hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEP C IN THE NEWS

DOES TREATMENT HELP?

We used to think our goal was an SVR (Sustained Viral Response), but the goal now is a CURE. A cure means we can't spread the disease to our loved ones. We must not forget that an important long-term goal is to prevent Hep-C related death or disability.

Five hepatology centres in Canada and Europe analyzed data from 530 patients treated with IFN regimens between 1990 and 2003. 193 patients had SVR, and of those, 13 died. 91.1% of the patients survived 10 years-a rate comparable to the non-HCV+ population. On the other hand, in 100 patients who didn't respond with an SVR, the rate of 10-year survival was 74%. We will have to wait a while to get the 10-year survival rate for those who have been cured with the new drugs.

Source: http://www.jwatch.org/ na36305/2014/11/19/effective-hcv-treatmentprolongs-survival#sthash.uC3e6NDp.dpuf

DACLATASVIR UNBUNDLED

As you may know, the original submission of Bristol-Myers Squibb to the US FDA was for the combination of the NS5A inhibitor daclatasvir (DaklinzaTM) with their protease inhibitor asunaprevir. They later withdrew asunaprevir from the submission, with the intention of being able to combine daclatasvir alone with other DAAs. The FDA has replied to BMS's request by asking for additional data with the results of those combinations. Discussions are taking place. Francis Cuss of BMS stated: "Our commitment remains to make daclatasvir-based regimens available to help these difficult-to-treat patients achieve cure, and we will continue to collaborate with the FDA to bring daclatasvir to patients in the U.S. as quickly as possible." BMS still has submissions for approval of asunaprevir in countries, including other Canada. Source:

http://www.streetinsider.com/Corporate+News/ <u>Bristol-Myers+Squibb+(BMY)</u> +Receives+Complete+Response+Letter+from+F

(Continued on page 2)

CDEC Recommendations for Direct-Acting Antiviral Agents (DAAs) for Chronic Hepatitis C (CHC) Genotype 1

1. CDEC (Canada Drug Expert Committee) recommends the DAA simeprevir (GalexosTM) daily for 12 weeks, in combination with PR (pegylated interferon + ribavirin) for 24 to 48 weeks, as the protease inhibitor of choice for treatment-naive patients or for treatment-experienced patients with prior relapse.

2. No definitive recommendation regarding the place in therapy for the DAA sofosbuvir (SOVALDITM), relative to available protease inhibitors, can be made by CDEC at this time.

3. CDEC recommends that a DAA (directacting antiviral) plus PR treatment should be offered only to persons with CHC who have fibrosis stages F2, F3, or F4.

4. CDEC recommends that persons in whom a DAA plus PR regimen has failed not be re-treated with another DAA plus PR regimen.

Reasons for Recommendation 3:

1. No liver-related morbidity is expected in the short-term for patients with no fibrosis or a low fibrosis stage (stages F0 and F1).

2. In all analyses, treatment of patients with higher stages of fibrosis was more cost-effective.

http://www.cadth.ca/media/pdf/ TR0007 HepC RecsReport e.pdf

INSIDE THIS ISSUE

NEWS / CDEC / Arlene Darlington

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Our dear friend Arlene passed away, and we didn't find out about it until now. She dedicated hours and hours of work to us at HepCBC from 2000 through 2003, even after her husband Frank, one of our founders, succumbed to Hep C. Arlene was on our Board as Treasurer, and with her brilliant mind, was a wonderful asset to the group.

Arlene was also predeceased by her daughter Pamela, of whom she spoke often. Surviving her are her children Joe (Brenda), Laurel, (Greg) Feal, Tara Drake, and Thomas (who also volunteered with us), and her grandchildren Kenny, Akemi and Jojo. We are happy to reconnect with the family through Laurel, who recently contacted us.



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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.

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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.

Thanks THANKS! to hepc.bull & FAQ sponsor Bristol-Myers

Squibb.

Bristol-Myers Squibb Canada Co. La Société Bristol-Myers Squibb Canada

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

Please patronize these businesses that have helped us: Top Shelf Bookkeeping, Merck Canada, Roche Canada, Vertex, Gilead, Janssen, Boerhinger-Ingelheim, AbbVie, Rx&D, VanCity, Country Grocer, and Thrifty Foods.

(Hep C in the NEWS—Cont'd from page 1) DA+for+Daclatasvir+NDA/10051465.html November 26, 2014

LIVERS REPAIRED...WITH WHAT??!!

Most of us have heard how difficult it is to get a transplant. There are not enough livers to go around, and not enough ways to fix a "broken" one. The situation isn't improving. As baby boomers age, we will need still more livers.

