WANT TO BE TREATED?

Through an on-line survey for treatment-naïve patients, researchers asked why they hadn't chosen to be treated for Hep C. They also asked treatment-experienced patients what problems they had with treatment. The never-treated were questioned about their treatment plans and how much they knew about treatment. The already-treated were asked how long it took after being diagnosed to start treatment, what influenced their choice, and what the experience was like.

A total of 151 patients participated and 12 took part in more interviews. The answers of 13 were not counted because of "illogical responses." Those who had been treated tended to be older and were more likely to be non-smokers than the never-treated. More of those treated had insurance. 84% of both groups felt hopeful about their future health. Of those never treated, 59% did not plan on treatment in the future. 37% were symptomless. 24% were afraid of side effects. 24% couldn't afford treatment. Some didn't want IFN. Some thought they were too old. Some didn't like the length of the treatment. Of those already treated, 34% had discontinued treatment. Some said the treatment was difficult to follow and reported missing doses. The reasons they started treatment were to deal with symptoms, to comply with the recommendation of their doctor, the hope for a cure, the desire to be sure of not spreading the virus, and the wish to stop worrying about the disease.

The researchers think it would help if they understand why patients stay on treatment, so there could be more SVRs. Earlier studies have shown patients want effective treatment which is easy to take, with fewer side effects than IFN (flu-like symptoms, fatigue, some hair loss, depression, etc.)

Source:

www.natap.org/2012/HCV/071012_01.htm

LIVER CANCER: A RISK IN SPITE OF SVR

We recently lost our friend Gloria Adams to liver cancer (HCC), even though she had achieved an SVR (Sustained Viral Response) to therapy. This was heart-breaking, but unfortunately, not unexpected, even by her. Starting in 2001, researchers were following 351 HCV-infected, cirrhotic patients: 110 had SVR, 193 were non-responders, and 48 were never treated. Six of the SVR patients developed HCC between 0.04 and 7.6 years after achieving SVR. Instances of HCC, liver complications or death due to liver problems, and any other death per 100 person-years were definitely lower in those with SVR (1.0, 0.9, 0.7, and 1.9) compared to non-SVR (2.3, 3.2, 3.0, and 4.1) and never-

treated (4.0, 4.9, 4.5, and 5.1). [Note: 100 people × 1 years = 100 person years] Even after SVR, a risk of developing liver cancer remains for up to 8 years. Cirrhotic SVR patients should continue with their regular monitoring (ultrasound and AFP tests, etc.)

Source: 2013 May 14 www.ncbi.nlm.nih.gov/pubmed/23616492/?i=4&from=/19879972/related

DOES VIRAL LOAD PREDICT PROGRESSION?

Most investigators don't believe that viral load matters, but these do, although their results haven't been duplicated. This study showed that the risk for liver cancer (HCC) increased in those with higher viral loads (amounts of Hep C virus in the blood) from 1.1% in those with no virus, to 6.4% in those with low viral loads, to 14.7 % in those with high viral loads. The study showed this risk factor was not influenced by others such as genotype 1 or ALT levels, which are known to be danger signs, and the researchers stress the need for early treatment or at least monitoring to help avoid liver damage.

Source:

http://natap.org/2013/HCV/051313_09.htm (05/13/13)

(Continued on page 6)

(EQUITY—Continued from page 3)

voice representing the HCV+ (and HBV+) populations at the national level. But due to the nature of its membership and secretariat (mostly AIDS service organizations – ASOs), there is no representation (other than myself) of the hepatitis-positive communities in sight. In this case, AHC's claim to represent our interests or to speak on our behalf could be perceived as illegitimate, or at best, patronizing.

SOME POSSIBLE DIRECTIONS:

(1) **BRING IN POSITIVE VOICES:** The World Hepatitis Alliance (WHA) is an international umbrella organization of groups which serve the needs of hepatitis-positive people. WHA is a member of the World Health Organization and HepCBC is a long-time voting member. WHA allows two tiers of membership: "Voting Members" are organizations with at least one HCV+ or HBV+ individual on their "governing board"; organizations without such voices on their boards are "Non-Voting Members". Similarly, Canadian ASOs generally require that certain board and staff positions are taken up by HIV+ individuals. **To the extent that these organizations receive funding targeted for HCV, we should insist that a similar policy be established to give a voice and benefits to HCV+ individuals within those organizations.** I have suggested that Action Hepatitis Canada also develop such a policy for its member organizations, and possibly for its own governance (the steering committee) as well.

(2) **START OUR OWN NATIONAL-LEVEL HCV+ ORGANIZATION:** If you have the time, energy, and funds for this incredible "capacity-building" exercise, go right ahead, and good luck!

QUESTIONS FOR YOU:

Should the HCV+ population have a proportionately-representative voice in the ASOs now representing our interests, and funded by the government to do so? If so, how do we, as grassroots-level, poorly-funded HCV+ individuals and groups, "build our own capacity"; how do we pull ourselves up by our own bootstraps? Why and how should we do this? Who might be our allies? If we are to be represented fairly in national-level ASOs who have taken on HCV, how are these representatives to be selected? Many of us are ill, suffering from fatigue, pain, brain fog, or all three. In addition, the strongest voices for self-advocacy are often discouraged from doing so by anti-advocacy constraints to which organizations responding to HBV or HCV usually must abide.

