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Canada's Hepatitis C News Bulletin

www.hepcbc.ca

LIVING IN BALANCE

A Cautionary Tale

A recent series of events has led me to believe that I have been living a life very close to perfect balance. Though this sounds wonderful and it is, there are certain realizations that arrive through this close-to-bliss existence. First let me give you a bit of background.

My name is Del. I will be 57 on October 13, 2013, and have been married for 33 years, with two children (grown) and almost 6 grandchildren. I have been in the employment of AIDS Vancouver Island for over 10 years, and am presently the Harm Reduction Worker for Courtenay. Living in the Comox Valley on Vancouver Island, I think life just doesn't get much better, in my estimation, and I am grateful to be able to experience and acknowledge this.

I have been learning to live with the Dragon (HCV) since 1998, when I was diagnosed HCV+ on retiring from the Canadian Armed Forces.

My journeys with the Dragon have taken me down many paths, bringing me to the balance that I have found in my life. To live fully and completely and stay in balance is a challenge worth taking, and to do this amid a myriad of chronic health conditions is sometimes difficult to maintain (or re-establish when it has been shaken or disturbed), but the bliss that one finds allows the effort to vaporise like the grey morning mists.

The perils of living in balance are not many, but they are consistent and almost instant. My job helps me to achieve this balance, as I must maintain a non-judgmental environment to be totally effective; as well, my role is to help people in whatever way they require (within ethical boundaries). This practice has enabled me to find what is described as Ego and remove it from my decision-making process, though, as in any process, we are not always bang on and tend to slip every once in a while.

(Continued on page 6)

FACTS ABOUT HCV AND THE BRAIN

- Psychiatric co-morbidity is significantly more prevalent in chronic HCV patients than in the general population.
- Psychiatric morbidity is associated with an increased risk for HCV infection.
- Some psychiatric symptoms (e.g., depression, fatigue) are experienced with chronic HCV infection.
- Chronic HCV leads to a high degree of psychological distress (stigmatization, anxiety, reduced quality of life).
- There is evidence that HCV alters CNS metabolism, directly or indirectly.
- Recent studies suggest that HCV may enter and replicate within the central nervous system.

Source: "Hepatitis C infection, antiviral treatment and mental health: A European expert consensus statement." Martin Schaefer, et al.
Journal of Hepatology 2012 vol. 57 j 1379–1390

[Thank you, Chaim-David Mazoff, PhD (HCVAdvocate, HepCBC*) for submitting this summary.]*

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KENNETH S THOMSON

July 24, 1954 - August 14, 2013

Ken died in Trail Hospital, and his memorial service took place on August 31 at the Grand Forks Funeral Home. He is survived by Teresa and her spouse Brian, by his son Dylan, and by his sister Debra, his brother Jim, and their spouses Brad and Connie. He will be missed by Tamara, Mitch, and Andrew, his niece and nephews, and of course, his friends and other relatives.

Ken worked for ANKORS, and was one of our most important, trained advocates. He did a lot of outreach work with youth. He had a good mind and excellent organizational skills, so it was a pleasure to work with him. Ken was in charge of what is now the PHCN (Pacific Hepatitis C Network)…what we used to call the "Circle." HepCBC was the agency of record, so I had the honour to work with Ken back in those years, fixing all the little glitches that would come up. Ken was a member of our Yahoo! group HepCan. You can search his posts there, and get to know who he was and what he stood for. Unfortunately, his health made it necessary for him to cut back on the work he did, and he eventually left his position of leadership with the "Circle", and we lost touch. But he has not been forgotten. His friends at ANKORS were extremely upset to hear about his death. He was not only a co-worker, but a best friend. He truly cared about his "clients,"

(Continued on page 2)

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☐Donation enclosed…….……………….$_______

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☐"I want to volunteer. Please contact me."

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(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 jking2005@shaw.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING:* *The deadline for placing advertisements in the* hepc.bull *is the 12th of each month. Rates are as follows:

Newsletter Ads: Maximum 4 per issue, if space allows. $20 for business card size ad, per issue. Payments will be refunded if the ad is not published.

