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Canada's Hepatitis C News Bulletin

www.hepcbc.ca

BC TRANSPLANT HURDLES

B.C. HEPATITIS C LIVER TRANSPLANT PATIENTS FROM OUTSIDE VANCOUVER FACE ADDITIONAL HURDLES

Victoria, B.C. – August 21, 2013 - Today, "Dale" from Kamloops lies in a coma, awaiting a liver transplant that may never come. Because he doesn't live in Vancouver, the only transplant centre in the province, he and his family face additional obstacles, claims Stephen Farmer, Victoria businessman, liver transplant recipient, and President of HepCBC Hepatitis C Education and Prevention Society. Farmer says Dale's case is typical and illustrates serious regional inequities in B.C.'s current organ transplant policy. Getting tested for hepatitis C and treated quickly with one of the improved new treatments is a patient's best chance for long-term survival. Liver transplant is an extremely expensive and painful last resort, and many on B.C.'s long waiting list die before a liver becomes available. To make it worse, people living outside Vancouver who need a liver transplant are at a disadvantage, particularly if they lack family and friends in the area.

Dale, a 56-year old heavy-equipment operator from Kamloops, was unknowingly infected with hepatitis C at birth, through a transfusion of tainted blood. He found out he was infected when he donated blood in 1992. Dale was offered a year-long hepatitis C treatment in 2000 (with Rebetron) which was terribly hard on his body, and which, unfortunately, didn't cure him, either. Dale had to stop working due to his disease in 2005, but was able to collect a small disability pension and received a 'tainted blood' settlement from the Canadian Blood Services in 2011.

This summer, Dale's belly swelled up with fluid (ascites); eventually pain (peripheral neuropathy) and fatigue sent him to bed. Ammonia accumulated in his blood, causing hepatic encephalopathy (HE), a form of demen-

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URGENT REQUEST FOR YOUR INPUT Into a new HCV drug, SIMEPRE VIR

On August 22nd, 2013 the Canadian Agency for Drugs and Technologies in Health (CADTH) released a call for patient input into Janssen Inc.'s new HCV drug, SIMEPRE VIR. In order to prepare our Patient Group submission by the September 13th deadline, HepCBC is asking for input from HCV+ people and caregivers from throughout Canada, by Wednesday, September 11th. See our website <http://hepcbc.ca/cadh-questions-about-simeprevir/> for details on how you can have a voice in determining whether this new treatment should be available in Canada, by contributing your ideas and experiences to HepCBC's group submission.

Primarily aimed at the hard-to-treat (and most numerous in North America) Genotype 1 patients, simeprevir is also being studied with Genotype 4 patients, and with Genotype 1 patients co-infected with HIV. Simeprevir, like telaprevir and boceprevir, would be used in a new "Triple Therapy" in combination with interferon and ribavirin to treat Genotype 1 patients. Duration of treatment is either 24 or 48 weeks, depending on a patient's history and early response to the medication. In experimental trials, less than 3% of patients had to stop treatment due to its 'mild to moderate' side effects. Only one simeprevir pill per day is taken, and though it must be taken with food, it does not re-

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HEALTH UNLOCKED: HepCBC'S ONLINE SUPPORT COMMUNITY

Join HepCBC's new Online Support Community. HepCBC recently set up a "Health Unlocked" online support community for Hepatitis C in Canada.

Go to www.healthunlocked.com/hepcbc/ to visit or become a community member.

We are hoping soon we will have many new HCV+ members, though caregivers and medical people are welcome to visit and/or join as well.

Hopefully we'll soon see new posts, polls, and questions and some great advice from our very large, spread-out, and stigmatized community. We may ask some of the most active participants and best givers-of-advice to take on "moderator" roles in the future. Note that Health Unlocked is now undergoing a complete website face-lift, so if things are not looking or working 100% now, they will be soon.

There are many safeguards for preserving client confidentiality on this platform; no one can trace your postings to your email address. HepCBC gets this service for free. Pharmaceutical companies and marketers support the site by paying for information it can provide about the needs of our community in "aggregate" form (such as totals and percentages on polls, and postings with no information attached which would tie it to a particular individual). Thanks for trying this great new support system out. Your feedback will be much appreciated.

