



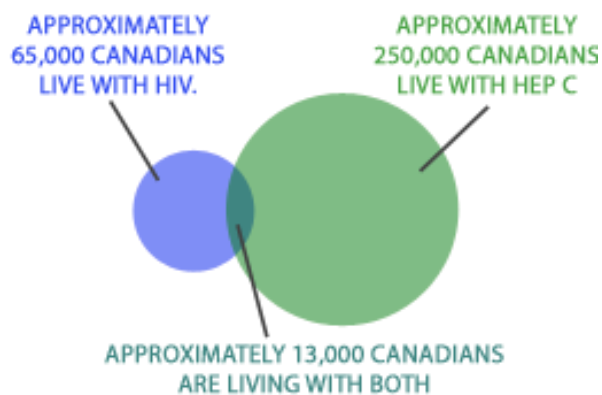
## Announcement: HepCBC boycotting Pacific AIDS Network (PAN)

October 23, 2016, Vancouver, BC

HepCBC Hepatitis C Education and Prevention Society (HepCBC) has decided to withdraw from further participation with, and support for, Pacific AIDS Network (PAN). HepCBC, in an October 13<sup>th</sup> letter to PAN, stated that PAN – **“due to its very nature, history, culture, and organizational structure – [cannot] speak for, nor advocate on behalf of, people with hepatitis C, particularly those in the majority who are mono-infected.”**

PAN is a strong believer in and proponent of the guiding principle of GIPA and MIPA: “Nothing about us without us.” As such, HIV+ individuals comprise 50% or more of PAN’s Board of Directors, and only organizations which “demonstrate significant and appropriate representation of people living with HIV/AIDS or who [are] **HIV/HCV co-infected**” and “provide significant HIV/AIDS and/or **HIV/HCV Co-infection** programming” are welcomed as full organizational (voting) members. Even associate organizations are required to offer HIV/AIDS and/or **HIV/HCV co-infection** programming. PAN truly does a great job of consulting with and speaking legitimately on behalf of the HIV+ and **HIV/HCV co-infected** populations.

The reality is that **95% of the 250,000+ hepatitis C-positive (HCV+) people in Canada are mono-infected**, while 13,000 are co-infected. While this number is 20% of HIV+ people, **it is only 5% of HCV+ people** as the chart below clearly shows:



(Graphic above thanks to [www.cocostudy.ca](http://www.cocostudy.ca))

Seeing PAN moving towards integrating hep C into its mandate and services, and that it was being given a significant share of the PHAC Western Region’s hep C-specific funding, HepCBC was pleased when invited by PAN to apply for membership. HepCBC’s application was not accepted by the PAN Board, due to its lack of services specifically targeting HIV/HCV co-infected people (HepCBC did not see a need to duplicate the work of its partner organizations, AVI or VIPWAS, which both offer excellent HIV/HCV programming). However HepCBC has continued to engage in PAN’s conferences and seminars over the years. HepCBC does not find PAN’s organizational structure or culture inherently problematic; rather, it objects to PAN’s tacit acceptance of five egregious policies having a direct, negative impact on HepCBC and people mono-infected with hepatitis C:

First, **the number of people affected by hepatitis C is over 4 times as great as the number of those living with HIV**, and the number of people dying from hepatitis C has been greater than those dying from HIV/AIDS since 2007. Yet, until just recently when the funds were amalgamated, **PHAC budgeted almost 8 times the amount of money for HIV/AIDS than for HCV** (\$23 million vs. \$3.5 million) annually. And now the actual allocation is hidden in its “integrated” model.

Hepatitis C is increasingly a far more significant burden on Canada's social, financial, and health systems than HIV/AIDS, yet programs for HCV+ people are rare unless they are part of an HIV organization that provides prevention and support to at-risk populations. Important HCV issues, HCV-related research questions, and patient needs specific to hepatitis C are de-emphasized, even ignored in **this system which inexplicably remains disproportionately weighted towards HIV and co-infection.**

Second, PAN's support of organizations responding to hepatitis C has been weighted more towards **decreasing the rate of new infections** at the provincial level (within incident populations such as IVDU and MSM) than towards **preventing morbidity and mortality** among British Columbians who have had the disease for an extended period (prevalent populations), but are no longer engaging in risky behaviours. In particular, PAN provides capacity, skills-building and networking opportunities to member organizations which provide services that contribute to reducing new infections. While both approaches are of great importance, this **system, disproportionately weighted toward the prevention model**, ignores the need to find the 44% of Canada's HCV+ population which remains undiagnosed ([www.phac-aspc.gc.ca/publicat/ccdr-rmtc/14vol40/dr-rm40-19/surveillance-b-eng.php](http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/14vol40/dr-rm40-19/surveillance-b-eng.php)), and the urgency of providing a cure to those who can benefit from it before it is too late.

Third, the financial resources of the Public Health Agency of Canada for fighting hepatitis C in Pacific Canada are primarily being distributed to PAN while the **organizations such as HepCBC and Pacific Hepatitis C Network (PHCN), which specialize in providing education, prevention, and support services to the 95% of HCV+ people who are mono-infected, are being denied PHAC funding.** Both organizations are scarcely staffed and both rely on volunteers, many of whom are aging, to provide services and supports now funded largely by pharmaceutical companies. When the governmental funding opportunities arise, the question of 'capacity' inevitably comes up. This question, in the face of starvation resources, is an insult. The question should be, "How do you do the amazing work you do with next to no funding, and how can we help?" Services for mono-infected people – both diagnosed and undiagnosed – are often spotty and inconsistent, reflecting how volunteer administrators of the few organizations working with this population scramble to find funding just to keep their websites online, their helplines open, and a handful of pamphlets published and distributed to a diverse and widespread population. Not all organizations responding to HCV need be cut out with the same cookie-cutter; the variety of populations we deal with see a value in our diversity which PHAC seems unwilling to recognize or support financially.