But it may be that tonsils can come to the rescue. A report published in ACS Applied Materials & Interfaces says that stem cells from tonsils may save lives. Thousands of tonsils [including mine!!] have been thrown away every year. Tonsils are part of our immune system, but we can live without them. Korean researchers at Ewha Womans University decided to use stem cells from tonsils, instead of from bone marrow, to replace liver tissue by adding produced factors. They growth а biodegradable gel containing liver cells. They hope it can be used as a non-surgical treatment, administered by injection. The article suggests that the idea needs more PR, since no one has gotten excited about it...yet. [Me? I think it's a great idea. Ladies at Ewha, please, let's get some clinical trials going!]

Source: http://pubs.acs.org/doi/ipdf/10.1021/ am504652v

HEP C TSUNAMI WARNING

Vancouver's own Dr. Julio Montaner was honoured last week for his great contributions to HIV/AIDS research and treatment and to achieving an "AIDS-free

generation." And there's good news for Hep C sufferers. He's interested in us! He stated, "Hepatitis C is a bigger deal today. We haven't yet seen the face of it because it takes a long time to become a real disease. The tsunami is about to start....People are starting to show up with failing livers." He intends to use his experience with the HIV/AIDS epidemic to deal with the HCV threat.

He reminded his audience that 20 years ago, if a 20 year old woman were diagnosed with HIV, she would be dead in 15 years, after passing the disease on to her children. Today, he could tell her that she would live as long as her friends, and that her children would not be infected. She would just have to take one pill per day.

The anti-retroviral drugs have helped, but Montaner's method of dealing with the crisis working with Vancouver's at-risk is populations — IVDUs and sex-trade workers, among others- promoting testing, treatment and safer practices. His tactics have been praised by the UN and are now being used all over the world. His system has reduced new HIV infections in BC from 835 in the 1990s to 238 new cases in 2012, and deaths have dropped by over 95%. The AIDS ward at St. Paul's has been shut down! But there is still a problem. Many of these people are dying of liver failure due to Hep C, now his priority.

"Unlike AIDS, which made carriers sick within months, hep C can linger undetected for decades before beginning to cause liver damage," he reminds us.

Those who were at risk for AIDs are often affected by HCV, but perhaps up to 70% of BC's approximately 80,000 people with Hep C are baby boomers, and tragically, up to half of those don't even know they are infected... vet. Many infections were the result of inadequate disinfection during medical procedures. Without testing, many won't know, but the middle class will go to their doctor when they start getting symptoms. The at-risk population needs to be prompted to get tested. Treating baby boomers is good, but won't affect the number of new infections.

Montaner is encouraged by the new treatments for hepatitis C and drugs in pill form that can cure the disease in three months or less, in over 90% of patients, with few if any side-effects-a huge improvement over earlier treatment. The cost of those drugs, however, is a big obstacle. They can cost \$60,000 per patient, a price set by drug companies who fear that few patients will use them, explained Montaner, who added, "I'm saying, well, if you thought that you were going to treat one per cent of people infected with hepatitis C, and I'm telling you now that we would like to try to treat 90 per cent, we need to have a different conversation."

(Continued on page 3)

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(**Hep C in the NEWS**—*Cont'd from page 2*) Source: The Province 30 Nov 2014 http://www.theprovince.com/health/ Vancouver+doctor+warns+hepatitis+tsunami+amo ng+baby+boomers/10423334/story.html

LIVER-CLEANSING FOODS

Click on the link below: a short video about 14 foods that can cleanse the liver, and why:

- 1. Garlic
- 2. Grapefruit (ask your doctor!)
- 3. Beets and carrots
- 4. Green tea
- 5. Leafy greens (cooked/raw)
- 6. Avocados
- 7. Apples
- 8. Olive oil
- 9. Whole grains
- 10. Cruciferous vegetables
- 11. Lemons/limes
- 12. Walnuts
- 13. Cabbage
- 14. Tumeric

(He also mentions a link to a liver cleanse. Before you do any cleanses, look up the substance(s) used and search each one for warnings and side effects. Natural doesn't mean it's safe. Be aware that many meds are affected by grapefruit juice.)

http://o.canada.com/health/tonsils-could-helptreat-liver-disease#14FoodsthatCleansetheLiver

VACCINE IN PHASE I TRIALS

It has been very difficult to develop an effective vaccine against HCV, but it is still the dream of researchers. The problem is that the virus develops mutations to survive any vaccines...up until now.

Some patients can get rid of HCV spontaneously, with no treatment, probably due to T cell immunity. These researchers have developed a powerful T cell vaccine to imitate that process, stopping the disease from becoming chronic. Subjects have been identified from groups of IVDUs who could be suitable candidates for clinical trials, and the first study has begun in the US (NCT01436357). It will examine the potency and safety in a large group of volunteers who are exposed to different genotypes of HCV.

Researchers have used chimpanzees to develop the vaccine with an approach that produces great numbers of CD4+ and CD+ T cells, which target the virus without having to worry about the genetic makeup of the patient. Using well-known technologies, the researchers can see that the T cells generated by the vaccine become more powerful over time.