—Cheryl Reitz, M.A., HCV+ Volunteer

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

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LETTERS TO THE EDITOR:

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

NEW CIHR HIV/HCV GUIDELINES

New CIHR Canadian HIV Trials Network HIV-Hepatitis C (HCV) Co-infection Management and Treatment Guidelines

It's been a decade since the Canadian HIV-HCV co-infection treatment guidelines were last updated. In that time much has changed and the management of HIV-HCV co-infection has become more complex. Drs. Curtis Cooper (University of Ottawa), Marina Klein (McGill University) and Mark Hull (BC Centre for Excellence in HIV/AIDS) are the lead authors driving the CIHR Canadian HIV Trials (CTN) initiative to publish new Canadian HIV-HCV treatment guidelines. In addition to filling an important knowledge gap, these guidelines come on the heels of new Canadian HCV mono-infection treatment guidelines, and at a time where many new HCV treatments are currently being tested.

"The goal," says Dr. Hull, "is to provide Canadian doctors and health care professionals with a solid set of treatment and care recommendations that reflects our current understanding of social and clinical realities supported by the latest research findings." In the document the authors provide 46 recommendations for evaluating co-infected patients, addressing barriers to care, selecting treatments, determining treatment timing, and addressing the drug-drug interactions. The authors note that the recommendations are intended to aid clinicians in the management of co-infections but do not supersede individual clinical judgment. "It's a document for clinicians," says Dr. Cooper, "and it goes beyond that too. It will be useful to epidemiologists, social scientists, basic scientists, and people living with HIV and HCV."

Co-author Dr. Klein estimates that 30 per cent of people living with HIV in Canada also contend with HCV. Currently, injection drug use (IDU) is the main mode of HCV transmission (responsible for about 80 per cent of infections) and is an important risk for HIV infection accounting for an estimated 17 per cent of new HIV infections in 2008. Co-infected persons are highly vulnerable in a number of ways that impact health, access to care and treatment. Women, youth and Aboriginal IDU are particularly at risk for co-infection because of shared vulnerabilities.

Aboriginal people comprised 3.8 per cent of the Canadian population in 2006 but 8 per cent of prevalent HIV infections. HIV diagnosis among Aboriginal women was

14 times more common than among non-Aboriginal women in 1999-2003, the gap increasing to almost 20 times the non-indigenous rate in 2004-2008. High rates of IDU are resulting in parallel increases in HCV co-infection. The highest rates of these new HIV diagnoses are in Saskatchewan, 75 per cent of which are associated with IDU, and consequently, HCV co-infection rates approach 90 per cent.

End stage liver disease (ESLD) due to HCV is now a primary cause of morbidity and mortality in people living with HIV. Despite growing awareness, many cases of HCV still go undiagnosed and untreated. One key recommendation in the guidelines is for broader and more robust screening for HCV for people living with HIV. The guidelines also recommend that everyone living with HIV-HCV co-infections be assessed for HCV therapy. Early initiation of HCV treatment may avoid any drug-drug interactions, may diminish pill burden issues due to simultaneous HIV and HCV medication dosing, and may improve future tolerability of antiretroviral therapy (ART) for HIV. In individuals who are unable to initiate HCV therapy due to unstable co-morbid conditions, consideration should be given to early ART initiation as a means to slow liver disease progression. The guidelines also recommend that HIV should not be considered a barrier to liver transplant in co-infected patients.

In 2012, leading up to the publication of the guidelines, Dr. Klein released a report stating that that, after having observed over a thousand Canadians living with HIV-HCV for a number of years in the Canadian Co-infection Cohort Study (CTN 222), over 50 per cent of the deaths recorded might have been preventable. She says, "There is a strong need to start targeting interventions aimed at minimizing vulnerabilities and improving social circumstances, reducing the harms from drug and alcohol use and increasing the delivery of HCV treatment."

The guidelines are a step in the right direction and present a strong case for shifts in clinical practice and policy. The full version of the guidelines will be available from the *Canadian Journal of Infectious Diseases & Medical Microbiology*. Details are also available by visiting the CTN website at www.hivnet.ubc.ca or www.hivnet.ubc.ca/2013/06/hiv_hcv/ or by contacting ctninfo@hivnet.ubc.ca.

