

hepc . bull

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

HEPCBC OUTREACH ROADSHOW 2014

HepCBC's recent Hepatitis C Outreach Roadshow trip to northern British Columbia was extremely successful. In 21 communities, we showed the astounding new one-hour movie "DEAL WITH IT: Untold Stories of Hepatitis C in Canada" which has been entered in the Toronto International Film Festival. Besides the film, in each of the 21 three-hour presentations we also shared a meal and did a hepatitis C workshop. This took place in 21 remote and rural communities between Williams Lake and Bella Coola, and between Prince George and Kitimaat Village. We also made another 16 less formal mini-presentations in communities along the way.

The trip took over 18 days and involved driving an SUV up from Vancouver, totaling 5600 km in all. Two nurses (Fran Falconer and Rosemary Plummer) and a hepatitis C "survivor" (Cheryl Reitz) - all female volunteers in their 60s, made the trip together. On the second day of the trip, Fran sustained a mini-concussion in a fall, and after an ambulance ride and hospital exam, insisted on carrying on with the trip. It was not easy for her. She is our heroine; bless you Fran! We'll let the pictures tell the rest of the story...



Pictured here are Nurse Fran Falconer (far left) and some of the workshop participants at Yunesit'in Youth Centre near Hanceville, BC watching DEAL WITH IT film. They were surprised to hear about the prevalence of hepatitis C in the aboriginal population (3X to 4X that of general Canadian population), and

(Continued on page 4)

THE UNTOLD STORY

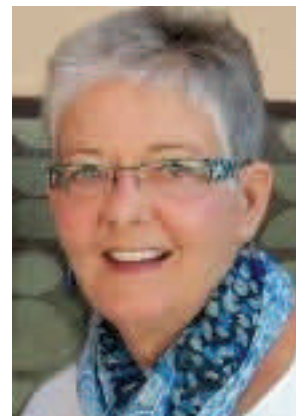
Dear Editor,

I think our readers may appreciate my experiences. Years ago, when I read the possible side effects of interferon treatment (suicidal ideation, anemia, "metal-mouth", rash, etc.), I didn't pay too much attention. I was just too eager to start treatment to take them to heart. I have included photos of my rashes. When I read about possible rashes, my brain said, "Rash? Yeah. Small rash. Will probably go away." No way, Jose! Ten years ago, my specialist took me off treatment at week 12, because I had immediately experienced rash, anemia and bleeding as if I were whipped with a cat of nine tails.



The itchiness would subside, but not before I had already laced my back open with a 12" flat screwdriver. I still suffer from itchiness and resulting bloody sheets. My doctor and I have tried for over four years since then to find some relief from. The last skin specialist said it is irreversible, and that I'll have it forever and ever, amen. We tried ointments and creams.

(Cont'd on page 2)



**BEVERLY JUNE
ARSENAULT**

September 17, 1950 – May 14, 2014

We have lost one of our finest advocates, Beverly Arsenault. Beverly, originally from Roshtern, SK, was a resident of Penticton. She leaves behind her husband Ron, their son Adam and daughter-in-law Kelly, grandson Finley, and three older sisters, Shirley, Deanna and Dolly.

Beverly began her career as a nurse in 1971 in Saskatchewan and BC. She worked in Critical Care in Penticton, and completed her degree at UVic in 1991.

"She held leadership positions in Intensive Care, Emergency and the Integrated Health Center. Bev was the driving force in championing the Healthy Heart Program in Penticton and throughout BC. She was also an enthusiastic leader and pioneer in chronic disease management creating the Integrated Health Center in 2003 - one of the first chronic disease management programs in BC."

She taught her chronic disease patients that such diseases can inspire people to be positive and strong, rather than burden them with a "disabled" label.

(Continued on page 6)

INSIDE THIS ISSUE

HepCBC Roadshow / The Untold Story	1
Beverly June Arsenault	1
Summer / Marathon News / Percuro	2
New Drugs Now	3
Workshops / Untreated Hep C in Canada	5
World Hep Day / Honour Roll	6
Care Programs / Compensation	7
Coming Up	8

SUBSCRIPTION/ORDER FORM

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

HepCBC
1139 Yates Street
Victoria, BC V8V 3N2

Name: _____

Address: _____

City: _____ Prov. ____ PC _____

Home () _____ Work () _____

Email: _____

Please email me a PDF copy, free of charge.