HOW TO REACH US:

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

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

LETTERS TO THE EDITOR:

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

HEPATITIS C AMONG NEW AND IMMIGRANT CANADIANS

HepCBC had a great table again this year at the VIRCS (Victoria Immigrant and Refugee Centre Society) annual Multicultural Food and Health Fair September 21st in Victoria, BC. The photos tell the story! Newcomers to British Columbia, Canada, from all over the world are welcomed at VIRCS, and their health is of paramount concern. Hepatitis C and B both have a very high prevalence among immigrants, especially those from countries in Asia, northern and central Africa, and eastern and southern Europe, and central South America. 40% of hepatitis C worldwide was caused by unsafe medical practices. Caregivers need education about how to combat stigma and stereotypes which prevent newcomers from accessing life-saving treatments.

HepCBC Board Directors Dr. Chaim-David Mazoff, left and Wally Mutch, right, are shown sharing ideas with a new friend from Kenya, middle. HepCBC offered materials in Chinese, Arabic, French, Punjabi, Urdu, Tagalog, Amharic, Oromo, Somali, Swahili, and Tigrigna. If you can help translate materials into these or another language, contact htuscano@catie.ca of CATIE.

World maps, above, show the countries with high prevalence of hepatitis C (right) and the distribution of the various genotypes (left). In Canada, 2 out of 10 people with hepatitis C are newcomers or immigrants. Re-use of un-sterilized immunization equipment, other medical instruments and tools that break the skin for cultural and traditional practices quickly spread hepatitis C in many areas.

Because of language problems, it is a challenge to get the word out to those who are most at risk of having hepatitis C (and/or B) and not knowing it, unaware of current ways of dealing with the disease, or that greatly improved treatments are available. Education of caregivers who interact with the newcomer population is a critical need. In particular they need basic facts about the very different ways hepatitis A, B, and C are spread and treated.

(**KEN THOMSON**—*Continued from page 1)*

and was always looking for ways to make a difference in their lives.

"What I remember most about those days was the quiet dogged determination that Ken shared with all of us in the circle or on the council. Many of you, especially those who were more local to Ken, got to spend more time with the phenomenon that he was. He did not apologize for his life as society would have liked; rather he showed us the way to present working and reasonable solutions and take the fight to the government in a way they could understand and accept. It was a great honour to follow him as the lead in our fight. I hope he has finally found peace, or heaven is about to have a major dissident problem!" -- Del (HepCan)

"I first met Ken back in the 90's and traveled to several conferences with him and was there when we put together our group. He treated everyone as an equal and his strength and courage was beyond that of a hero. He worked hard every second of the day for Hep C people and solutions. God speed my friend. May you now get some much needed comfort in Heaven, where you surely will be still watching out for us. Good night, my friend!" --Robin (HepCan)

You can read more about Ken and his achievements at *http://www.pacifichepc.org/remembering-ken-thomson*

Sources:
www.legacy.com/obituaries/vancouversun/obituary.aspx?pid=166583381#fbLoggedOut
www.grandforksgazette.ca/obituaries/>*http://www.grandforksgazette.ca/obituaries/*
http://pubs.cpha.ca/PDF/P21/21256.pdf>*http://pubs.cpha.ca/PDF/P21/21256.pdf*

HEPCBC'S AGM: PRESIDENT'S REPORT

My name is Stephen Farmer, and I am a Hep C survivor. In January 2004 I was diagnosed with end-stage liver disease, which I later found out was caused by many years of having hepatitis C. I probably got it in my teens and had no idea that I had it. I was told that, without a liver transplant, I would be dead within a couple of years.

That year was a year of hell for me, having experienced three trips to intensive care after falling into a hepatic coma. I was unable to work or drive, missing almost all celebrations like my children's birthdays, Thanksgiving, and Christmas, spending weeks at a time in the hospital having to drain excess fluid that was constantly building up in my stomach and lung cavity. I went through almost daily blood work, x-rays and weekly doctor appointments, plus trips to Vancouver for interviews with the BC transplant office.

I had to come to terms with living with the undeniable facts that I was, indeed, dying, that one in three patients do die while waiting for a transplant, that probabilities were that I would not see my children grow up, that I would not grow old, and that I would not see the world outside my home or my hospital room window, while getting sicker and more disorientated every day.

Then came New Year's Eve 2005. I got a call at 2:00 AM. They had found a liver for me, and on January 1, 2005, I received my new liver.

However I still had the Hep C virus, which would continue to attack my new liver, so two years after my surgery, I was put on interferon/ribavirin treatment for a period of 72 weeks, which came with all sorts of side effects, including severe anemia, which in the final 6 months of treatment, could only be controlled by weekly blood transfusions. I thought this to be a little ironic—that a virus probably transmitted by a blood transfusion was, in the end, treated with blood transfusions.