Heiko Decosas is the communications and information officer at the CIHR Canadian Trials Network in Vancouver.



ANNUAL GENERAL MEETING

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

**1947 Cook Street,
Victoria, BC**

(Victoria Health Unit, Activity Room)

Schedule:

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

AGENDA:

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

Main Speaker & Topic: Fran Falconer, RN
Refreshments provided. Public welcome. No charge. Must be a member to vote. Hope to see you there.

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

(SIMEPREVIR—Continued from page 1)

quire any particular sort of food. Read more about its safety, efficacy, etc. [here: www.careeducation.ca/breaking-news/2013/5/7/canadian-perspectives-from-easl-2013-2.html](http://www.careeducation.ca/breaking-news/2013/5/7/canadian-perspectives-from-easl-2013-2.html).

Simeprevir is being reviewed by Health Canada for an NOC (Notice of Compliance) clearance as well. Once CADTH recommends a prescription drug (in this case roughly projected as early 2014), it is then up to the provincial governments to decide if and how their health insurance plans will cover the drug. HepCBC will make a British Columbia "Your Voice" group submission, and individuals will also be able to send personal submissions at that point. BC Pharmacare typically takes up to 6 months to complete post-CADTH approvals.

HepCBC confidentially collects data from HCV+ people and their caregivers through our support groups, website and email mailing list. If you are not on our mailing list yet, you can visit www.hepcbc.ca to sign up. While we welcome simeprevir to the arsenal of available or soon-to-be-available HCV treatments, it should be noted that numerous other drugs are also in the pipeline which will offer interferon-free and ribavirin-free options in the next couple of years. It is an encouraging time for hepatitis C treatment, though the high cost of all of these drugs will continue to be a big challenge, particularly for the poor - even in the developed world - and for most patients in the developing world, as well.

CALENDAR: SAVE THESE IMPORTANT DATES!!

GOODLIFE FITNESS VICTORIA MARATHON



SEPTEMBER 15, 2013: Last Day to Register for Victoria's (October) "Goodlife Fitness" Marathon at Regular Prices

OCTOBER 13, 2013: GOODLIFE FITNESS VICTORIA MARATHON. If you are considering joining the HepCBC Liver Warriors team this year (our THIRD YEAR!) in the Goodlife Fitness Victoria Marathon to be held October 13, 2013, you should register very soon! The last day to register at Regular Pricing is September 15th.

You can WALK, WHEELCHAIR, or RUN 8k (road race), 21k (half marathon) or 42k (full marathon). If you're a serious racer, this is a Boston Marathon Qualifier. Other reasons to participate: Help fight stigma against hepatitis C, help publicize the benefits of exercise for those with liver disease, raise funds to help HepCBC continue its education, prevention, and support programs, and personally have fun, get healthy, and meet some great new friends! Register at <http://www.runvictoriamarathon.com/events/register.php>. Be sure to select us from the dropdown list of teams: "HepCBC Liver Warriors"!

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

HEPCBC ANNUAL GENERAL MEETING

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

(TRANSPLANT HURDLES—Cont'd from page 1)

tia. On July 25th he was admitted to hospital in a hepatic coma. He is now unable to eat on his own, and when awake is confused and irritable. However, he is mostly uncommunicative, asleep about 90% of the time.

Outside Vancouver there are few liver specialists, so rural hepatitis C patients largely depend on their family doctor for care. Some doctors may not know that HE and hepatic coma reverse following a successful liver transplant; consequently some patients who should be assessed for transplant may be incorrectly diagnosed as "incurable" by their healthcare team, and denied consideration for this potential cure; Dale was luckier than many. Earlier this spring, Dale had been told he needed a liver transplant, and arrangements began with the "Pre-Assessment Solid Organ Transplant Clinic" at the Diamond Health Care Centre in downtown Vancouver. If Dale gets on the "active" transplant list, he will be given a beeper that rings when the liver he is awaiting becomes available, and he would immediately be flown out for emergency surgery in Vancouver. Dale passed most of the transplant team's requirements. He was sent home to Kamloops to await news of an available liver and fulfill two missing requirements.