Membership + Subscription (1 year) ... \$20.00

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

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

Peppermint Patti's FAQ \$15.00

Resource CD \$10.00

Donation enclosed \$ _____

TOTAL: \$ _____

"I want to volunteer. Please contact me."

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

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

You may also subscribe or donate on line via

PayPal at www.hepcbc.ca/orderform.htm

Download the *hepc.bull* free at

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

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

Joan King
(250) 595-3892
(250) 595-3865
info@hepcbc.ca
www.hepcbc.ca

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

LETTERS TO THE EDITOR

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

hepc.bull

SUMMER ANNOUNCEMENTS

JULY IS VACATION MONTH THIS YEAR FOR THE BULL. We will do a July/August issue.

ALSO: IF YOU ARE SUSPENDING MEETINGS FOR THE SUMMER, let us know, please, at info@hepcbc.ca

PLEASE TELL US WHAT YOU ARE DOING FOR WORLD HEPATITIS DAY



THANKS!!

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

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

HEPC CLINIC AT PERCURO



The Hepatology Clinic at PerCuro provides HCV education and long-term support to patients and their families undergoing HCV treatment in the Greater Victoria/Southern Vancouver Island region, according to their individual needs. Specialized nurses help procure financial coverage for treatment, ensure lab tests are scheduled, teach self-administration of injectable medication, help manage side effects, facilitate a monthly support group, and liaise with family doctors and specialists regarding the patient's treatment and any other issues of concern.

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

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

There is no cost involved.

Nursing Support improves outcomes.
Contact 250-382-6270

(THE UNTOLD STORY—Cont'd from p. 1)

He wouldn't let me even try salt injections because of contraindications for my other meds.

I contacted a lawyer to see if I had a possible suit against the pharmaceutical company. He was concerned, however, that his firm would be doing me a disservice by taking my money to pursue this, as the defense would question why, after 10 years, I would start seeking legal restitution. There is a statute of limitation for such grievances. So my lawyer advised me to pick my fights wisely. I would like to say it's not about the money, and believe me, it is not. It wasn't ever about the money. The truth is, it's for us, so that in the future, new compounds will have to be all the more safe for us, the patients. "Do no harm." Isn't that a hit record for a group called The Medics?

My son looked into the living liver donation program. So he was well aware of the

(Continued on page 3)



MARATHON

Mark this date on your calendar:

October 12, 2014 is the date of the Victoria, BC "Goodlife Fitness Marathon" (8k Road Race \$40, Half Marathon \$75, Full Marathon \$100—EARLY RATES UNTIL JULY 15th!) Remember, running is not the only option! You can WALK either the Half or Full Marathon, and you can use a WHEELCHAIR for any of the events. To register, go to

www.runvictoriamarathon.com/events/register.php

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

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



(THE UNTOLD STORY - Cont'd from page 2)

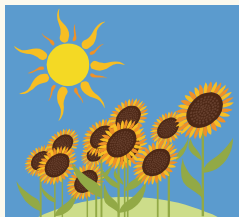
timeline for transplant. I told him there was too much time needed to heal (I think it's 6 months), however, his offer resulted in a teary-eyed dad. I told him I would just re-infect the new portion, so we both agreed to give up that idea. I asked him if I should talk to a different lawyer about pursuing a claim, and how much we should seek, but he didn't know and I didn't know. So we abandoned that train of thought.

Had the rash spread across my face, I would have contacted someone immediately, but I continued for 10 years trying to find a cure, with faith in the medical community. I share this with "our community", as I have never read about this aspect of treatment.

I would like to applaud all of "our family" who have bravely and courageously endured treatments with interferon or interferon alchemy. Hats off to you. You're still standing! Anyone who's been treated with IFN (and lived to tell about it) knows the side effects. They can be grueling. Let's not just sweep it under the carpet. I congratulate you in your pursuit of healing your bodies. We've taken a lickin', but we are still tickin'.