The treatment, however, was a success, and for the last 4 1/2 years, I have been HCV-free.

While searching for information and support for Hep C treatment, I came across an ad in the paper about a meeting put on by HepCBC at the Richmond Pavilion at Royal Jubilee Hospital. That's where I first met this bunch of volunteers with connections to hepatitis C, either directly or through a friend or loved one, who were trying to spread awareness and help those infected by the virus with support and information. They had little or no help from any outside agencies, and were operating on practically no budget, but were very fortunate to receive a substantial donation from a Mr. John Crook, who unfortunately died from hepatitis but left half of his tainted-blood compensation money to HepCBC. That has been the primary source of income for the organization for the last 6 years. Those funds have almost been used up now.

I knew what happened to me could have been prevented, and I became determined to do what I could to prevent others from suffering my fate. If I had known that I had Hep C earlier in my life, I could have been treated or at least lived a better lifestyle to avoid cirrhosis.

Hep C took a huge toll on my life. It ended my 13-year marriage. I lost several years of being there for my children. It hit me financially, and it took me several years to regain my health. As I said before, it all could have been prevented.

So I jumped on board with these 6 or so volunteers in the hope that I could help prevent others from suffering a similar fate.

That was seven years ago, and I believe we have made a difference. I believe we have helped educate the public, relieved some of the stigma associated with hepatitis C, and helped those who have requested support and information.

But it's not over. Thousands of new cases are reported every year, and people are still dying. Thankfully healthcare and the pharmaceutical companies are taking note and are finally expressing a desire to partner with groups like HepCBC. New drugs are being developed and the word is getting out that getting tested can save your life.

For me, I'm thankful for the friends that I have met through HepCBC and the Canadian Transplant Association. I hope that the things I have done with this organization over the past seven years have made a difference. If one life was saved, then my volunteer time has been rewarded.

I hope that one day this group and those like it will not be needed, but for now we *are* needed, and the support from all of you is needed too. At the end of the day, we can hold our heads up high and say, "Yes! We made a difference. We helped improve or even saved somebody's life."

To that end I would like to thank all the volunteers of HepCBC since its inception, and urge newcomers to volunteer a little bit of their time to aid the war against hepatitis C—the silent killer.

—Stephen Farmer, retiring president, HepCBC.

[Editor: We at HepCBC wish to take this opportunity to thank retiring president, Steve, and board members Coralie and Fran, and we hope they will miss us and come back soon. At the same time, we wish to welcome back David and Rosemary. They are both returning members. Many thanks also to Cheryl, Wally and Joan, who are continuing on the board, and to our dear office manager, Anamaria.]

CALENDAR: SAVE THESE IMPORTANT DATES!!

GOODLIFE FITNESS VICTORIA MARATHON

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 (Late Registration rates) is October 12th.

You can WALK, WHEELCHAIR, or RUN 8k (road race), 21k (half marathon) or 42k (full marathon). If you cannot participate, please consider making a DONATION at our site: *http://www.canadahelps.org/GivingPages/GivingPage.aspx?gpID=19683*

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!

MEETING OUR NEEDS

“Meeting the Needs of Canada’s HCV+ Population under Canada’s New Integrated Public Health Policy” Speech given Sept. 19, 2013 at the national “New Science, New Directions in HIV & HCV” Forum of the Canadian AIDS Treatment Information Exchange (CATIE)

by HepCBC Board Member, Cheryl Reitz of Victoria, BC

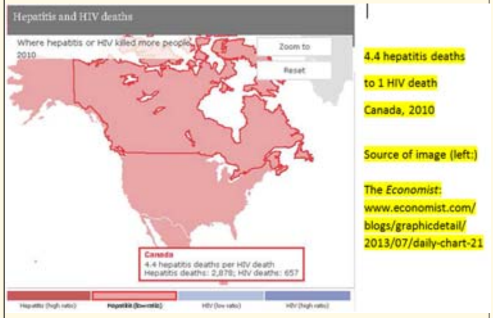
Thanks, CATIE, for inviting me here to share my thoughts about “integration” *(Public Health Agency of Canada’s [PHAC’s] directive to combine HIV, HCV, TB, and all other sexually transmitted infections and blood-borne diseases under one “STIBBI umbrella” – with regional AIDS service organizations [ASOs] serving as the interface between PHAC and local community health and service organizations)* from my perspective, but I’m only one of 250,000 members of Canada’s HCV+ community.