Fourth, **hepatitis C organizations fill several public and government messaging and advocacy gaps which PAN ignores.** HCV+ volunteers have taken on the issue of trying to find those who are HCV+ (but do not know it) by encouraging non-risk-based (or 'cohort') testing. By publicizing the diverse variety of risk factors, we send the strong anti-stigma message that anyone can have hepatitis C. Our volunteers also educate public servants about hepatitis C-related policy issues, and are often called upon to consult and share our lived experience on a variety of "HCV-lived experience (or patient) panels" at forums organized by AIDS service organizations (ASO's) such as PAN. Of particular value to the federal and provincial governments, hepatitis C-specific organizations research new treatments (see PHCN's <http://www.hepctip.ca>), review the work of PMPRB and BCCfE, and submit "patient group reviews" of all the new hepatitis C medications coming out. For an example of all of the reviews HepCBC has submitted since 2011 (by volunteer labour in most cases) see <http://hepcbc.ca/patient-group-submissions-bc-pharmacare-cadth/>. Of particular note is that **the majority of organizations which regularly submit HCV (and HIV) pharmaceutical reviews to CADTH have now been defunded by PHAC. Some will close and some will be forced to reassess their commitment to the CADTH project.**

And finally, hepatitis C organizations have been **marginalized** by PHAC, **patronized** as "unprofessional" but **denied funding** with which to hire professionals, and **pushed into inappropriate alliances** in the name of integration. Their members have been **paraded out as token HCV patients** in panels, workshops, and advisory boards for organizations funded by PHAC, while the needs of the larger population of HCV+ people are **discounted or ignored.** Aging HCV+ volunteers' **decades of unpaid work is taken for granted and they are offered no funds for support services.** To quietly demur while an organization – in which we are not even allowed to sit as members – accepts the large part of the funding available for hepatitis C-specific work and presumes to speak on our behalf is simply the final straw.

HepCBC has stepped away from the PAN umbrella to speak freely about this inequitable situation. Hopefully those who back the GIPA/MIPA model for HIV will see the irony here and will understand these HCV organizations' GIPA/MIPA right to **control their agendas and messaging to reflect the actual experiences of the majority of HCV+ people living with and dying from this disease, instead of acquiescing while this power and voice is given to an organization in which they have no stake or say.** As our friend Patricia Bacon (PhD), Chair of Action Hepatitis Canada, put it, "Always the little sister at the back of the bus, organizations working in Hepatitis C were basically thrown under the bus in this latest round of funding decisions by PHAC." HepCBC holds no animosity towards PAN, which was pushed into this role by PHAC and BC's Provincial Health Services Authority. HepCBC looks forward to working with PAN, members of PAN, and perhaps even PHAC, on future projects when our purposes and roles come into much closer alignment than they are at present, sharing the common goal of eliminating hepatitis C from the face of the earth, starting in British Columbia.

**HepCBC invites individuals and groups to support these GIPA/MIPA-inspired principles for people with HCV:**

- Greater and meaningful involvement of people with HCV at all levels of civil society, community organizations, and government (volunteers, staff, spokespeople, and decision-makers)
- The principle that people with HCV be actively and closely involved in the design and delivery of services we need: **"Nothing about us without us!"**
- The involvement of people with HCV at every level of decision-making and specifically serving on the boards of directors of HCV service-provider organizations
- Stable and proportionate funding for HCV organizations and groups which reflects the **burden of the disease.** When appropriate, include people who are mono-infected with HCV (95% of all people with HCV) in funded programs for HIV+/HCV+ people.
- Broader testing of baby-boomers and other groups that are most affected by HCV based on epi-data, to locate people who have HCV but do not know it so that they may be offered life-saving treatment and support.

The HCV Manifesto ([www.hepcbc.ca/hcv-manifesto/](http://www.hepcbc.ca/hcv-manifesto/)), in which the above principles are included, was a joint project (2014) of HepCBC, Canadian Treatment Action Council (CTAC) and Centre Associatif Polyvalent d'Aide Hépatite C (CAPAHC). The document has been signed by

AIDS Network Kootenay Outreach and Support Society ([ANKORS](#))  
AIDS Vancouver Island ([AVI](#))  
ASK Wellness Society ([ASK](#))  
[BLOOM CLINIC](#) of the Bramalea Community Health Centre in the Region of Peel, Ontario  
Canadian AIDS Society ([CAS](#))  
Canadian AIDS Treatment Information Exchange ([CATIE](#))  
Canadian Hemophilia Society | Société canadienne de l'hémophilie ([CHS](#))  
Canadian HIV/AIDS Legal Network ([AIDSLAW](#))  
Canadian Treatment Action Council ([CTAC](#))  
Centre Associatif Polyvalent d'Aide Hépatite C ([CAPAHC](#))  
[HEPCBC](#) Hepatitis C Education and Prevention Society  
Prisoners with HIV/AIDS Support Action Network ([PASAN](#))  
Positive Living Fraser Valley Society ([PLFV](#))  
Vancouver Island Persons with AIDS Society ([VIPWAS](#))