

2017/2018 ACTIVITY REPORT: HepCBC Hepatitis C Education & Prevention Society

PURPOSES of HEPCBC (from our newly-amended Constitution):

- To provide education and support to people living with or recovering from viral hepatitis, and their families;
- To inform the public about actions they can take to eliminate viral hepatitis and its stigma;
- To monitor policies promoting elimination of viral hepatitis; and
- To provide a safe and collective forum for people with living experience of viral hepatitis to express their voices and share their experiences with the twin goals of advancing education about viral hepatitis and of promoting measures that will help de-stigmatize or eliminate it.

HOW HEPCBC WORKS:

- HepCBC is a non-profit organization, a grassroots patient group originally run by and for people infected and affected by hepatitis C. Sometimes we have paid support staff but currently we are operating on a volunteer-only basis.
- We advocate in a variety of forums for changes that will help eliminate viral hepatitis in Canada; we work closely with medical professionals, other patient groups, politicians, and individual patients.
- While the focus of HepCBC has always been on peer support and education, the particular geography and demographics of BC with its diverse cultural and ethno-linguistic groups make these activities challenging.
- In 2018, HepCBC consolidated our work with two populations newly-targeted in 2017: those living with hepatitis B, and the currently or formerly incarcerated. Unexpected opportunities have also come with health professionals.

OBJECTIVES OF OUR EDUCATION PROGRAMS:

- i. to **provide the most current, evidence-based and stigma-free knowledge and information** about hepatitis C and B, by patients and caregivers - for patients and caregivers, in both personal and community settings, to British Columbians irrespective of location, language, or lifestyle, in a variety of forums including face-to-face, toll-free phone, Skype, email, Social Media, webinar and website.
- ii. **to provide support to ensure** that anyone in British Columbia with hepatitis C or B has **access to appropriate treatment, as well as linkage to care** for ongoing monitoring, counselling and follow up, particularly for those with advanced disease.
- iii. to provide any **patient group support** (advocacy, testimony, peer navigation, publicity, etc.) **required by physicians** (both PCPs and specialists), **NPs**, other medical professionals, professional associations, and governmental agencies who are **interested in broadening current treatment opportunities** for viral hepatitis through any means including professional development and activation/expansion of existing telehealth-and related networks.
- iv. to **collaborate with** a variety of **aboriginal groups, BC NGOs and both public and private clinics** whose objectives, target populations, and methods overlap with our own in areas such as hepatitis B or C **outreach education, screening, linkage to care, and peer navigation**. Our major partners this past year have been Vancouver Infectious Diseases Centre, Positive Living BC (prison outreach staff), BCCfE (PerSVR), nurses and CHRs with First Nations Health Authority (Vancouver Island), Island Health nurses, and AIDS Vancouver Island.
- v. To **advocate** alone - or when possible in collaboration with NGOs and/or medical partners - to service clubs, professional groups, in letters to editor, among public servants, etc., **for policies that would help Canada fulfill its federal mandate to eliminate viral hepatitis by 2030** such as broader screening guidelines and development of a national (and/or provincial) viral hepatitis strategy. In particular we hope to advocate for policies which will result in **raising BC's % of treatment of residents with chronic hepatitis C from its current 1.5% per year to 6.3% or more per year**, and **raising BC's number of physicians and nurse-practitioner trained and enabled to treat hepatitis C** to reflect this increased response.
- vi. To **collaborate with experts in community-based research** to set up ways **to monitor success** of the above objectives, **and determine ways to improve** our methods in future. We have been offered help from CBR researchers from the Pacific AIDS Network as well as both Vancouver Island and provincial committees of SPOR/CSIH

tasked with patient-based research. We have not had an opportunity to take them up on these offers yet but hope to this coming year.

PRINCIPAL TARGET POPULATIONS:

PEOPLE LIVING WITH OR AFFECTED BY HEPATITIS C. This is the large group we have been consistently focused on, and *we always have included in this population “those who have HCV and do not yet know it.”* This is the population we’ve targeted in our testing and anti-stigma campaigns through the years, exemplified by our five bus ad campaigns spanning 20 years (recently suspended due to funding issues).