I gratefully acknowledge CATIE for devoting significant time, money, and staff to developing and distributing your great HCV resources and programs! Thank you so much! As HCV+ people and organizations develop our capacity and voices, I hope we will become stronger and better allies with you in the battle against HCV.

I also want to congratulate everyone here, especially CATIE and all the other ASOs who have been working, and continue tirelessly, to prevent new cases of HIV, and to lower the death rate from HIV/AIDS in Canada to less than 700 per year! HAART therapy has meant that some of my friends can now look forward to playing with their grandchildren, when not so long ago they were preparing to say their goodbyes.

Jade Hood
1951-2012

Before sharing my personal journey with you, I really need to get off my chest two glaring inequities which are often-sidestepped, but must be addressed to ensure a successful integration.

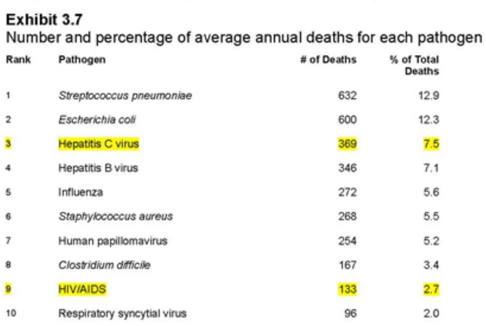


4.4 hepatitis deaths to 1 HIV death Canada, 2010

Source of image (left:)

The *Economist*: www.economist.com/blogs/graphicdetail/2013/07/daily-chart-21

While not wishing to diminish in any way the crushing burden and heartbreak of HIV/AIDS, we must also acknowledge the burden of viral hepatitis, which the *Economist*[1] magazine says is now killing over 4 times as many Canadians per year as is HIV/AIDS; with the majority of these deaths due to hepatitis C.



OBOIDS (Ontario Burden of InfectiousDisease Study), an OAHPP/ICES Report Dec., 2010. Chapter 3

The nine pathogens that caused the greatest number of deaths also caused the greatest disease burden, with some change in ranking order.

Exhibit 3.7

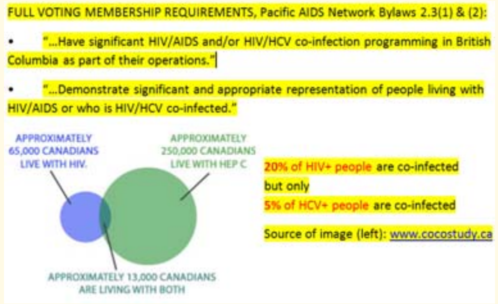
Number and percentage of average annual deaths for each pathogen

Rank	Pathogen	# of Deaths	% of Total Deaths
1	*Streptococcus pneumoniae*	632	12.9
2	*Escherichia coli*	600	12.3
3	Hepatitis C virus	369	7.5
4	Hepatitis B virus	346	7.1
5	Influenza	272	5.6
6	*Staphylococcus aureus*	268	5.5
7	Human papillomavirus	254	5.2
8	*Clostridium difficile*	167	3.4
9	HIV/AIDS	133	2.7
10	Respiratory syncytial virus	96	2.0

The OBOIDS[2] study backs this up, with HCV killing 369 in a year in Ontario, while 133 died of HIV/AIDS.

This leads to the first inequity: the government of Canada spends **$23 million annually for HIV compared to $3.5 million for HCV.** Let's face it; positive people with either HIV/AIDS or HCV are stigmatized and marginalized by society in general. But when HCV+ people see these figures, they feel they are being marginalized a second time, this time by their own government. HCV+ people would want the amount budgeted for HIV/AIDS to stay the same, but the amount spent on HCV increased to reflect the actual burden of the disease.

The second inequity: We know that regional ASOs will play a significant role in the federal integration processes unfolding over the next three years. Our regional ASO recently was forced to turn down an application for membership from my organization, HepCBC. We do not conform to its bylaws for membership because we don’t provide services for HIV+ or co-infected people. Instead, HepCBC serves the 95% of HCV+ people who are mono-infected.