Now, here's a postscript for all of us mainline druggies: We tried to be as careful as we possibly could to practice cleanliness of our "rigs" (hypodermics, needles). We were basically boiling the needles and hypos, thinking we would be free of infection. However, at the time, our government made it illegal for pharmacists to sell out-fits (rigs, works). The only people who could purchase them were diabetics. I remember that a kindly pharmacist on Hastings St. (Vancouver) would leave himself open for criminal charges and dismissal from his career. You'd go in. If there were customers within earshot, you'd just flip through a couple of magazines. You'd get "the nod," which meant "wait until the customers are gone." He would have kits to give to the addicts, which consisted of an eyedropper and a needle and a Coca-Cola bottle cap (inside plastic removed) to cook with. His conscience told him to have compassion on all of us little "street urchins." It was one of the most guarded secrets, and we were very cool not to bring heat on him.

Your friend,
R Bowie



NEW DRUGS NOW

[Editor: I am following "The Untold Story" with this pertinent, as yet unpublished, letter from one of our readers to the editor of the Winnipeg Free Press.]

Dear Editor of the Free Press:

I have read the article that Don Marks wrote this past week:

(www.winnipegfreepress.com/opinion/analysis/the-deadly-toll-of-drug-approval-drag-241154481.html) I decided I needed to respond to what he had written. I understand what he is saying because I too have found that the wheels of government turn very slowly unless it is something that involves them. I also know that Canadians are very different from North Americans. They are very careful about what they do or not do. In the case of the new drugs for Hep C, I find that this practise of being slow is unacceptable.

If Health Canada needs to take their time in issuing new drugs that come out because they are doing research, there is a way to speed that up. I am on a Yahoo group for people with Hep C, and I read their stories about the treatments they have been through. I read what the older drugs of interferon and ribavirin have done to some of these people. Some have been cured, but 30% cure rate is sad, and then the medical problems that continue to exist for years after they are finished are not good.

Yet these very same drugs are still being pushed today, combined with some of the newer drugs. I hear different stories now of people who are doing the clinical studies with the brand new drugs which Merck, Gilead, BMS, and AbbVie are bringing out. Instead of 48 weeks of torture, they are now being cured in 4 to 24 weeks, depending on the strain of the virus, and without interferon. There is a cure rate of 90-100%. Now I would ask, why do Health Canada and the Provincial Health Departments not spend some time reading some of these stories? Why do they not believe that these drugs are doing the job that the older ones cannot do? Why does it have to take so long to get their facts together? Five years is a long time for some of the people suffering from Hep C to wait for their turn for a cure. For those who have cirrhosis due to this disease, they may not have five years left to wait. The side effects of these new drugs are minimal. In fact, the drugs that are being pushed on patients for hypertension, Aspirin, Advil or cholesterol drugs for example, have more

severe side effects, and still patients are being told they have to take them to survive.

Why are some people allowed to cure this virus and others are being told they have to wait, when they may not have that time? When the liver stops working there are only two options, either wait until cancer sets in, or wait for a transplant and hope you get one before you do die. I understand that these new drugs are expensive. I know that the older drugs were \$1800.00 a month, and treatment took 48 weeks, if you were able to tolerate that. Some people go through treatment several times with these old drugs and don't get the cure they are hoping for. That's expensive especially if it doesn't cure or kill the virus. Then there are the drugs (Sovaldi) Don mentioned which are costing \$1000.00 per pill for 12 or 24 weeks. For those of us who cannot take the interferon and need the cure, this is a light at the end of the tunnel. A transplant on the other hand costs anywhere from \$30,505 - \$121,732 plus the cost of hospital stay, and then there is the cost of anti-rejection drugs, which patients have to take for the rest of their lives, but only if the virus has been killed off before the transplant. Do the math. Which is more cost effective?

Why do I care? I am one of the Hep C carriers with stage four cirrhosis. I cannot take interferon because of damage it caused to my eyesight 3 years ago. At this point in time, there is no combination of drugs that I can take because of the strain of virus I have, that does not require the interferon.