The strategy is "simple, safe, and well tolerated," say the researchers, speaking of the Phase Ι trial in humans.

http://www.sciencemag.jp/article/51872

AASLD 2014 SNIPPETS

65th Annual Meeting of the American Association for the **Study of Liver Diseases** Boston, MA Nov 7-11 2014

A presentation on November 9 reported that an all-oral regimen of 109 transplanted patients with SOF+SMV (sofosbuvir + simeprevir) with or without RBV was welltolerated, and resulted in an SVR in over 90% of patients. One patient died of lung injury 4 weeks post treatment. One developed pancreatitis, but after resuming treatment, achieved SVR12.

Another trial in 223 GT 1 or 4 post transplant patients treated with HarvoniTM (LDV+SOF) + RBV for 12 or 24 weeks resulted in SVR rates of 60-98% SVR12, depending on the grade of fibrosis/cirrhosis at baseline.

There is a group of academic and medical centres in Canada, Germany and the US called HCV-TARGET, which is conducting an observational study in posttransplant patients. The regimen (always including SOF) is chosen by the patient's health care provider. Data from 227 patients were presented. 27 took SOF/PR. 57 took SOF/RBV, 111 took SOF/SMV and 32 took SOF/SMV/RBV. The preliminary results seem to be in the **90 percentile**, so far.

The Turquoise-II trial of ABT-450r/ Ombitasvir/Dasbuvir/RBV (also called the 3D Regimen) in cirrhotic GT1a patients resulted in over 90% SVR12 and 98.5% in GT1b patients. The factors involved with treatment failure were having GT1a, a previous null response to pegIFN/RBV and the IL28b TT allele. No other characteristics mattered (age, baseline RNA, etc.)

The Phase II C-SWIFT trial, Grazoprevir (MK-5172) + Elbasvir (MK-8742) + SOF, in 102 GT1 treatment-naïve (TN) patients with or without cirrhosis, were treated for 4, 6 or 8 weeks. The interim results were announced, and showed that 28 of the patients had relapsed.

San Francisco company Alios presented data from pre-clinical studies of its nucleotide analogs AL-335 and AL-516, with results that convinced Johnson & Johnson to acquire the rights to the product. They plan to do clinical trials in 2015, combining the drugs with simeprevir.

Achillon is still in the picture, combining SOF with its ACH-3012 in 12 GT1 treatment-naïve patients during a 6 or 8-week Phase II trial. 6 other patients were enrolled but only observed. Of those treated, 100% achieved SVR12. There have been no relapses. Another drug, ACH-3422, is showing good preclinical results.

One of the presentations looked at "brain fog." [Finally!!] HCV has been found in parts of the brain. GT 1 treatment-naïve (TN) patients were analyzed in a ledipasvir/sofosbuvir trial (AKA Harvoni), using cerebral MR spectroscopy (MRS) and patient input. The results showed improved neuronal function, but that RBV may have a negative effect.

Another presentation from the Harvoni trials looked at the results in a real-life setting, and the results were similar to the trials: about 88% SVR per protocol. The conclusions are notable: "Cirrhosis is the most important predictor of response to 12 week regimens..." [Editor: Is this not a compelling reason to treat **BEFORE** patients become cirrhotic?]

Harvoni was used again, with or without RBV, in a study with data from 513 patients with compensated cirrhosis, achieving an SVR of 96%. Extending treatment time improved SVR, but with more side-effects. The data was pooled from Phase II studies LONESTAR, ELEC-TRON, ELECTRON-2, 337-0113, ION-1, ION-2, and SIRIUS trials.

There was good news at the Conference for cirrhotic patients who failed previous PI -based triple therapy. 97% of the 155 patients treated achieved SRV12 with Harvoni.

Results in GT3 treatment-experienced (TE) patients taking SOF/RBV for 24 weeks resulted in SVR12 of 87% of those without cirrhosis and 62% with cirrhosis. In an earlier report, 100% of 26 TN patients treated with Harvoni/RBV for 12 weeks achieved SVR12.

In **GT6** patients, SOF + PegIFN/RBV for 12 weeks resulted in SVR12 of **100%** in all of the 6 patients.

A trial of sofosbuvir + GS-5816 + RBV for 8 or 12 weeks in TN patients with any genotype resulted in SVR12 in over 90%. The 12-week arm was more successful. The Electron-2 Study added RBV arms for GT3 TN, non cirrhotic patients, who were treated for 8 weeks, resulting in high SVR rates.

BMS presented data from its ALLY-3 trial, combining daclatasvir (DCV) and SOF. 152 GT3 TN and TE patients were recruited. The treatment, lasting 12 weeks, resulted in an SVR12 of 90% in TN and 86% in TE subjects. This is important because progression is faster in GT3 patients.

Sources: http://natap.org/2014/AASLD/ http://depts.washington.edu/hepstudy/ presentations/uploads/136/turquoise23d.pdf

Many thanks to Jules Levin for his faithful reporting year after year!