So send HepCBC your thoughts. No rants, no regrets. This is reality. People are dying and time is short, so creative but positive suggestions are the only ones that will be considered. I will continue to keep the HCV+ community informed about AHC from an HCV+ person's point of view, and share your suggestions as well through www.hepcbc.ca and the monthly *hepc.bull*. AHC is an exciting development, but we as a community urgently need to become informed about AHC, and as soon as possible become an integral part of it. We don't want to be marginalized or stigmatized again! Thanks!

-- Cheryl Reitz, HCV+ Board Member and Volunteer at HepCBC, and member of the Steering Committee of Action Hepatitis Canada

WORLD HEPATITIS DAY IN BC

World Hepatitis Day 2013 in British Columbia

All the World Hepatitis Day events in B.C. that we know of are listed below. ALL will have speakers, information tables, and refreshments. Some of the events also include live HCV testing, a memorial service, picnic, barbeque, live music, fashion show, temporary tattoos, carnival, games and prizes, fun for kids, etc. For DETAILS of your city's event, see <http://whdcanada.org/events/>.



LOWER MAINLAND

VANCOUVER

Wednesday, July 24
11:00am - 3:00pm
John Hendry Park-Trout Lake

SURREY

Friday, July 26
12:00 noon to 3:00pm
KEYS: Housing and Health Solutions
10697-135A Street



ABBOTSFORD

Friday, July 26
11:00am - 3:00pm
Jubilee Park (McCallum & 5 Corners)
Speaker: Dr. Brian Conway @ 1:00pm



VANCOUVER ISLAND

VICTORIA

Saturday, July 27
11:00 am - 2:00pm
Centennial Square (Yoga on the grass!)

NANAIMO

Saturday, July 20
10:00am - 2:00pm
Bowen Park



COURTENAY

Friday, July 26
11:30am - 1:30pm
Courthouse Lawn, 6th & England

CAMPBELL RIVER

Thursday, July 25
11:30am - 1:30pm
Spirit Square, Shoppers Row



INTERIOR

GRAND FORKS

Friday, July 26
7:00am - 2:00pm
R.E.D.U.N & ANKORS's table at Farmer's Market
(Interior Health mascot Sir Ringe will attend)

WILLIAMS LAKE

Saturday, July 27
12 noon - 4:00pm
Red Shreds Bike & Board Shed, 95 South 1st Ave.

NELSON

Tuesday, July 23
12:00 noon - 2:00pm
Rotary Shelter at Lakeside Park
(WHA monkeys and International hepatitis C Quilt)



COMPLETE LIST OF WHD EVENTS:

<http://whdcanada.org/events/>



#SeeHearSpeakNo
WORLD HEPATITIS DAY
28th July 2013

OTHER WHD EVENTS IN CANADA:

NIAGARA HEALTH SYSTEM

Information displays as follows:

PORT COLBORNE HOSPITAL SITE
Monday July 22 9am to 12pm

DOUGLAS MEMORIAL SITE
Monday July 22 1pm - 4:30pm

NIAGARA-ON-THE-LAKE SITE
Tuesday July 23 12:30pm - 4:30pm

GREATER NIAGARA GENERAL SITE
Wed July 24 9am - 4pm

WELLAND HOSPITAL SITE
Thursday July 25 9am - 4pm

ST. CATHARINES HOSPITAL SITE
Friday July 26 9am - 4pm

Contact: NHS - Hepatitis C Care Clinic
905-378-4647 Ext. 32554

SANDI'S CRUSADE AGAINST HEPATITIS C

WHD Community Education & Awareness Event

Sat. July 27 10am- 6pm and Sun. July 28, 2013 Noon-5 p.m.
S & H Health Foods, Five Points Mall, 285 Taunton Rd. East, #57, Oshawa, Ontario (Corner of Taunton and Ritson Rd.)
Contact: Sandi, sandiscrusade@yahoo.ca
www.creativeintensity.com/smking/

Sandi, the manager, will have a table at the front of the store with educational material on hepatitis. The window display will be focused on support for Liver Health. 'See No Evil, Hear No Evil, Speak No Evil', featuring the Three Wise Monkeys

CLF WINNIPEG FLASH MOB

In collaboration with Canadian Hemophilia Society, Hepatitis C Support Community Inc., Winnipeg Regional Health Authority, Public Health Agency of Canada, 595 Prevention.

Wed, July 31; 11:30am - 1:00pm
201 Portage Avenue, Winnipeg
Contact: Ruth Magnuson
rmagnuson@liver.ca <http://www.liver.ca>



Transplant patients from outside Vancouver face the "Social Support" requirement hurdle.



Meet Dale. Dale disclosed that his greatest stressor is waiting for the transplant, not knowing if it will come in time. He says he feels like a ticking time bomb.