There has not been a clinical trial here in Manitoba that I can take because of the parameters of whom they want to try their drugs on. I would be willing to be that guinea pig just to get rid of the virus.

What do I have to lose by doing that? What does my future hold? I just told you what it will be. It takes time to get these drugs moving through the red tape. There are those of us who don't have the time to wait for 5-10 years before these drugs come onto the market. Remember 1 out of about 40 people in the world has Hep C. One of those people could be you, and what will you do? I have had mine for 37.5 years, through no fault of mine. It is a silent disease like hypertension. You can have it and not know, because symptoms don't typically occur until the end stages.

As Don said, the process to approve these new drugs for use in Canada needs to be sped up. We are far behind the US, Europe, China and Japan.

If everyone waiting for the new drugs to come out would send a letter to their provincial Health Department, as well as to the

(Continued on page 6)

(ROADSHOW 2014—Continued from page 1)
 now want to further educate people in their community about hepatitis C. Far right: Lois Williams, Health Director.



HepCBC President Rosemary Plummer (far left) and Cheryl Reitz with some of the participants at the Nuxalt Elders Centre in Bella Coola. A simple but healthy meal which brought us all together, was served at every presentation. Community Health Representative Marietta Hans, second from right.



Some of the participants at the Stellat'en First Nation Wellness Centre outside Fraser Lake. Community Health Representative Cynthia Munger, second from right with her mother (far right) and aunt (bottom right). The job of Patient Travel Rep Denise Smith (third from left) is critical in this remote community. Cynthia also showed us their "sealed" Tele-Health room which is used for remote medical consultations.



Three young attendees filling out evaluation forms after a large, mixed-age presentation in the tiny community of Tachet Village outside Granisle. We were so impressed by the strong leadership qualities evident in this particular group of young people. Curious, polite, engaged, and verbal, they asked great questions, had ready laughter, and showed a degree of respect for their elders and culture we don't see so often among teens 'down south.'



The people in this extremely remote village of Fort Babine were most welcoming and genuinely pleased that we'd taken the time to come visit them, and that we were volunteering our time. They kept asking, "When are you coming back?" In this group, as well as many others, they mentioned people they knew who either now have, or have died of, hepatitis C. In many cases this was due to a pre-1992 blood transfusion or shared needle during childhood immunization, such as at Residential School.



Some of the lunchtime participants and volunteers at Positive Living North in Smithers. This society's small office space becomes a soup kitchen (thanks to Chef in Chief: Steve Monds!) serving a large number of community members every day on a very small budget. It is a great place to discuss health issues with people who ask challenging questions and know firsthand about harm-reduction and its importance in limiting the spread of hepatitis C among the North's at-risk population.



Medical personnel with Gitksan Health Society made up most of our audience in Hazelton. They provided excellent information to us about the differences between First Nations treaty and non-treaty communities in medical care and pharmaceutical coverage. Gitksan Health Society Nursing

Coordinator Mavis Sebastian (back row, third from left) suggested we return to show the movie at their upcoming Elders Conference in June.



Women from First Nations Health Authority and from Northern Health Authority joined us. Fort St. James is a community with many medical and social services which seem to cooperate and work together well. We talked a lot about Tele-Health in this room which is equipped and often used for this purpose.



The community of Tachie Village (in Tlazten Nation) was expecting us the previous day, due to a miscommunication. Nevertheless many of their staff came to view the movie. This audience was unique on this trip in that the men outnumbered the women! Their Community Health Representative is also male; we were happy to meet him because hepatitis C greatly affects the male population, yet the aboriginal health community is disproportionately female.



Staff members of Positive Living North Prince George welcome us to their office, following our presentation. This was the last

(Continued on page 5)

(ROADSHOW 2014—Continued from page 4)

of our trip, and the largest audience (over 30), consisting of about 1/3 nurses, 1/3 counsellors, and 1/3 HCV+ people or PLN volunteers. We wish we'd been able to schedule an all day sharing session with this incredible group of people!