First, Dale was required to submit a signed letter affirming his attendance at a group session. This would have been an easy requirement, except that it also involved Dale

reading through and filling out many pages of forms. By the time he received the forms, he was so confused and unable to concentrate (due to HE) that he couldn't complete the forms before he lapsed into his current coma. Had he lived in Vancouver, he would have had greater access to support, and probably would have completed the forms in time. The hope is that medications his Kamloops doctors are now giving Dale will enable him to awaken from his coma long enough to fulfill this requirement standing in the way of his transplant.

Second, patients must submit a plan proving they have sufficient "social support" on hand during the pre-transplant waiting period, while they are in the hospital, and following hospital discharge for approximately three months. This support involves providing personal care, taking patients to appointments, doing shopping, cooking, laundry, and providing "an environment of hopeful optimism to promote healing and recovery." The Happy Liver Society offers housing for some patients and their support person. (www.happyliversociety.org) However, for a patient's partner or friend to leave job and family responsibilities behind for several months is, in most cases, a logistical and financial nightmare. Unless they can afford to hire a local support person, it is extremely difficult for people from outside Vancouver to get a liver transplant in B.C. Again, Dale was lucky, because Larry Loranger, Dale's

(Continued on page 6)

In our August issue, WHD 2013 events in Nanaimo and Vancouver were featured, but that was just the beginning.

From Sally Errey of **Boys and Girls Club, Williams Lake, BC**: "Attached is a photo showing our Hep C Board, consisting of CATIE's "Think Before You Ink" educational post-cards, with a temporary tattoo attached to each card, spelling Hep C. As people interacted with the board, learning more about Hep C testing in our areas (with the Street Nurses contact cards), they could peel off the cards and tattoos. The idea was that as people get more educated and participate by taking one, they help Hep C 'disappear'."



From Kelly Ferguson of **ANKORS of Cranbrook, BC**: "Attached is a photo of the Community Art project that was displayed on City Hall in Cranbrook from July 24 to July 29, 2013 in connection with World Hepatitis Day. This project was a representation of the 1 in 12 people worldwide who are living with Hepatitis B or C. Pictures of one hundred people's hands were taken and then 8 of them were labeled with a B or C or both, to represent 8 people out of one hundred people living with hepatitis B or C. This project was well received and people stopped by to look and comment on the number of hand with a B or C label. Because the peo-



ple's hands were from Cranbrook this also made the issue of hepatitis more relevant to the onlookers. In addition to the project there was also a piece in the local Newspaper."

Sarah Sullivan of **AVI, Courtenay and Campbell River, BC**: "Hepatitis Day events sponsored by AIDS Vancouver Island were a great success in the North Island. On July 25th, 125 people came to Spirit Square in the heart of the Campbell River downtown to enjoy a healthy BBQ meal and some cake

while learning through the Viral Jeopardy game and exploring information tables from VIHA public health, North Island Liver Services, the Campbell River Youth Clinic, the Campbell River Women's Centre and Laichwiltach Family Life Society. July 26th, 100 people gathered on the Courtenay Courthouse Lawn also shared a delicious meal, informative games and support from the Comox Valley Nursing Centre, LUSH Comox Valley, Wachiyai Friendship Centre and the Immigrant Welcome Centre."

From **Positive Living Fraser Valley Society of Abbotsford, BC**: "Thanks to the hard work of staff and volunteers our 2013 Hep C Event 'It's your health... be invested...get tested' went off very well and was well attended. We especially appreciated Dr. Farley for stepping in at the last minute and giving a wonderful talk on a variety of topics regarding Hep C. We are hoping to post his talk on our website in



Dr. John Farley



the near future. We gave out over 200 hamburgers and hot dogs and everyone loved the live music of the Welsh Brothers!

From a testing perspective it was a huge success as we are told Fraser Health nurses had to take a list of persons to be tested at a later date. They simply did not have time to test everyone that came. We couldn't have asked for better weather and are already planning for next year!"