PEOPLE LIVING WITH OR AFFECTED BY HEPATITIS B: HepCBC has continued to offer our support and expertise, whenever appropriate, to BC’s **hepatitis B community**, trying to shine a light on it as it has been in the shadows too long. We are finding that adding hepatitis B to our presentations to immigrant groups makes it so much easier to get into conversations by comparing the two types of viral hepatitis. Also, the fact there is new CHB treatment is leading these communities into renewed interest in treating the untreated, as well as finding the undiagnosed and linking them to appropriate care. During the last few months, we have translated and published three new HBV pamphlets in English, Hindi, Punjabi, (all in both hard copy and online) and Chinese (online only at present). We have been pleased to note that over the last couple years, an awareness of the danger of HBV, and the value of both vaccine and using harm reduction in limiting HBV’s scope, is slowly spreading among members of the IVDU, sex worker, prisoner, and MSM communities (and those who treat and support them) with whom we’ve been in contact through our PRIDE, World AIDS Day and World Hepatitis Day information booths during 2016-2018.

PEOPLE LIVING IN REMOTE PARTS OF BC.: In March, three HepCBC volunteers (one nurse, the two others with lived experience – one of whom was First Nations) travelled throughout northern Vancouver Island with our new messages on screening and preventing hepatitis B as well as C. We were again happy to see how very much our message and pamphlets resonated with nurses, CHRs, and Band Councilors in small, seldom-visited remote communities. They respect our using bus and car travel, taking the time to see the country and talk face-to-face in their home communities, assessing their needs for information and services from a patient’s and nurse’s perspective. (see photos in 3 albums at https://www.facebook.com/pg/HepCBCFace/photos/?tab=album&album_id=10156549872454941 https://www.facebook.com/pg/HepCBCFace/photos/?tab=album&album_id=10156550030744941 and https://www.facebook.com/pg/HepCBCFace/photos/?tab=album&album_id=10156550090449941). We also were able to interface with BC’s various aboriginal communities by our visits to Nanaimo, Courtenay, Comox, and other middle-size towns in northern Vancouver Island, by exhibiting at an amazing Snaw-Naw-As Health Fair sponsored by the Tsow-Tun Le Lum Society, and through participating at events for urban marginalized populations sponsored by BC Centre for Excellence in HIV-AIDS, the Carnegie Centre, and other groups.

ETHNO-CULTURAL COMMUNITIES, PARTICULARLY THOSE REPRESENTING COUNTRIES WITH HIGH VIRAL HEPATITIS PREVALENCE, INCLUDING IMMIGRANTS, MIGRANTS AND REFUGEES: We provide HCV and HBV pamphlets in many languages (mostly from CATIE and World Hepatitis Alliance) to immigrant and refugee societies, religious group dinners, and health fairs. And besides the new HBV pamphlets noted above, HepCBC has translated our HCV pamphlet targeting those born 1945-1975 into both Hindi and Punjabi (for all 4 pamphlets see <http://hepcbc.ca/2018/08/19/hindi-and-punjabi-hbv-and-hcv-pamphlets-now-available/>) and are planning to translate it into Chinese and possibly for other local cultural communities. We discuss stigma, immigration and disclosure fears, risk factors and prevalence of HCV and HBV among each of their groups. We continue to collaborate with the Vancouver Infectious Disease Clinic (VIDC) on screening Asian immigrants by FibrosScan, and linking them to care. We look forward to working with larger immigrant societies, community groups and clinics on viral hepatitis in BC’s immigrant communities through 2019.

IVDU, SEX WORKERS and MEN-WHO-HAVE-SEX-WITH-MEN: This year we connected with IVDU and sex workers through events with the Lookout Society, Positive Living BC, and others; we also participated actively in four PRIDE events in both cities. Our emphasis on an older age cohort is particularly appreciated by the elder members of all of these group, some of whom no longer are engaging in risky behaviours, but are in need of linkage to care for monitoring and, in some cases, treatment.

CURRENTLY OR FORMERLY INCARCERATED: one former long-time inmate now serves on our Board and is Chair of a new Viral Hepatitis Prison Outreach Project. We set up a toll-free prison HCV prison line last year, which we continue to man. This year we published 1300 of our new 32-page “Hep B and Hep C Serious” colouring books (http://hepcbc.ca/wp-content/uploads/2018/07/ColouringBook_edition1b_Jul2018.pdf). So far, we’ve distributed 800 copies of the colouring books and hundreds of our prison pamphlets as well (http://hepcbc.ca/wp-content/uploads/2018/07/BC_Prisoner_HCV_Brochure_Jul2018.pdf), both in person at 5 federal prison facilities, and through the mail. We have received bulk orders for the books from halfway houses and mental health programs.