Though not officially part of our trip, this presentation of the film in Victoria on May 27th was modeled on the Outreach Trip, and was the Victoria "Premiere" of the film. Of the 25 attendees, these seven attendees were also "stars" in the film. From left: Cheryl Reitz, Karen Felske, Hayley MacPhail, Anita York, Chantal Vaillancourt, Chaim-David Mazoff, and Douglas Laird. Cheryl, Karen, and Douglas have been cured recently, Anita and Chaim-David are awaiting treatment, and the other two are Percuro Clinic nurses.

Thanks to the "Hepatitis C Outreach Roadshow 2014" sponsors Gilead Sciences, BC Centre for Disease Control, and Bang Albino films!

RDSP WORKSHOP

On June 17th, we're holding a workshop on the Registered Disability Savings Plan (RDSP) and the Disability Tax Credit (DTC). We'll also cover some basic financial literacy topics. The workshop is designed for people who are receiving the Persons with Disabilities Benefit (PWD) or who are living on very low incomes. We will also be happy to help workshop participants on a one-on-one basis to apply for the DTC and the RDSP and to answer any questions about these programs. Even if you are living on a very low income, it is possible to save money.

This and future workshops have been made possible through the generous support of Vancity.

The workshop will run 1pm-3pm at the BCCPD office (#204-456 West Broadway, Vancouver). Light refreshments will be provided.

To register, please contact Val at 604-875-0188 or by email at feedback@bccpd.bc.ca.

UNTREATED HEP C IN CANADA

Canada's top liver physicians released new figures showing dramatically increased costs due to untreated hepatitis C which would place a far greater burden on our medical system over the next 20 years than that projected currently by the Public Health Agency of Canada. Their goal was to determine a baseline estimate of the burden of HCV in Canada before widespread use of the newer "Direct-Acting-Antiviral" treatments which will be able to cure 90 to 100% of those treated. While the cost of these "DAAs" is, arguably, quite high, this study shows the tremendous cost, in both human and financial terms, of restricting access to HCV treatment.

The authors state that "Already, there is evidence in Ontario that the disease burden from HCV exceeds that of all other infectious diseases; these data are likely generalizable to the remainder of the country." This is in reference to the 2010 ONBOIDS report

www.publichealthontario.ca/en/eRepository/ONBOIDSSummaryPresentation_Jan13_FINAL.pdf which found that in Ontario, the burden of hepatitis C virus in terms of life lost due to premature mortality far surpassed that of all other infectious disease (almost doubling that of HIV/AIDS). ONBOIDS (Ontario Burden of Infectious Disease Study) also found that most of the burden of HCV is due to premature mortality rather than from living with reduced functioning. They go on to state, "We project that without increased treatment access and uptake, approximately 32,500 HCV-infected individuals will die of liver-related causes between 2013 and 2035." The mean age of these deaths would be 68 years compared to average Canadian life expectancy of 82 years.

The new study shows the prevalence of HCV+ persons in Canada was estimated as approximately 1% in 2011 and that over 70% of this infected population was born between 1945 and 1975, which is why the Canadian Liver Foundation and the US Centre for Disease Control have strongly recommended one-time HCV testing of everyone in this cohort. In contrast, the peak age of hepatitis C incidence (new cases) is among a younger population currently using recreational IV or intranasal drugs. Currently both the incidence and prevalence of HCV in Canada are trending downwards; however, the prevalence of advanced liver disease and premature death due to HCV-related causes such as cirrhosis or liver cancer is rapidly increasing. It is not expected to peak until 2032.

In 2013, the lifetime medical cost for an individual with HCV infection was approximately \$64,694; this does not consider other expenses such as loss of

productivity or quality of life. If a person ends up requiring a liver transplant, lifetime cost goes up to \$327,608. With no changes to treatment methods or policies, the annual medical cost of chronic HCV in Canada will increase by at least 60% between 2013 and 2032: from \$161 million in 2013 to \$258 million (projected up to even as high as \$395 million) in 2032. Most of this cost increase would be due to increase in advanced liver disease.