HEPCBC NEWS by Cheryl Reitz

COMPETITION IS GOOD! HELP GET NEW DRUGS APPROVED FASTER

Dec. 18th Deadline to Contribute YOUR PATIENT VOICE to AbbVie "3D" ombitasvir/paritaprevir+ritonavir/ dasabuvir submission to CADTH*

HepCBC has been asked by CADTH* to do a Patient Group Review of the new IN-TERFERON-FREE 3-drug combo ombitasvir (ABT-267), paritaprevir (ABT-450)+ritonavir, and dasubuvir (ABT -333) which was developed for chronic hepatitis C by AbbVie Pharmaceuticals. We urgently request input from individual HCV+ people with any genotype (both those who have and have not tried this drug combination).

For background info see:

http://hepcbc.ca/contribute-to-abbvie-3dsubmission-to-cadth/

For the actual questionnaire, go to: <u>http://hepcbc.ca/questions-cadth-abbvie-3-</u> drug/.

DEADLINE: Thursday, December 18th, 2014 (midnight).

To watch a Dec. 10 (11 am, PST) webinar about this drug combo, email Adam Cook for directions: <<u>adam@ctac.ca</u>>.

SHORT SUMMARY (IF YOU JUST WANT THE FACTS!):

WHAT IT IS:

The combo (no trade-name yet) is made from ombitasvir, paritaprevir+ritonavir, and dasubuvir, either with - or sometimes without - the addition of ribavirin (IBAVYR). The decision to add ribavirin is up to your doctor, depending on the extent of your liver damage, genotype, and other factors.

EFFECTIVENESS:

Between 92% and 100% of patients were cured (achieved SVR12), depending on whether the study included people with cirrhosis, treatment time 12 weeks vs. 24 weeks, and whether ribavirin was added.

GENOTYPE:

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This submission is for genotype 1 only, but the combo is being tested on other genotypes (showing particular promise for hard-to-treat genotype 4), so the company may be making re-submissions for broader coverage once drug-trial results are finalized.

WHO CAN TAKE IT?

This combo has been proven to work very well on patients with compensated cirrhosis (the less serious stage, not end-stage or de-compensated cirrhosis), post-transplant patients, treatment naïve, treatmentexperienced, non- and partial-responders, and relapsers (we're talking here about people who have previous treatment with interferon+ribavirin, not those who took it with boceprevir or telaprevir added). We have not yet seen results for those who are coinfected with HIV; possible interaction with HIV drugs must be considered.

HOW IT IS GIVEN:

Four pills per day (3 in morning, 1 in evening) are given for 12-24 weeks. The amount of drug given and the length of treatment also depends on various factors.

SIDE EFFECTS:

They are very minimal compared to current standard-of-care, partially because of the reduced time you have to take these drugs. Slightly over 1% of patients had to discontinue treatment due to side effects. Here were the most commonly reported: fatigue, headache, nausea, insomnia, itching, diarrhea, weakness, shortness of breath, cough, and rash.

IF YOU WANT MORE DETAILS: THE BEST (THOROUGH BUT EASY TO UNDERSTAND): <u>http://www.hepatitisc.uw.edu/page/treatment/</u>

<u>drugs/3d#drug-summary</u> (even has a great slideshow!)

ONE PAGER! READ THIS AMAZING FACT SHEET from HCV ADVOCATE (USA):

http://www.hcvadvocate.org/hepatitis/ factsheets_pdf/

Phase 3 Genotype 1 AbbVie.pdf

*CADTH = Canadian Agency for Drugs and Technologies in Health, which does government-requested reviews for Health Canada and the Canadian Drug Review process.

WHY CADTH NEEDS PATIENT GROUP INPUT FROM HEPCBC and WHY HEPCBC URGENTLY REQUESTS YOUR INPUT

Patient Groups such as HepCBC provide patient input to the Canadian Agency for Drugs and Technologies in Health (CADTH) and the Canadian Drug Review (CDR) which helps them determine whether they should approve drugs for use in Canada, and what restrictions and criteria should be applied to their use. Here are some *new* (SHORT but GREAT!) YouTube videos which show why this input is so critical, and how it is used to benefits patients such as US!

Click below to view:

<u>www.youtube.com/watch?</u> <u>v=kop9yWq6tN0&index=1&list=PL45wcLqNa3</u> <u>c6sYRD7XLM9akLF3y6dbz3W</u>

After you watch these videos, please take a the few minutes to fill out *our most recent re-*

quest for hepatitis C patient input, which will be used to determine if the AbbVie 3-drug combo will be approved for use by Canadian HCV patients. To access this,

CLICK HERE. http://hepcbc.ca/2014/11/ urgent-request-patient-input-interferon-freehcv-3-drug-combo-abbvie/

You can view all of the 12 Patient Group Reviews HepCBC has submitted since 2011 to CADTH and BC PharmaCare (so people like you can get the drug costs reimbursed) HERE: <u>http://hepcbc.ca/patient-groupsubmissions-bc-pharmacare-cadth/</u> THANKS!!



