



ACTION HEPATITIS CANADA

AHC

ACTION HÉPATITES CANADA

Impact Report 2018

WHO WE ARE

Action Hepatitis Canada (AHC) is a pan-Canadian coalition working toward the elimination of viral hepatitis.

Our work engages government, policy makers, and civil society across Canada to promote hepatitis B and C prevention, improve access to care and treatment, increase knowledge and innovation, create public health awareness, build health-professional capacity, and support community-based groups and initiatives.

OUR VALUES



- Health Equity
- Commitment to Collective Community Action
- Meaningful Engagement of People Living with Viral Hepatitis
- Harm Reduction
- Evidence-Based Policy
- Rights-Based Policy

OUR HISTORY

In the early 2000s, Canadian organizations involved in addressing viral hepatitis came together to form the first hepatitis network.

This first hepatitis network focused on a call to governments for the development of hepatitis strategies, and introduced the document, “Responding to the Epidemic: Recommendations for a Canadian Hepatitis C Strategy”.

After a short gap of lessened activity, in 2010, organizations came together once again to form the “Canadian Coalition of Organizations Responding to Hepatitis B and C,” which in 2013 became Action Hepatitis Canada.



THE OPPORTUNITY

The advent of highly effective curative HCV treatments in 2014 brought enormous hope and the opportunity to eliminate this chronic virus from our population, prevent needless suffering, and save lives. In Canada there are an estimated 250,000 people living with chronic hepatitis C.

THE OBSTACLES

Unfortunately, these new curative HCV therapies were introduced at a price that was deemed unaffordable for the Canadian healthcare system, and there have been significant policy barriers to overcome related to testing guidelines, treatment access, pricing, and national leadership on an HCV Elimination Strategy.

In 2015, Action Hepatitis Canada hired a policy researcher/writer to help us identify the key policy barriers and develop four asks to guide our advocacy work:

FOUR ASKS (2015-2018)



AHC calls for all adults born between 1945-1975 to be offered a one-time blood test for the hepatitis C virus.



AHC calls for direct-acting antiviral (DAA) medications to be accessible to all Canadians who are living with chronic hepatitis C, regardless of their stage of disease progression.



AHC calls on the Government of Canada to review and update legislative and regulatory frameworks involved in the establishment of pharmaceutical pricing in Canada. AHC is also calling for a re-evaluation of the prices that have been established for curative hepatitis C medicines that came to market beginning in 2014.



AHC calls on the Government of Canada to develop a national strategy towards the elimination of hepatitis C in Canada.

ADVOCACY ON BEHALF OF OUR MEMBERSHIP

- Many meetings in Ottawa: Public Health Agency of Canada (PHAC), MPs, Ministers, Policy Advisors
- Hep C Education Session for MPs on Parliament Hill
- Hep C Education Breakfast at Queen's Park in Toronto for Ontario MPPs
- Letters to Health Ministers, PHAC, pCPA
- Participation in consultations through PMPRB, CADTH
- Submission to Canadian Task Force on Preventative Health on testing guidelines
- Pre-budget submissions to federal government, Ontario government
- Ontario 2018 election candidate questionnaire
- World Hepatitis Day press releases
- Presentations and representation at national and international conferences
- Involvement in the first NOhep Village
- Partners in the CanHepC Elimination Blueprint Project
- Semi-annual face-to-face Steering Committee meetings to set strategic priorities and work plans.



Gaps in the road to the ELIMINATION of hepatitis C

Action Hepatitis Canada (AHC) is a national coalition of organizations responding to hepatitis B and C. Currently our work engages government, policy makers and civil society, with the goal of eliminating hepatitis C in Canada. To guide us in this work, we have identified key policy gaps that will need to be addressed to achieve this goal.

Diagnosis of Chronic Hep C

A lack of access to comprehensive HEPATITIS C testing is a barrier to diagnosis. 1/2 of Canadians with chronic hepatitis C are not aware they have the virus.

Treatment Eligibility

2014
2015
2016
2017

National Action Plan

2014-16
2017

learn more at www.actionhepatitiscanada.ca

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ACTION HEPATITIS CANADA

The AHC contacted the Ontario Provincial Election candidates and all 4 main party senior policy advisors, and asked them 8 questions about hepatitis C.

We received responses from 8 candidates:

- NDP Candidates
- Liberal Candidates
- PC Candidate

Elections Ontario
To find out how to vote, visit www.elections.on.ca

Question #1 Over the curative treatments available and the high costs of ongoing hepatitis C treatment and care, an investment in diagnosis, treatment, and care for all Ontarians living with chronic hepatitis C is both fiscally and morally sound. Do you agree with this statement?

All candidates responded that yes, they agreed with this statement.

Question #2 There is now a cure for hepatitis C, and as of February 2018 it is available to everyone in Ontario diagnosed with chronic hepatitis C who hasn't already been treated. One remaining barrier is that, while treatment eligibility restrictions have been lifted, there is still a bottleneck caused by the limited human resources available to prescribe and care for all eligible persons. Would you be supportive of investments in the human resources needed to deliver hepatitis C treatment and care, in order to overcome this barrier?