Approximately 75% of HCV-infected individuals do not yet have cirrhosis, and this is the ideal time for treatment which can "prevent progression to more advanced stages when treatment becomes less effective and less tolerated, at least with interferon-based treatments." Of course, besides preventing advancing illness and premature death, this would lead to multiple other savings in preventing loss of productivity and adding to quality years of life for individuals and their families.

Read abstract: *Burden of Disease and Cost of Chronic Hepatitis C Virus Infection in Canada* in *Cdn. J. of Gastroenterology & Hepatology, May 2014. RP Myers MD MSc, et al.*
www.pulsus.com/journals/abstract.jsp?jnlKy=2&atlKy=12851&isuKy=1207&isArt=1

WORKSHOP/ ROUNDTABLE

We are looking forward to seeing ALL service providers at a FREE workshop and roundtable discussion on service delivery in the Fraser Valley.

WHEN? June 23rd 8:30 AM to 4PM

WHERE? ABC Family Restaurant, 32080 Marshall Road, Abbotsford BC

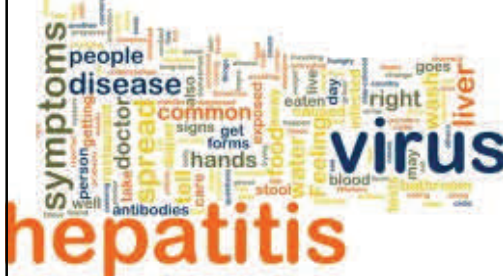
AGENDA: The 8:45 to noon session, will consist of a 45 minute talk with a Hep C specialist, with Q&A time. Questions on HIV are also welcomed. Other presentations will follow on Sexually Transmitted Blood Borne Infections including TB, and brief presentations from various service providers on what they do. A FREE lunch provided, followed by a service provider roundtable to discuss our delivery and how we can work together better and more effectively.

Dr. Ruth Elwood Martin, head of family medicine at UBC, has graciously agreed to facilitate. Thank you Dr. Martin! We have seating for approximately 40 persons and you must pre-register. RSVP soon. Please help us make this a success!

Contact Kari Hackett at Positive Living Fraser Valley Society to book seats via email to director@plfv.org or by telephone or text to 778-982-0147. Please indicate if you are attending the entire day or just morning or afternoon sessions with or without lunch.



WORLD HEPATITIS DAY



AN OPPORTUNITY TO EDUCATE AND TO FIGHT STIGMA

On July 28th every year, people living with and fighting hepatitis B and C throughout the world join hands to let others know of their struggles and how others can help them try to eradicate these two terrible diseases from the face of the earth. It is also a wonderful opportunity to show the diversity of our faces and stories; nothing dissolves stigma faster than when a real person we can relate to replaces a negative stereotype in our minds, right?

This year HepCBC once again is working with other groups to organize and publicize World Hepatitis Day events throughout the province. Let us know what you are planning to do in your community before July 1st, and your event will get advertised in BC's three major newspapers. Last year 11 communities were on the ad. Of course, we're hoping to include more this year! The best events are educational, friendly, colourful, meaningful, musical, and tasty!

VANCOUVER WHD 2014 will be the largest yet, held at the outside Georgia St. entrance to the Vancouver Art Gallery. Tents, tables, speakers, and music in (we hope!) the sun. The Planning Committee this year includes representatives from First Nations Health Authority, BC Centre for Disease Control, HepCBC, SUCCESS (the major hepatitis B group in BC), and the Purpose Society.

We hope you will consider hosting a unique and wonderful event in your community, and let HepCBC know about it so we can add it to the list in the World Hepatitis Day ads. The number one priority is getting information across, so you could set up a stall and talk to your local medical centre about a special drop-in clinic on World Hepatitis Day, which might include anonymous testing. For ideas and promotional materials, go to

<http://whdcanada.org/>
and

<http://worldhepatitisalliance.org/en/about-whd-2014.html>

(CZ's LETTER—Continued from page 3)

Minister of Health in Ottawa, maybe they would listen to our concerns. I have already done that. What about you?

Sincerely,
CZ

Editor: Here is the helpful part of reply to CZ from the Minister of Health's office, in reply to the letter they received:

“Certain drugs are available through Health Canada's Special Access Programme (SAP).