AGE COHORTS AT-RISK b. 1945 – 1957 (Seniors 61+) & 1958 – 1975 (Middle Aged Adults) have always been our main audiences, since we were started by people infected through the blood system. We continue to attend info booths at health and street fairs, and distribute pamphlets aimed at these two age groups. Now that we are adding hepatitis B, we expect to find even more in both of these age cohorts, particularly among immigrants and their middle-aged children. *Being born within this age-based (rather than a risky behaviour-based) cohort has enabled countless more people to ask for testing, and get treated, without fear of stigmatization.*

PUBLIC HEALTH and HEALTHCARE PROFESSIONALS. HepCBC has contributed over 30 different patient group submissions to both CADTH and BC PharmaCare since 2011, including our first hepatitis B submission recently (see <http://hepcbc.ca/patient-group-submissions-bc-pharmacare-cadth/>). This year we completely redesigned our Physician-Treaters list we have maintained since the late 1990s (see <http://hepcbc.ca/physician-treaters-british-columbia/>) and have been adding to it regularly as more physicians are coming forward to treat viral hepatitis. We actively promoted and contributed patient voices in both days of INHSU training for healthcare professionals, and participated actively with the World Hepatitis Day 2018 Vancouver webinar to promote PCPs treating viral hepatitis (<http://mediasite.phsa.ca/Mediasite/Play/6dd5d9d31e5a4b97a645503a35680ddf1d?catalog=8b83c4e8-dc95-40b0-8787-fc2a880b79b3>). We are hoping to continue this kind of work in the coming year.

HepCBC Events between Sept. 12, 2017 AGM and Nov. 3, 2018 AGM

- 36 events in which we actively participated or co-sponsored, had a booth, or provided a speaker
- 11--day Roadshow to numerous small, remote northern Vancouver Island communities (by 3 volunteers)
- 5 days of visits to federal prisons (by 4 volunteers)
- In addition, various HepCBC volunteers attended conferences sponsored by Action Hepatitis Canada, CAHN, CADTH, Hepatitis Symposium, etc.

2017		17-21	North Vancouver Island HepC HepB Roadshow (Various Locations throughout North Island)
September		April	
13	Volunteer Fair at St. Michael’s University School, Victoria	12	Snaw-Naw-As Health Fair, Lantzville
16	AIDS Walk to Thrive, Vancouver	17	CADTH Conference, Halifax (attended by President Sue Malloch)
17	SUCCESS Health Fair, Vancouver	21	Mini Health Fair at Water Polo Competition, Surrey
19	Alley Health Fair DTES, Vancouver	June	
21-23	Gastro Nurses (CSGNA) conference, Victoria	18-22	Federal Prison Health Fairs
23	55+ Show, Vancouver	22	PRIDE Eastside, Vancouver
October		July	
5	UVic Volunteer Fair, Victoria	8	PRIDE, Victoria
November		21	PRIDE, Sports Day, Vancouver
4 – 5	INHSU Trainings in Treating HCV in Marginalized Populations (Vancouver & Surrey)	27	WHD Webinar with BC, Expanding Screening & Treatment Access, Vancouver
15	Langara Nurses Flu Health Fair (info booth)	August	
December		5	PRIDE Sunset Beach, Vancouver
1	World AIDS Day, Carnegie Centre, Vancouver	16	WHD Lookout Society, Surrey
20	Juan de Fuca Library info booth, Colwood	September	
22	Nellie McClung Library info booth, Victoria	13	WHD Carnegie Centre, DTES, Vancouver
2018		16	SUCCESS Chinese Health Fair, Burnaby
February		18	Recovery Day, Victoria
2-3	WC Filmfest, Courtenay	25	Alley Health Fair, DTES, Vancouver
15	LGBTQ2, Victoria	October	
22	HeartYourParts, Victoria	2	Grand Rounds BCCDC HCV Treatment in Australian Prisons Webinar, Vancouver
27	Year of the Peer Conference, Burnaby	12	Info Table, Coast Mental Health Clubhouse
March		19	Hep Edu Can Liver Forum, Vancouver
7	Year of the Peer Conference, Chilliwack	30-31	Pacific AIDS Network Fall Conference, Kelowna
14	Year of the Peer Conference, Surrey		