FULL VOTING MEMBERSHIP REQUIREMENTS, Pacific AIDS Network Bylaws 2.3(1) & (2):

- “...Have significant HIV/AIDS and/or HIV/HCV co-infection programming in British Columbia as part of their operations.”
- “...Demonstrate significant and appropriate representation of people living with HIV/AIDS or who is HIV/HCV co-infected.”

20% of HIV+ people are co-infected but only 5% of HCV+ people are co-infected

Source of image (left): www.cocostudy.ca

In the “Spirit of MIPA and GIPA” *(policies which ensure that HIV+ people are significantly involved in governance, staff, etc. in any organization which accepts funds, speaks, or acts on behalf of the HIV+ community)*, it is critical that mono-infected HCV+ people and their organizations be meaningfully involved in the integration process and that they have a much stronger voice in these regional organizations, adding their voices to those of HIV/HCV co-infected people who are already represented in most regional ASOs.

As for myself, I'm an ‘elder’ in Canada’s Baby Boomer generation, a group dying of hepatitis C-related causes at an alarming rate. The long-predicted HCV ‘Time Bomb’ has finally detonated. I’ve lost many friends to liver cancer or sudden liver failure.

RUDY LANG
1940-2004

God knows, I wish one of the wonderful spokespeople whose photos I’ll be sharing with you could be up at this podium instead of me. I’ve been HCV+ for 38-55 years, and have been virus-free since finishing a clinical trial last December. However, I still have compensated cirrhosis, with Fibroscan stiffness of almost 50. So I will remain at high risk for liver cancer and failure for many years to come.

I have a large supportive family, have worked and travelled in many parts of the world, and still enjoy a healthy lifestyle. I tell people

(Continued on page 5)

(MEETING NEEDS—*Continued from page 4)*

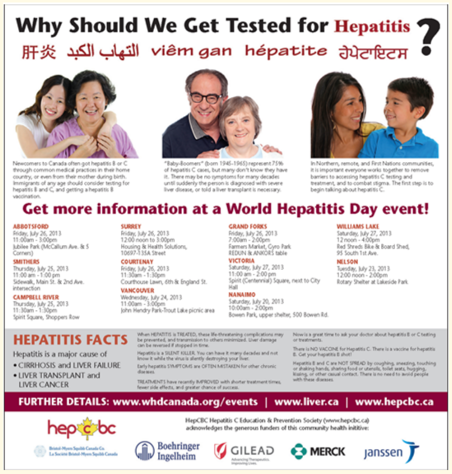
"Living well with HCV" is a realistic goal.

DAVE FITZGERALD
1936-2006

My organization, HepCBC, was originally formed in 1997 by a group of HCV+ people infected primarily through the medical system—collectively seeking information, compensation, and a cure—while trying to support one another and alert others about this insidious, little-known disease.

HepCBC is based in BC, but reaches out through its monthly *hepc.bull* newsletter, website, and support services to chronically-infected people throughout the world—primarily persons who were infected with HCV long ago, but not diagnosed until several decades after exposure. This could have been through a long-forgotten transfusion, one-time use of an IV drug or a shared cocaine straw; an unsafe tattoo or piercing, a substandard medical practice in a developing country, or during mass-immunization in the military.

For our target population, hepatitis C is generally not a co-infection, and only very rarely is it sexually-transmitted. These people are worried about things like losing their job if their status is discovered, or whether they'll be able to buy life insurance, or be able to continue supporting loved ones while undergoing treatment. They generally don't require harm reduction supplies or housing, and they only need to be tested once. Many of our target population do not know they have HCV, and do not even realize they are at risk, and neither do their GPs.



Why Should We Get Tested for Hepatitis?

肝炎 التهاب الكبد viêm gan hépatite ਹੈਪੇਟਾਇਟਸ

Newcomers to Canada often got hepatitis B or C through common medical practices in their home country, or even from their mother during birth. Immigrants of any age should consider testing for hepatitis B and C, and getting a hepatitis B vaccination.

"Baby-Boomers" (born 1945-1965) represent 75% of hepatitis C cases, but many don't know they have it. There may be no symptoms for many decades until suddenly the person is diagnosed with severe liver disease, or told a liver transplant is necessary.

In Northern, remote, and First Nations communities, it is important everyone works together to remove barriers to accessing hepatitis C testing and treatment, and to combat stigma. The first step is to begin talking about hepatitis C.

Get more information at a World Hepatitis Day event!