Keys: Housing and Health Solutions in Surrey held a well-attended event. Music was provided by DJ Freestyle. Elder Tom led the opening ceremony. Speakers included Shayne Williams (Executive Director), Monika Verma (Health Programs Director) Jasbir Sandhu (MP, Surrey North), Minister of Education Peter Fassbender, Bruce Ralston (MLA Surrey-Whalley), Sue Hammel

(MLA, Surrey Green Timbers), and Harry Bains (MLA, Surrey Newton.) They were



followed by Dr. Tam LAIR (LAIR Clinic), Petra Hoffmann, who shared her experiences, and Dr. Ramji (Pacific Gastroenterology, Vancouver), who presented an education session. A remembrance memorial and names were read for those we have lost. There was a fashion show "Runway to Hope" and a carnival (BBQ, music, information booths, games, dunking, etc.)

Watch the event [here: www.youtube.com/watch?v=-6f_aWJq_sw&feature=c4-overview&list=UUCDPemGc4wKN7bZYCDuiwQ](http://www.youtube.com/watch?v=-6f_aWJq_sw&feature=c4-overview&list=UUCDPemGc4wKN7bZYCDuiwQ)

AVI's Hermione Jefferis says, **Victoria, BC** acknowledged World Hepatitis Awareness Day 2013



HepCBC Board Members manning a booth at the AVI Fair.

by having its **4th Annual Love Your Liver Health Fair** in Centennial Square. Once again, **AIDS Vancouver Island (AVI)** organized other local healthcare and service providers to set up info-booths, provide healthy



snacks, pamphlets and information, harm reduction supplies, referrals, and on-site testing. There were several esteemed speakers, and also performances from some wonderful local musicians. "Thank you to everyone who came out and enjoyed the glorious sunshine with us!"

Let's work together to reach more in 2014!

From Elsy: "My agency (**Blood Ties Four Directions Centre in Whitehorse, Yukon**) ran a carnival for World Hepatitis Day."

From Kirk L: "We held a **WHD event in Winnipeg**, but had it on July 31. Everyone leaves the city on the weekend and there would have been no one attending. As it was, we were able to get people out on the 31st, but it's like pulling teeth to get people involved. We had wanted to do a Flash Mob, but that didn't work out. I worked with Ruth Magnusson at the Liver Foundation and we held an event at Portage and Main with HCV facts on the Jumbotron, an aboriginal drummer and we had the press there for interviews while hep C affected spoke to the lunch time crowd."

On July 27th, for WHD 2013, the **Hepatitis Outreach Society of Nova Scotia (HepNS)** combined the mission of disseminating information about hepatitis with the celebration of Pride. There were over 100,000 at-



tendees. HepNS volunteers and staff marched in the Pride Parade and handed out WHD giveaways, and afterwards, manned a booth at the Community Fair, where adults and children made buttons, got free t-shirts, and learned about hepatitis, and we increased awareness of our agency and its services. HepNS has developed a poster campaign to encourage testing. It identifies modes of HCV transmission and encourages testing



for anyone at risk. Most people can check off at least one risk factor. HepNS would like to thank our staff, volunteers, and all those who helped make our WHD/Pride event a fun, informative, and productive day!

The new wave of Hep C treatments is coming.

Treating hepatitis C (HCV) presents challenges for those taking medications, but it looks like that's going to change dramatically over the next few years, thanks to new treatments on the horizon. Being tested in clinical trials right now, they aim to increase the cure rate, shorten the treatment time, decrease side effects and cut the number of doses taken per day – good news for the approximate quarter of a million Canadians with HCV.

What is treatment like today?

Currently, HCV treatment is a combination of two drugs, peg-interferon and ribavirin. Peg-interferon is taken as a weekly injection for six months to a year and can cause fatigue, depression and other side effects. This treatment results in a cure 45 to 80 per cent of the time, depending on the strain of the virus. Dual therapy was the only treatment available until 2011, when two new drugs were approved: telaprevir (Incivek) and boceprevir (Victrelis). Both are called direct-acting antiviral (DAA) medications, which means they act to disrupt how copies of HCV are made. These treatments are also known as 'triple therapies' because each is taken in combination with peg-interferon and ribavirin. They increase the cure rate from 45 per cent to 75 per cent for people with genotype 1, the most common strain of the virus in Canada. However, telaprevir can cause rashes and both drugs cause an increase in anemia (low red blood cells and iron in blood) and other side effects. They need to be taken two or three times per day with food, which can be difficult to manage.