The mandate of SAP is to provide timely access to drugs, that are not approved in Canada, to physicians treating patients with serious or life threatening illnesses when conventional therapies have failed, are unsuitable, unavailable, or offer limited options. A physician wishing to request a product through SAP may contact the programme officer by telephone at (613) 941-2108, or by facsimile at (613) 941-3194, or by email: sapdrugs@hc-sc.gc.ca

Jacques Bouchard, Ph.D., Director
Bureau of Gastroenterology,
Infectious and Viral Diseases

TIP OF THE MONTH

Request and save copies of all tests and procedures. Make an effort to understand them. Look up definitions of new words.

Ask your doctor to explain what the results mean for your case!



(BEVERLY ARSENAULT—Continued from page 1)

Besides nursing, she was a talented singer and pianist and story teller. Her hobbies included reading, travelling, cooking, camping and bird watching.

“Bev’s vivacious and caring spirit touched everyone she met. She was an angel in our midst!”

We at HepCBC feel very honoured that she and her family would be inspired to request donations on our behalf in memory of her work.

Source: <http://clicktributes.com/hosted/obituary.cfm?profileID=12440&id=116>

SVR HONOUR ROLL

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

1. **GJ** - SVR Dec 1998 - IFN/RBV 52 wks - Dr Anderson /Natalie Rock, Vancouver, BC.
2. **Amberose** - 2000 (GT 2A/2C) - Schering IFN/RBV 24 wks
3. **Jeanie Villeneuve** - Oct 2000 - Schering IFN/RBV
4. **Kirk Leavesley** - (GT1) - 2004 - Roche
5. **Darlene Morrow** - (GT1 relapser) - Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.
6. **Beverly Atlas** - (GT1a) - 2005/2006 - Albuferon/RBV 44 wks
7. **Steve Farmer** - 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.
8. **Gloria Adams** - (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks - Drs Erb & Yoshida, Vancouver, BC.
9. **Don Crocock** - (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 weeks
10. **Daryl Luster** - (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
11. **Donna Krause** - (GT1 partial responder) SVR - Nov 2011- Pegasys/Copegus, Danoprevir/Ritonavir/RO5024048 24 wks - Dr. Erb, Vancouver.
12. **Cheryl Reitz** - (GT1b previous partial responder) SVR12 Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
13. **Anita Thompson** - (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
14. **Leon Anderson** - (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
15. **Joan King** - (GT1b treated 5 times) June 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC
16. **Sandy J.** (GT 1a treatment naïve) Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. Now SVR24.
17. **Andrew P.** - (GT 1a treatment veteran - multiple previous attempts including Incevik over 10+ years.) Jan 2014. GS-7977/GS-5885 (Sofosbuvir/Ledipasvir) + RBV 24 wks
18. **Diane Stoney** - Transfused 3/21/79 (GT 1a treatment naïve) 2/4/2014 - 12 wks placebo, then 12 wks on ABT-450/r+ABT-267+ABT-33+RBV. Dr. Tam, Vancouver, BC
19. **“C”** - (GT 1a treatment naïve) Mar 2014 MK5172/MK8742 12 weeks Dr. Ramji, Vancouver, BC.
20. **Jack Swartz**—(Treated 3 times) Apr 2014 IFN/RBV/Victrellis, Dr. S. Wong, WHSC.

We know there are many more of you. Please send your name and info to Joan at info@hepcbc.ca

CONFERENCES

6-7 June 2014

The Singapore Hepatitis Conference
Suntec, Singapore
<http://shc2014.com/>

28 July 2014

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

17-19 September 2014

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

9-11 October 2014

Viral Hepatitis Congress 2014
Frankfurt, Germany
<http://www.viral-hep.org/>



MOMENTUM SUPPORT

To learn more about SOVALDI™ or the Momentum Program in Canada, the patient should speak to his/her doctor or nurse or call the Gilead Sciences Canada medical information line at 1-866-207-4267. Eligible patients may receive an integrated offering of support services for patients and healthcare providers throughout the entire treatment journey, including:

- Access to dedicated case managers/reimbursement navigators to help patients and their providers with insurance-related needs, including identifying alternative coverage options through private, federal and provincially-insured programs.
- The SOVALDI™ Co-pay assistance program, which will provide financial assistance for eligible patients who need help paying for out-of-pocket medication costs.
- Medication delivery services.
- Compliance and adherence programs

NEUPOGEN

Amgen has a program for patients who have been prescribed Neupogen. Dependent on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge **as long as it is prescribed and dosed in accordance with the approved product monograph**. This service is accessed through the Victory Program: 1-888-706-4717.