ABBOTSFORD
Friday, July 26, 2013
11:00am - 3:00pm
Jubilee Park (McCallum Ave. & S Corners)

SMITHERS
Thursday, July 25, 2013
11:00 am - 1:00 pm
Sidewalk, Main St. & 2nd Ave. intersection

CAMPBELL RIVER
Thursday, July 25, 2013
11:30am - 1:30pm
Spirit Square, Shoppers Row

SURREY
Friday, July 26, 2013
12:00 noon to 3:00pm
Housing & Health Solutions, 10697-135A Street

COURTENAY
Friday, July 26, 2013
11:30am - 1:30pm
Courthouse Lawn, 6th & England St.

VANCOUVER
Wednesday, July 24, 2013
11:00am - 3:00pm
John Hendry Park-Trout Lake picnic area

GRAND FORKS
Friday, July 26, 2013
7:00am - 2:00pm
Farmers Market, Gyro Park
REDUN & ANKORS table

VICTORIA
Saturday, July 27, 2013
11:00 am - 2:00 pm
Spirit (Centennial) Square, next to City Hall

NANAIMO
Saturday, July 20, 2013
10:00am - 2:00pm
Bowen Park, upper shelter, 500 Bowen Rd.

WILLIAMS LAKE
Saturday, July 27, 2013
12 noon - 4:00pm
Red Shreds Bike & Board Shed, 95 South 1st Ave.

NELSON
Tuesday, July 23, 2013
12:00 noon - 2:00pm
Rotary Shelter at Lakeside Park

HEPATITIS FACTS

Hepatitis is a major cause of
- CIRRHOSIS and LIVER FAILURE
- LIVER TRANSPLANT and LIVER CANCER

When HEPATITIS is TREATED, these life-threatening complications may be prevented, and transmission to others minimized. Liver damage can be reversed if stopped in time.

Hepatitis is a SILENT KILLER. You can have it many decades and not know it while the virus is silently destroying your liver.

Early hepatitis SYMPTOMS are OFTEN MISTAKEN for other chronic diseases.

TREATMENTS have recently IMPROVED with shorter treatment times, fewer side effects, and greater chance of success.

Now is a great time to ask your doctor about hepatitis B or C testing or treatments.

There is NO VACCINE for Hepatitis C. There is a vaccine for hepatitis B. Get your hepatitis B shot!

Hepatitis B and C are NOT SPREAD by coughing, sneezing, touching or shaking hands, sharing food or utensils, toilet seats, hugging, kissing, or other casual contact. There is no need to avoid people with these diseases.

FURTHER DETAILS: www.whdcanada.org/events | www.liver.ca | www.hepcbc.ca

HepCBC Hepatitis C Education & Prevention Society (www.hepcbc.ca) acknowledges the generous funders of this community health initiative:

Bristol-Myers Squibb Canada Co. La Société Bristol-Myers Squibb Canada
Boehringer Ingelheim
GILEAD
MERCK
janssen

Therefore, in July this year, HepCBC put an ad into newspapers to encourage Baby Boomers, Newcomers, First Nations and northern residents to get one-time-only HCV testing, to inform them about new treatments, and to warn them about some lesser-known and less-stigmatized risk factors…And speaking of stigma…

Recently, I was on a bus trip to northern BC and stopped in several small communities with a suitcase of pamphlets, to talk to people in nursing stations, ASOs, and Friendship Centres about their needs for HCV support. I was continually struck by the disparities in awareness and visibility of HIV versus HCV.

I was overwhelmed by the plenitude of HIV/AIDS promotional items and colourful brochures, while I had to search high and low for any HCV pamphlets. Many of the people I met were surprised at my openness about being HCV+. I was told that HCV was a huge problem in most remote communities, but people were suspicious about the confidentiality of local testing and afraid to be heard even talking about HCV.

First Nations people in particular said that they really wished that openly HCV+ peers would visit their isolated communities to help people confront their fears about HCV and its stigma; to discuss the many ways to get HCV and why it's smart to get tested; why having HCV does not mean a person is 'dirty;' and (BEST of all) that a cure is possible.

HepCBC fights stigma through participating in parades and marathons; it also does outreach to Newcomer communities, focusing on stigma and using CATIE's wonderful pamphlets in translation! We are now involved with a BC Cancer Agency liver cancer project and provide phone peer support during treatment as well.