Interferon: Here to stay for a little while

Some new treatments will also need to be taken, at least initially, with peg-interferon and ribavirin, but will improve the experience of treatment. Remember these drug names; you'll soon be hearing more about them: daclatasvir, faldaprevir, simeprevir and sofosbuvir. These new triple therapies, which may be available as soon as 2014, will mean shorter treatment times, fewer pills and side effects, and a higher cure rate. However, side effects such as depression and fatigue from peg-interferon will still be hard for some people to manage.

Interferon-free treatments

It's been a long wait for treatments without interferon. These promising medications, now in the pipeline, are drug combinations that act on different parts of the viral life cycle. Some treatments will be as short as 12 weeks, with only one to two doses per day. For most strains of the virus, they may have cure rates of up to 90 per cent, even for people who did not previously respond to treat-

ment.

"The side effects will be much fewer, the treatment will be shorter, it will be easier for people who find it difficult to take medication and for people who have mental health issues," says Sandra Trifa, Hep C Outreach Nurse, CLSC métro, Montreal, QC.

The first interferon-free treatment may be available in 2014, and by 2015 or 2016 there could be multiple options for interferon-free treatment on the market for people with different strains of the virus.

New treatments, but will people be able to access them?

While these emerging treatments are good news, some troubling questions remain that could affect access to them. Their cost is unknown, but they are likely to be expensive, and cost could affect their being added to provincial/territorial drug formularies.

Will treatments be tested and approved for people with severe liver damage (cirrhosis) or co-infected with HIV? These people are often excluded from initial clinical trials, but need treatment the most.

Will there be enough trained doctors and nurses to accommodate all those wanting treatment? Many HCV-positive people have substance-use and mental health issues, and research shows that, with the support of multi-disciplinary teams that include doctors, nurses, social workers and peers, they can complete treatment.

HCV also affects some immigrant and newcomer communities that experience difficulties accessing testing and health care because of cultural and linguistic barriers. Will more be done to reach and support these groups?

It remains to be seen whether key barriers affecting access to treatment will be removed. If these new treatments succeed in reaching enough people, it will lead to a better quality of life for people living with HCV, and a dramatic reduction in the burden of HCV on the healthcare system in Canada.

"I think HCV is a disease we can eradicate in the long-term," says Dr. Jordan Feld, Hepatologist at the Toronto Western Hospital Francis Family Liver Clinic, "The progress has happened so fast with hepatitis C. To go from discovering the virus in 1989 to eliminating it from the blood supply, to developing therapy that cures people, and now getting to the point where we'll be able to cure almost everybody. It's a pretty remarkable feat."

Source: <http://www.catie.ca/en/news/easier-to-take-and-more-cures> (With permission to reprint)



NAULI YOGA: LIVER MASSAGE

Have you ever wanted to “unclog” your liver? You might want to try nauli, an exercise used in yoga, but ask your doctor first. The procedure is believed to cleanse internal organs such as the liver. It is not usually taught at your local YMCA or recreational centre, but it is part of the classical yoga tradition. Nauli consist of 4 types of movement:

1. You must “lock” your abdomen by breathing all your air out of your lungs, plugging your throat so air doesn’t come back in, and sucking your abdomen up.
2. Contracting the central abdominal muscle. (It may be easier to think of pulling your ribs together.)
3. Ideally you will be able to contract one side of the abdominal muscles and then the other side, to make a rolling motion.

The best way to learn this is from a yoga teacher. Don’t do it if you are pregnant. Check with your doctor if you have any doubts. Don’t do it if you feel any pain, or if you have a hernia, high blood pressure, heart disease, ulcers, cirrhosis or esophageal varices.



More info: www.nauli.org

Demos:

www.youtube.com/watch?v=FvLKvkd09VA

www.youtube.com/watch?v=U8SI6pwhbWM

THANKS!!

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

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

Special thanks to Thrifty Foods for putting our donation tins at their tills and to Sooke Shoppers Drug Mart, for donating the water for sale at the Christmas concert and for our CASL Forum. Thanks, Allison Crowe and Billie Wood for giving your 110% at the Christmas concert. Thanks also to Adrian for his continuous support.