MERCK CARE™

MerckCare™ is a program to help people who have been prescribed PEGETRON™, VICTRELIS™ or VICTRELIS TRIPLE™. The program provides:

- assistance with reimbursement and/or insurance claims.
- financial assistance for co-pay/deductible for people who qualify.
- 24/7 nursing support by phone.
- multilingual assistance.
- home delivery of medication.

MerckCare™ provides all of these services free of charge.

To enroll in MerckCare™, you can call 1-866-872-5773 or your doctor or nurse can submit an enrollment form for you. Reimbursement specialists are available from 8:00 a.m. to 8:00 p.m. EST Monday to Friday, excluding statutory holidays.

PEGASSIST

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM - 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or co-payments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

INCIVEK CARE

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

COMPENSATION

LAW FIRMS

1986-1990

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



Pre-1986/ Post-1990

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

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

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

LOOKBACK/TRACEBACK

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

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

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

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

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

Manitoba Traceback: 1-866-357-0196

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

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

CLASS ACTION/ COMPENSATION

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

CLAIMS ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

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

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

SUPPORT BC/YUKON

Armstrong HepCURE Phone support 1-888-437-2873

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more:

♦ **Campbell River:** Drop in, needle exchange, advocacy. 1371 C - Cedar St.

Contact leanne.cunningham@avi.org 250-830-0787

♦ **Comox Valley** Harm reduction, counselling, advocacy. 355 6th St., Courtenay. Contact Sarah sarah.sullivan@avi.org 250-338-7400

♦ **Nanaimo** Counseling, advocacy. 201-55 Victoria Rd. Contact Anita for details. 250-753-2437

anital.rosewall@avi.org

♦ **Port Hardy** (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shomcliffe Rd. Contact Tom, 250-949-0432 tom.fenton@avi.org.

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

ANKORS Hepatitis C Project (Boundary, Nelson, West Kootenay) Hep C Info, support for prevention, testing, treatment and living well with Hep C. Women's gathering monthly. 101 Baker St, Nelson.

Contact Laura 1-800-421-2437 250-505-5506 ankorshepc@ankors.bc.ca

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. birdsall@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 250-331-8524. Cheryl.taylor@viha.ca

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 deggrinstad@shaw.ca

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

Haida Gwaii support. Contact Wendy wendy@wendyswellness.ca www.wendyswellness.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 9AM-10PM.

♦ **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 & counselling 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 Cherri 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

New Westminster Stride with Purpose "HepC" Support Group 1st&3rd Fri monthly 10:30-11:30. BBP Nursing Team, refreshments/lunch. Contact: Stride Workers 604-526-2522, mail@purposesociety.org

Positive Wellness North Island-North Island Liver Service Info, support, treatment/pre-post treatment groups. 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:** Treatment/pre&post-treatment support group 1st&3rd Thu monthly 10-12pm, Sunshine Wellness Centre, Discovery Room, Campbell River Hospital. Caroline: caroline.miskenack@viha.ca, 250-850-2620

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 #108-32883 S. Fraser Way, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or plfvcentre@plfv.org

Powell River Hepatology Service Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact Melinda 604-485-3310 Melinda.herceg@vch.ca

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

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

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 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 hars@kingston.net www.hars.ca

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, Port Colborne and St. Catharines Clinics. Education, counseling, individual/group support, treatment, 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 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

CAPAHC support group meetings 3rd Thurs. monthly 6-8PM, 5055 Rivard St., (Montreal) Contact 514-521-0444 or 1-866-522-0444

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@hepnns.ca
www.hepnns.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!