We recently got a letter from a prisoner stating, "Your newsletter has been very informative for me as well as many other inmates. It's concise, updated, and factual; with (it) we can demand new treatments and talk informatively."

On the national level, HepCBC is a founding member of Action Hepatitis Canada; we provide patient group input for drug submissions, and are a long-time member of the World Hepatitis Alliance… In short, HepCBC does a LOT with very little.

But HepCBC no longer has funding for an office or an executive director. For the last few years, our work has been entirely done from out of our homes by mostly HCV+ volunteers – most of us ill and several of us volunteering fulltime. Lacking a reliable source of operational funding, we also lack what it takes to research and write proposals, assess needs, or properly evaluate. We receive sporadic, project-based funding from pharma – but no government funding whatsoever.

Keeping in mind this situation plus the inequities I referred to earlier, HepCBC has six ideas we hope those implementing integration will consider:

FIRST: Support all recent hepatitis C recommendations from the Canadian Liver Foundation[3], Canadian Assn. for the Study of the Liver, and Canadian Assn. of Hepatology Nurses such as: "One-time testing for baby boomers;" abolish "significant liver damage" pre-requisites to treatment; re-assess patients who were previously assessed as either "too healthy" - or "too sick" to be treated; and make prison a place HCV is stopped and cured, not spread. The initial up-front cost in finding and treating these additional patients—before liver failure or cancer strikes—would be more than justified by downstream health and cost savings.

BRUCE DEVENNE
1946-2011

SECOND: Integrate diseases when it is practical. When screening for HIV, screen for Hep B and C with the same blood draw! Newcomer Outreach can cover both hepatitis B and C, while teaching critical similarities and differences in transmission and treatment. Consider that patients with HBV, HCV and those aging with HIV all experience the same cirrhosis, liver cancer, and transplant issues!

THIRD: DON'T conflate HIV or HBV with HCV when it increases stigma, or confuses caregivers! A recently-run advertisement gives the misleading impression that HCV is commonly spread via semen; or from mother-to-child; or through sharing food or beverages cooked or served by a

(Continued on page 6)

(**MEETING NEEDS**—*Continued from page 5)*

HCV+ person.

FOURTH: Consider your target group's lifestyle! Be aware that referring mainstream, mono-infected HCV+ people to resources full of stories about HIV and MSM, or images of drug paraphernalia, can simply harden their pre-existing HCV stereotypes and lead to self-stigmatization. This can result in devastated people who just want to hide – they may avoid testing, treatment and support, or even disclosing to loved ones.

KELLY O'DELL
1965(?)-2011

FIFTH: Establish equity in funding hepatitis C research, training, prevention, treatment, support, and organizational capacity-building.

LAST: Ensure the voices of HCV+ people are proportionately included in any organizations that speak for us or accept and distribute funds on our behalf.

That's it. I hope my perspective has contributed something of value to this important conversation. Thanks so much.

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[1] *The Economist Magazine's blog about hepatitis deaths compared to HIV deaths, worldwide,* *http://www.economist.com/blogs/graphicdetail/2013/07/daily-chart-21*

[2] *Ontario Burden of Infectious Diseases Study (Dec. 2010 – an OAHPP/ICES Report.), Chapter 3, p. 28, Exhibit 3.6*

[3] *Liver Disease in Canada, a Crisis in the Making (Canadian Liver Foundation, March 2013).* *http://liver.ca/files/PDF/Liver_Disease_Report_2013/Liver_Disease_in_Canada_-_E.pdf*

*(**LIVING IN BALANCE**—Continued from page 1)*

Near the beginning of September this year I registered to walk a half marathon in Victoria. The Goodlife Fitness Marathon is also a fundraising event and helps to support HepCBC so I was pleased to be able to join the "Liver Warriors" team for the event. So here is the thing: I know Karma works. I see it everyday—in my life and in my work.

The morning the confirmation email from the marathon arrived, I was carrying the garbage down the back stairs when it occurred to me that this was kind of a "cool" thing. I mean here I am. I will be doing my first marathon (even if it is just a ½) on my 57th birthday! Remember I mentioned that Karma works…? As these thoughts were going through the often empty hallways of my mind, I reached the last step of the stairs and stepped out onto the landing, when my left foot rolled over, nearly dislocating the ankle, leaving it badly swollen and bruised, and my training schedule, interrupted.

I managed to get back to training quickly with some good support in my hiking boots and just got back into the rhythm when I got hit with an infection in the throat and couldn't eat for a week.