From left: Daryl Luster, a speaker at the conference and President of Pacific Hepatitis C Network; Leslie Gallagher, RN, of Canadian Association of Hepatology Nurses; and Cheryl Reitz, Volunteer and Board Secretary of HepCBC

This was the "British Columbia Contingent" in Toronto, Nov. 3-6. 2014. We first attended an Action Hepatitis Canada Steering Committee meeting, then went to an international conference: "1st International Hepatitis Cure & Eradication Meeting 2014" hosted by Virology-Education. We hope to share some of the exciting things we learned in the coming weeks.



From Left: Richard Lee, MLA Burnaby North, Parliamentary Secretary for Asia Pacific; Anita York from HepCBC; Marc Dalton, MLA Maple Ridge Mission; Deb Schmitz from Pacific Hepatitis C Network; and Linda Reimer, MLA Port Moody Coquitlam, Parliamentary Secretary for Communities.

This photo was taken at an educational luncheon about hepatitis C for 16 BC legislators, which was hosted by Pacific Hepatitis C Network on Nov. 18, 2014 in Victoria. Speakers included Terry Lake, BC Minister of Health; Dr. Mel Krajden of BC Centre for Disease Control; and Daryl Luster of Pacific Hepatitis C Network. It was an excellent presentation. It was a closed meeting, and we wish more people could have heard what these important decision-makers said about hepatitis C policies in our province.

NOW RECRUITING: CLINICAL TRIALS

There are two new or relatively new, interferon-free Gilead trials recruiting patients. Please check if you are interested in treatment. They may fill up fast.

The **ASTRAL-1** trial is for **genotypes 1, 2**, 4. 5. 6 or indeterminate.

This trial compares Sovaldi/GS-5816 for 12 weeks to a placebo.

Please go to:

http://www.clinicaltrials.gov/ct2/show/study/ NCT02201940/

The ASTRAL-3 trial is for those infected with genotype 3. The trial treats the patients with Sovaldi plus GS-5816 or a placebo. : Please go to http://www.clinicaltrials.gov/ct2/ show/study/NCT02201953/

This trial compares Sovaldi/GS-5816 for 12 weeks with Sovaldi/RBV for 24 weeks. Please refer to this study by its ClinicalTrials.gov identifier: NCT02201953

Gilead is recruiting for both of these trials in these locations in BC:

Diamond Healthcare Centre, VGH Vancouver, BC, Canada, V5Z 1M9

Vancouver Infectious Diseases Clinic Vancouver, BC, Canada, V6Z 2C7

Other locations recruiting for the above trials are in Calgary, Edmonton, Ottawa, Montreal **FAWARENESS and PUBLICITY** and Toronto.

An Efficacy and Safety Study of Grazoprevir (MK-5172) + Elbasvir (MK-8742) in the Treatment of Chronic Hepatitis C Virus Genotype 1, 4, or 6 Infection in Treatment-Naïve Participants Who Are on Opiate Substitution Therapy (MK-5172-062) Recruiting only in Kirkland, Quebec, Contact: Merck Canada 514-428-8600 / 1-800-567-2594

A Study to Evaluate the Safety and Efficacy of Ombitasvir/ABT-450/Ritonavir and Dasabuvir in Adults With Genotype 1b Chronic Hepatitis C Virus (HCV) Infection and Cirrhosis (TURQUOISE-III) Locations: Toronto, ON M6H 3M1 Vancouver, BC, V5Z 1H2

Contact: Melanie Gloria, BS (847) 936-0714 melanie.gloria@abbvie.com





Victoria, December 1st, 2014

BEST OF THE UPCOMING FESTIVE SEASON TO ALL!

The holiday season gives us time to reflect on activities of the past year, savour our successes, and plan an even better future. Along with our warmest wishes, we would like to share with you some of HepCBC's many achievements and challenges, and request your continued support in 2015.

For over 15 years, HepCBC has consistently provided crucial support and information to the hepatitis C community. This last year, thanks to donations, we have been able to re-open our office. Because both the hepatitis C and broader communities recognize the high quality of our primarily volunteer-run, client-focused services, we are happy that we have been able to keep our part-time employee, and continue offering our volunteer-run services. However, we still must watch our budget and limit our F spending. If all our past donors simply gave again this year, we might not have to worry about fundraising for the rest of the year. Here is what we do now:

EDUCATION and OUTREACH

We have continued to publish the *hepc.bull*, Canada's leading hepatitis C newsletter, every month since March, 1996. Our website (www.hepcbc.ca), pamphlet series, and FAO's provide relevant, up-to-date information for people infected or affected by hepatitis C - in both official languages and Spanish. We put up information tables at events like the Goodyear Marathon.