He has no "Social Support." Can you and your friends help?

Many medical hurdles must be crossed before you, an HCV+ patient, can become eligible for a liver transplant. Are you sick enough that you would die without a transplant, or, with lifestyle changes, could you eventually heal on your own? Are you too ill to survive the operation? But beyond these obvious criteria, patients must submit a plan proving they have sufficient "social support" on hand during the pre-transplant waiting period, in the hospital, and for approximately three months following hospital discharge. In B.C., liver transplants are only done in Vancouver, so for patients living outside the Vancouver area, this "social support" requirement can become the highest hurdle of all. It's hard enough for the transplant patient to spend months away from family in Vancouver, unable to work but forced to spend money to live away from home. The Happy Liver Society often steps in to assist them with housing. But for a spouse or friend to leave job and family responsibilities behind for several months as well is, in most cases, a logistical and financial impossibility.

At HepCBC we understand that this requirement is justified in that patients definitely need help. The Vancouver Health Authority document *Social Support for Transplantation* says the support person(s) must "offer both instrumental and emotional support." Instrumental support means such things as personal care, transporting and accompanying the patient to and from appointments, making sure medications and treatments are followed, doing shopping, cooking, laundry, and so on. Emotional support would include providing "an environment of hopeful optimism to promote healing and recovery" and ensuring the patient remains free of substance abuse during this period.

Of course the liver transplant team cannot provide what it correctly acknowledges are essential elements in the healing process. What we at HepCBC object to is the unjust advantage those residing in close proximity to the transplant centre have over those living outside Vancouver. Unless they can afford to hire a support person, it is impossible for a

person from Nelson or Prince George to get a liver transplant. We do not have a solution for this but are hoping that, once this situation is publicized, some Vancouver-area service organizations, church groups, or other volunteers may recognize forming a team of "liver transplant support volunteers" as an opportunity to save lives and make our transplant system more just for people from all over the province. We encourage any such groups to contact HepCBC or talk to the Pre-Assessment team at BC's Organ Transplant Clinic (2775 Laurel Street, 5th floor. Phone 604-875-5182).

(HEP C NEWS—Continued from page 4)

BEETROOT: DON'T THROW IT AWAY!

A daily cup of beetroot juice can lower high blood pressure often by 10 points for 24 hours, according to a new study from the University of London that tested 15 patients. They say the results are from the nitrates taken in from the soil and converted to nitric oxide, which relaxes blood vessels. Other vegetables that are high in nitrates are lettuce, fennel and cabbage and other green leafy vegetables. Blood pressure may also be lowered by using less salt, losing weight, taking high doses of vitamin C, and best of all, eating dark chocolate—moderately!

Source: www.medicalnewstoday.com/articles/259113.php

VITAMIN E VS. FATTY LIVER

Researchers have found that vitamin E may help 63 million people in the US alone who risk getting fatty liver—which can really hurt the liver of those with hepatitis C. The researchers were studying how vitamin E deficiency affects people by testing their surgical skills on liver tissue of genetically-modified mice who showed advanced fatty liver—a common cause of non-alcoholic cirrhosis commonly found in subjects who are severely overweight (be they mice or men.) The scientists were trying to confirm the suspicion that vitamin E could decrease fatty liver damage, and indeed, the supplements helped rid most of the mice of their symptoms. The recommended daily allowance of the vitamin is 15 mg, and it is found in leafy green vegetables, nuts, seeds, and some fortified cereals.

Source: www.redorbit.com/news/health/1112829670/obesity-liver-disease-help-from-antioxidant-vitamin-e-042413/

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. **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. **Gloria Adams** (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks -Drs Erb & Yoshida, Vancouver, BC.
7. **Don Crocock** (GT1) Stage II - Dec. 2010 IFN/RBV - 48 weeks [NEW ADDITION]
8. **Daryl Luster** (GT1a) - Feb 2011 - IFN/ RBV/RO5024048 48 wks.
9. **Donna Krause** (GT1 partial responder) SVR -Nov 2011– Pegasys/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks - Dr. Erb, Vancouver. [NEW ADDITION]
10. **Cheryl Reitz** (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
11. **Anita Thompson** (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
12. **Joan King** (GT1b treated 5 times) SVR12 Apr 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC.
13. **Leon Anderson** (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver. [NEW ADDITION]
14. This could be **YOU!**

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

(ALANA—Continued from page 1)

cheques payable to 'Vancouver Monthly Meeting' with earmark scholarship fund and send them to 103-8644 French Street, Vancouver V6P 4W6.

Source: <http://kearneyfs.com/book-of-memories/1584956/Montgomerie-Alana/index.php>

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
November 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/

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 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://lblavocats.ca/en/class-actions/hepatitis-c/active/red-cross.php>

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

LOOKBACK/TRACEBACK

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

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

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

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

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

Manitoba Traceback: 1-866-357-0196

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

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

CLASS ACTION/COMPENSATION

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

CLAIMS ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

Administrator 1-866-334-3361
preposthepc@crowco.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 dgrinstad@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 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.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 250-524-2487, 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](tel: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!