So now I am carefully walking back and forth to work and trying to maintain my non-judgmental balance. Perhaps I will risk a bit of self indulgence and be pleased with myself when the marathon is over, but the real goal has always been to help me achieve a better balance between food and exercise to help control my energy levels. I walk in the sun, the wind and the rain. I walk with purpose, I walk through pain. And now I walk without ego!

Hope to see you at the marathon…

Love and Peace to All, Del

THANKS!!

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

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

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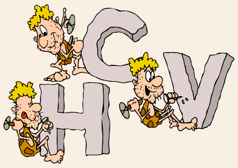
SVR HONOUR ROLL

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

1. **GJ** - Dec 1998 - IFN/RBV 52 wks—Dr Anderson /Natalie Rock , 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. **Steve Farmer** 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.**[NEW ADDITION]**
7. **Gloria Adams** (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks -Drs Erb & Yoshida, Vancouver, BC.
8. **Don Crocock** (GT1) Stage II - Dec. 2010 IFN/RBV - 48 weeks
9. **Daryl Luster** (GT1a) - Feb 2011 - IFN/RBV/RO5024048 48 wks.
10. **Donna Krause** (GT1 partial responder) SVR -Nov 2011– Pegasys/Copegus, Danoprevir/Ritonavir/R05024048 24 wks - Dr. Erb, Vancouver.
11. **Cheryl Reitz** (GT1b partial responder) SVR12 - Mar 2013 - Asunaprevir/Daclatasvir 24 wks - Dr. Ghesquierre, Victoria, BC.
12. **Anita Thompson** (GT1a treated 3 times) Cirrhosis - April 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.
13. **Joan King** (GT1b treated 5 times) SVR12 Apr 2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC.
14. **Leon Anderson** (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks - Dr. Alenezi & Dr. Conway- VIDC - Vancouver.
15. This could be **YOU!**

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



CONFERENCES

20th International Symposium on
Hepatitis C Virus & Related Viruses
6-10 October 2013
Melbourne, Australia
http://hcv2013.org/

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Hepatitis C Virus Infection: Looking Beyond the Interferon Alfa Era
8 October 2013
Chicago, IL, USA
www.iasusa.org/content/fall-2013-chicago-hep-cme-course

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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

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

—-

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

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

—-

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

—-

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

—-

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

—-

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

INCIVEK CARE

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

MERCK CARE™

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

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

MerckCare™ provides all of these services free of charge.

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

PEGASSIST

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

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

NEUPOGEN VICTORY PROGRAM

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

COMPENSATION

LAW FIRMS

1986-1990

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

Pre-1986/ Post-1990

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

Lauzon Belanger S.E.N.C. (Quebec)
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204
http://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 Shorncliffe Rd. Contact Tom, 250-949-0432 *tom.fenton@avi.org.*
- **Victoria** Access Health Centre, drop in, disability applications, peer training. Support group Tues 12:30 PM, 713 Johnson St., 3rd floor, 250-384-2366 *Hermione.jefferis@avi.org*

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

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

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

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

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

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

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

Cowichan Valley HCV Support Contact Leah 250-748-3432 *r-l-attig@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 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, *hepctxpeersupport@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.
- **Courteney**: 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 250-557-2487, 1-888-557-2487, *http://health.groups.yahoo.com/group/Network-BC/* *wendy@wendyswellness.ca* *www.wendyswellness.ca*

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

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources, contact Catriona 604-886-5613
catriona.hardwick@vch.ca or Brent, 604-740-9042 *brent.fitzsimmons@vch.ca*

VANDU The **Vancouver** Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061
vandu@vandu.org *www.vandu.org*

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

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

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

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

OTHER PROVINCES

ONTARIO:

Barrie Hepatitis Support Contact Jeanie for info/ appointment
jeanievilleneuve@hotmail.com

Hamilton Hepatitis C Support Group 1st Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St, Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 *mkowalski@hucchc.com*

Hep C Team, AIDS Committee of North Bay & Area. Education, outreach, treatment, individual & group support, harm reduction, needle exchange. 269 Main St. W, Suite 201, North Bay. Contact 705-497-3560, 1-800-387-3701 or *hepccommcoord@gmail.com*, *www.aidsnorthbay.com*

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

Kingston Hep C Info HIV/ AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 *www.hars.ca* *hars@kingston.net*

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

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