SUPPORT

HepCBC's Victoria office is our nerve centre, a safe place to meet, and home to our resource library. We regularly receive requests for information and support from all over North America and beyond, and still provide phone, email, or in-person peer support to anyone affected by this disease. Monthly peer support meetings are held in a friendly, informative, and confidential setting.

HepCBC works at local, provincial, federal, and international levels to combat ignorance and stigma about hepatitis C. Besides cooperating with local agencies, we actively participate in national and international hepatitis C organizations which inform decision-makers about hepatitis C needs, best-practices and current research.

ALLISON CROWE'S ANNUAL "TIDINGS CONCERT"

HepCBC once again presented Allison Crowe's popular "Tidings Concert" to benefit HepCBC and Artemis Place which took place November 29 (7:30 pm) at the Charlie White Theatre, Sidney, BC. Not only is this a lovely way to spend an evening, but it provides us with a chance to inform the public about hepatitis C.

TAX-DEDUCTIBLE DONATION: Your tax-deductible contribution will go directly to hepatitis C education, awareness and support. Thank you for giving generously.

. □ I want to help HepCBC! Please donate via our website: <u>http://hepcbc.ca/donate/</u> or mail your cheque and this form to:

HepCBC #20—1139 Yates Street Victoria, BC V8V 3N2

HepCBC Hepatitis C Education and Prevention Society is a Registered Canadian Charity: 86800-4979-RR0001

As a volunteer (we'll forward you information) \Box Here is my tax-deductible donation of \Box \$30 \Box \$50 \Box \$100 \Box Other

Name: _____

Email: Address:

Phone:

*********** HEPC.BULL

DECEMBER 2014

ISSUE NO. 183

VANCOUVER INFECTIOUS **DISEASES CENTRE - VIDC**

We are the largest centre in Canada for the treatment of HCV in active IDUs, and participate in most of the clinical trials of new antiviral agents. We have developed unique ways of engaging IDUs in care and getting liver cancer. Anyone infected with HCV is them on trials through our innovative "popup" clinics on the Downtown East Side of Vancouver.

Vancouver ID Centre

201-1200 Burrard St Vancouver, BC V6Z2C7 Telephone: 604-642-6429 (Trials for IDUs, "Pop-up" Clinics) www.vidc.ca

TORONTO COMMUNITY HEPATITIS C PROGRAM

955 Queen Street East Toronto, M4M 3P3, ON (416) 461-1925

This program is for hepatitis C-positive people who have had difficulty accessing treatment and care for their Hep C. Priority is given to people who are uninsured, use substances and/or have mental health issues. The program is centered on group support. People attend a weekly group focused on information about HEP C, treatment and healthy living. TTC and food are offered. The group is a closed group and runs on a 16 to 18-week cycle. The Hep C Clinic runs at the same time.

Hep C Patients can have access to:

- Physicians
- •Hep C Treatment Nurse
- •Nurses
- •Case Manager
- Infectious Disease Specialist
- Psychiatrist
- •Hep C Coordinator
- •Hep C Community Support Workers.

We offer:

- •Hep C information and treatment
- Advocacy
- Support
- •Informal counseling
- •Harm reduction counselling and supplies
- •Group support
- •Patient accompaniments

•Referrals to doctors, nurses, counselors / case managers, detoxes, housing workers and shelters

Please contact:

Hepatitis C Treatment Nurse Shannon Taylor 416-461-2493 ext. 846 staylor@srchc.com

HEPATITIS C CIRRHOSIS SUPPORT GROUP

Hepatitis C Cirrhosis Support is a secret group for people living with Hepatitis C stage 4 & 5 compensated and decompensated cirrhosis, end stage liver disease and welcome. Please introduce yourself when you join us and share what you are comfortable with. Ask any questions you may have and we will do our best to help. We are all in this together.

The group link does not show on Facebook unless you are a member. Please email me to be added.

wendy@wendyswellness.ca

Thanks

Wendy Mackay Haida Gwaii B.C. www.wendyswellness.ca



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

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

PerCuro also offers access to cutting edge clinical trials for both naïve and treatmentexperienced patients.

There is no cost involved.

Nursing Support improves outcomes. Contact 250-382-6270

LIVER HEALTH AND **HEPATITIS C CLINIC**

Durham Region Locations:

John Howard Society 79 McMillan Oshawa, Ont. Every Thursday 11:30 - 1 pm

Beaverton Town Hall Nov 11, Dec 9 and Jan 13 10am - 2pm

For More Information: 1 855 808 6242 Press 4 then 1

> Hosted by Oshawa Community Health Centre

SVR HONOUR ROLI

Have you been undetectable for a minimum of 12 weeks after treatment? Give others hope. Congratulations to our friends:

1. GJ - SVR Dec 1998 - IFN/RBV 52 wks - Dr. Anderson /Natalie Rock, Vancouver, BC.

2. Amberose - 2000 (GT2a/2c) - Schering IFN/RBV 24 wks

3. Jeanie Villeneuve - Oct 2000 - Schering IFN/RBV

4. Kirk Leavesley - (GT1) - 2004 - Roche

5. Darlene Morrow - (GT1 relapser) - Mar 2004 - Hyperthermia/Induction + pegIFN/RBV.

6. KG-Transfused 1987 (GT2a/2c treatment naïve) 2003-4 IFN/RBV 24 wks. Still undetectable in 2014.

7. Beverly Atlas - (GT1a) - 2005/2006 - Albuferon/RBV 44 wks

8. Steve Farmer - 2008 (Transplant Vancouver 2005) IFN/RBV 72 weeks.

9. Gloria Adams - (GT1b relapser) - Fall 2009 IFN/RBV/Telaprevir 48 wks - Drs. Erb & Yoshida, Vancouver, BC.

10. Don Crocock - (GT1 Stage II) - Dec. 2010 IFN/RBV - 48 weeks

11. Daryl Luster - (GT1a) - Feb 2011 - IFN/ RBV/RO5024048 48 wks.

12. Donna Krause - (GT1 partial responder) SVR Nov 2011- Pegays/Copegus, Danoprevir/ Ritonavir/R05024048 24 wks. Dr. Erb, Vancouver.

13. Chervl Reitz - (GT1b previous partial responder) SVR12 Mar 2013 - Asunaprevir/ Daclatasvir 24 wks - Dr. Ghesquiere, Victoria, BC.

14. Anita Thompson - (GT1a treated 3 times) Cirrhosis - Apr 2013 - Pegasys/Boceprevir 48 wks. Dr. M. Silverman, Whitby, ON.

15. Leon Anderson - (GT2 partial responder) SVR24 May 8, 2013 - GS-7977/RBV 16 weeks -

Dr. Alenezi & Dr. Conway- VIDC - Vancouver. 16. Joan King - (GT1b treated 5 times) June

2013 - Asunaprevir/Daclatasvir 24 wks Dr. Ramji, Vancouver, BC

17. Sandy J. (GT 1a treatment naïve) Oct 31, 2013 - IFN/RBV/Victrellis 28 wks. Fran Faulkner, RN, Vancouver Island. Now SVR24.

18. Andrew P. - (GT 1a many prev treatment attempts over 10+ years, including Incivek Jan 2014.) Sofosbuvir/Ledipasvir + RBV 24 wks

19. Diane Stoney - Transfused 3/21/79 (GT 1a treatment naïve) 2/4/2014 - 12 wks placebo, then wks on ABT-450/r+ABT-267+ABT-12 33+RBV. Dr. Tam, Vancouver, BC

20. Coreen Kendrick - (GT 1a treatment naïve) Mar 10, 2014 MK5172/MK8742 12 weeks Dr. Ramii. Vancouver. BC.

21. Jack Swartz—(Treated 3 times) Apr 2014 IFN/RBV/Victrellis, Dr. S. Wong, WHSC.

22. Del Grimstad July 2014, 12 weeks Simeprevir/Solvaldi

23. Linda May (GT 1b transfused, treatweeks ment-naïve) Asunaprevir/ 12 Daclatasvir . Dr. Tam, LAIR Centre.

Please send your name and info to Joan at info@hepcbc.ca

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HEP C CLINIC AT PERCURO

CONFERENCES

27 February 2015

4th Canadian Symposium on HCV National CIHR Research Training Program Banff, AB <u>www.ncrtp-hepc.ca/</u>

> **12-15 March 2015** 24th Conference of APASL 2015 Istanbul <u>www.apasl2015.org/</u>

25-28 June 2015 The Global Viral Hepatitis Summit 15th International Symposium on Viral Hepatitis and Liver Disease (AASLD Endorsed) Berlin, Germany www.isvhld2015.org/

2-4 September 2015

World Hepatitis Summit World Hepatitis Alliance Glasgow, Scotland <u>www.worldhepatitisalliance.org/en/world-hepatitis</u> -summit-2-4-september-2015.html

> **13-17 November 2015** The Liver Meeting® 2015 San Francisco

MOMENTUMTM SUPPORT

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

•Access to dedicated case managers/ reimbursement navigators to help patients and their providers with insurance-related needs, including identifying alternative coverage options through private, federal and provincially-insured programs.

•The SOVALDITM Co-pay assistance program, which will provide financial assistance for eligible patients who need help paying for out-of-pocket medication costs.

•Medication delivery services.

•Compliance and adherence programs.

NEUPOGEN

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

MERCK CARETM

MerckCareTM is a program to help people who have been prescribed PEGETRONTM, VICTRELISTM or VICTRELIS TRIPLETM. 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.

MerckCareTM provides all of these services free of charge.

To enroll in MerckCareTM, 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 copayments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

INCIVEK CARE

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

IBAVYRTM

Pendopharm has established the IBAVYR[™] Patient Support Program. The program will assist patients who have been prescribed IBAVYR[™] (ribavirin tablets) with reimbursement navigation, financial assistance and pharmacy services. Case managers will support patients with insurance-related matters and assess eligibility for financial support. Pharmacy services include adherence support, medication delivery and counselling.