(TRANSPLANT HURDLES—Cont’d from page 3)

social worker at the ASK Wellness Society of Kamloops, has kindly agreed to take on this role. However, Larry really needs a team of volunteers in Vancouver willing to help him help Dale. Once a team such as this is formed, it could help future liver transplant patients from outside Vancouver as well.

Farmer affirms that he had similar difficulties in 2005. "I had the same experience with having to stay in Vancouver for two months post-transplant. My spouse couldn't help as we had two school-age children at home who needed her care. It was quite an expensive juggling act for me to get caretakers and housing. Vancouverites certainly have an advantage." Farmer's elderly mother did her best to help him, though when faced with tasks such as changing bloody bandages or draining bags from a shunt, she found it very difficult to give her son some of the care he needed. While Farmer has no complaints about B.C.'s medical system and the wonderful people at B.C.'s Organ Transplant Clinic who saved his life, he says there is a great need for a Vancouver-based team of “rural liver transplant support” volunteers.

To make our liver transplant system more just and equitable for people from all over the province, and on behalf of Dale and many others like him, HepCBC (contact via www.hepcbc.ca) is trying to find Vancouver-area service organizations, church groups, or individuals willing to form, train, or sponsor such a team. For additional information about liver transplant, contact Vancouver Coastal Health's Solid Organ Transplant Program. If you are not yet registered to be an organ donor, visit www.transplant.bc.ca. Dale, his friends and family, and HepCBC send a big "Thanks!"



DALE



STEVE

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

We know there are 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.

† deceased



CONFERENCES

Strengthening the Pillars of Treatment Access in Canada
Canadian Treatment Action Coalition CTAC)
16-17 Sept 2013
Toronto, ON, Canada
www.ctac.ca

New Science, New Directions in HIV & HCV
Canada AIDS Treatment Information Exchange (CATIE)
17-19 Sept 2013.
Toronto, ON, Canada
www.catie.ca

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

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

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

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

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

DDW 2014
3-6 May, 2014
McCormick Place - Chicago, IL
www.gastro.org/education-meetings/live-meetings/digestive-disease-week-ddw

INCIVEK CARE

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

MERCK CARE™

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

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

MerckCare™ provides all of these services free of charge.

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

PEGASSIST

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

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

NEUPOGEN VICTORY PROGRAM

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

COMPENSATION

LAW FIRMS

1986-1990

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



Pre-1986/ Post-1990

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

Lauzon Belanger S.E.N.C. (Quebec)
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204
<http://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/

Armstrong HepCURE Phone support 1-888-437-2873

AIDS Vancouver Island The following groups provide info, harm reduction, support, education and more:
 ♦ **Campbell River:** Drop in, needle exchange, advocacy. 1371 C - Cedar St. Contact leanne.cunningham@avi.org 250-830-0787

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

♦ **Nanaimo** Counseling, advocacy. 201-55 Victoria Rd. Contact Anita for details. 250-753-2437 anital.rosewall@avi.org

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

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

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

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

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

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

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

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

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

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

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

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

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

Kamloops ASK Wellness Centre. Chronic illness health navigation/support.

info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing & counseling 250-315-0098

www.askwellness.ca

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

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

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

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

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

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

Positive Wellness North Island-North Island Liver Service Info, support, treatment. Doctor or self-referral. 1-877-215-7005 250-850-2605.

♦ **Courtenay:** 2nd Fri monthly 1PM, Drop-in, Comox Valley Nursing Centre (nurse)
 ♦ **Campbell River:** 2nd Tues monthly 1PM Drop-in, Salvation Army Lighthouse. (nurse)

Penticton & District Community Resources Society, Harm Reduction Program, Meetings every 2nd Mon., 2-3 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

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 hepcnetwork@gmail.com, www.aidsnorthbay.com

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

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

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

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

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

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

Owen Sound Info, support. Contact Debby Minielly 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257,

dminielly@publichealthgreybruce.on.ca www.publichealthgreybruce.on.ca/

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

healthline@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@hepnsc.ca www.hepnsc.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!