To enquire or to enroll, you can call 1-844-602-6858 Monday – Friday 7am to 11pm EST.

COMPENSATION

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 <u>HepatitisC@kpmg.ca</u> Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764

CLAIMS ADMINISTRATOR 1986-1990

Claimants may be reimbursed for costs of treatments and accepted hepatitis C medications not covered by public or private healthcare plan while they wait for reimbursement from the 1986-1990 plan.

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

Pre-86/Post-90

Administrator 1-866-334-3361 <u>preposthepc@crawco.ca</u> <u>www.pre86post90settlement.ca</u>

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, harm reduction, needle exchange, advocacy. 1371 C - Cedar St.

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

• Comox Valley Harm reduction, counsel-ling, advocacy. 355 6th St., Courtenay. Contact Sarah

sarah.sullivan@avi.org 250-338-7400

• Nanaimo AVI Health Centre. Counseling, advocacy. NEW: 102-55 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 Shane, 250-949-0432 shane.thomas@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

ANKORS Hepatitis C Project (Boundary, Nelson, West Kootenay) Hep C Info, support for prevention, testing, treatment and living well with Hep C. Women's gathering month-ly. 101 Baker St, Nelson. Contact Laura 1-800-421-2437 250-505-5566

ankorshepc@ankors.bc.ca

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

Chilliwack PCRS Hep C Prevention, harm reduction. 45904 Victoria Avenue, Chilliwack. Contact Kim Lloyd 604-798-1416. Ibirdsall@pcrs.ca www.pcrs.ca

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

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

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

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

Haida Gwaii support. Contact Wendy wendy@wendyswellness.ca www.wendyswellness.ca

HepCBC info@hepcbc.ca, www.hepcbc.ca Call for office hours.

•Victoria Peer Support: 4th Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Contact 250-595-3892 Phone support 9AM-10 PM. • 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 limortell@shaw.ca

Mid Island Hepatitis C Society Contact midislandhepc@hotmail.com

Nanaimo - Central Island Hepatitis Service: Nurses & doctors available for info, support, treatment. Clinic located in Nanaimo. Doctor or self-referral. Contact 1-855-740-2607, sarah.hughes@viha.ca or shelby.munk@viha.ca

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

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

Penticton & District Community Resources Society, Harm Reduction Program, Meetings every 2nd Tues, 12:30-1:30 PM. 330 Ellis Street. Contact Melanie: 250-488-1376 or 250-492 5814

Positive Haven Info, harm reduction, support, drop in, clinic. 10697 135A St. Surrey. Contact Monika 604-589-9004.

Positive Living Fraser Valley (Abbotsford) Hep C support, Drop-in centre #108-32883 S Fraser Way, M-F 10:30 AM-4:30PM. Info, support worker, rides to appointments in surrounding areas. Contact 604-854-1101 or plfvcentre@plfv.org

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

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

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

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

vandu@vandu.org www.vandu.org

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

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

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

YouthCO HIV and Hep C Society of BC. Call for appts or drop in M-F 10-6. 205-568 Seymour St,

Vancouver 604-688-1441, 1-855-YOUTHCO Stew art info@youthco.org, www.youthco.org

Whitehorse, Yukon-Blood Ties Four Directions Contact 867-633-2437 1-877-333-2437

MENNE CON

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, <u>www.aidsnorthbay.com</u>

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

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

Kitchener Area Support 3rd Wed. monthly, 7:30 PM, Ray of Hope Community Room, 659 King St. E 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. Port Colborne and St.

Catharines Clinics. Education, counseling, individual/group support, treatment, outreach, harm reduction. Contact 905-378-4647 ext 32554 HCCC@niagarahealth.on.ca www.niagarahealth.on.ca/ services/hepatitis-c-care

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

Owen Sound Info, support Contact Debby Minielly dminielly@publichealthgreybruce.on.ca

1-800-263-3456 Ext. 1257, 519-376-9420 Ext. 1257, www.publichealthgreybruce.on.ca

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

healthlinepeel@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 <u>www.liver.ca</u>

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

OUEBEC:

Ouebec City Region Contact Renée Daurio 418-836-2307 reneedaurio@hotmail.com

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

ATLANTIC PROVINCES

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767 Online Peer Support: <u>info@hepns.ca</u> www.hepns.ca

PRAIRIE PROVINCES:

Manitoba Hepatitis phone and email support and outreach. Contact Kirk at info@mbhepc.org. Direct line: 1-204-231-1437

Manitoba CLF each Thu 1:30-3. 375 York Avenue, Suite 210, Winnipeg, Con-tact Bianca 204-831-6231 bpengelly@liver.ca

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 <u>info@hepcbc.ca</u> by the 15th of the month. It's free!

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