All candidates responded that they would either "support" or "strongly support" increased funding (SpM 5000 between the two options).

Question #3 Give some background about the value of age cohort based testing and about if the candidate would support a one-time, voluntary, hepatitis C screening for Ontarians born between 1945-1975.

All candidates responded that they would either "support" or "strongly support" the request.

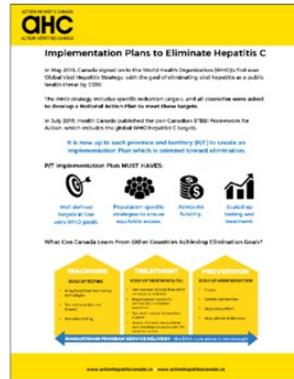
Question #4 Give some background about the federal government's AHC commitment, and about the STBBI Framework for Action, then asked, Do you support Ontario creating a plan with targets to eliminate hepatitis C as a public health threat by 2030?

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ADVOCACY THROUGH OUR MEMBERSHIP

Speak Up!

Got 60 seconds?
Join our 1-click letter writing campaign.

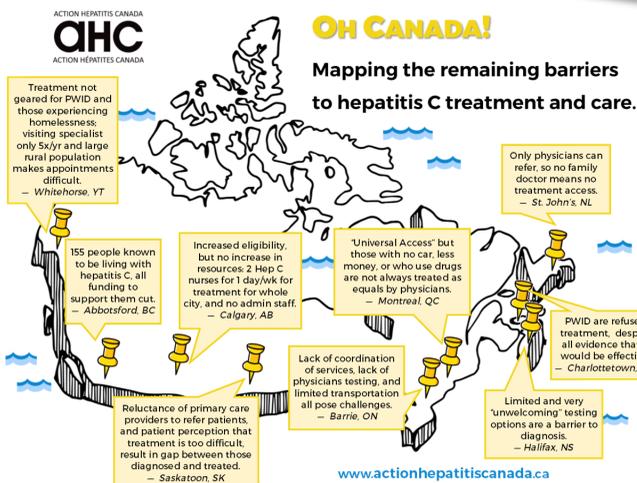


CLICK HERE to sign the Parliamentary Petition:
A National Strategy for Hepatitis C
We're 1/2 way there - sign on today! It's easy!



- Regional capacity-building meetings: Ontario, Atlantic Region, BC, Prairies
- Parliamentary petition for a National Hep C Strategy
- Postcard campaign targeting MPs
- Speak Up one-click letter writing campaign
- 1-pager briefs on key policy issues to prepare members to speak to local elected officials
- Social media toolkits, including videos
- Slide decks and assistance for meetings with local elected officials
- Press release and letter templates
- "Mapping the remaining barriers" project

“Being a member of Action Hepatitis Canada gives me instant credibility with my provincial government and local health authority. As a member I am invited into critical discussions regarding our response to hepatitis C.”



www.actionhepatitiscanada.ca

- AHC Steering Committee Member

WINS TO DATE

1. The Canadian government signed on to the World Health Organization (WHO) goals of eliminating hepatitis C as a public health threat by 2030, and released the pan-Canadian STBBI Framework for Action in mid-2018. AHC is working with CanHepC to create a complementary Hep C Elimination Blueprint for the provinces and territories.
2. One-time testing was not included in the updated screening guidelines released in 2017, leading to the guidelines being dismissed by many liver experts. However, the age-cohort testing recommendation was included in the 2018 treatments guidelines published in the Canadian Medical Association Journal (CMAJ) by the Canadian Association for the Study of the Liver (CASL).
3. The price of the hepatitis C cure in Canada went down significantly in 2017 due to pCPA negotiations. The PMPRB is also making significant changes to how excessive pricing is managed.
4. Fibrosis restrictions have been removed in all provinces and territories.

MEMBERSHIP ENGAGEMENT

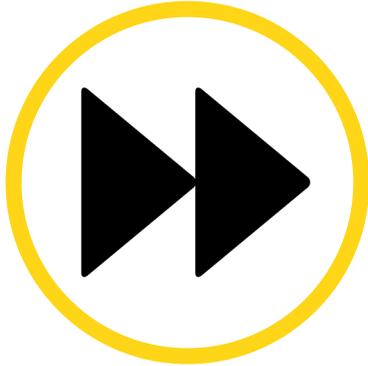


In the fall of 2018, AHC completed an Impact Assessment and Strategic Planning process where the strategies and accomplishments of the last four years were reviewed. As part of this process, the membership was surveyed to determine where they were receiving the most value from the AHC, how they liked to be engaged, what types of campaigns they were most likely to participate in, and what policy gaps they continued to face in their work. This data was very useful and fed into our Steering Committee's strategic planning session.

We learned from this process that while many of our members like to participate in advocacy campaigns, others preferred level of engagement is to receive updates on the advocacy work we are doing on their behalf.

Our membership continues to be one of our greatest strengths. Some members have signalled that they are ready and willing to engage at a deeper level, and we will continue to empower these members with tools they need to do their own advocacy at the provincial level, while respecting that not all members wish to engage in this way.

LEARNINGS MOVING FORWARD



Two crucial learnings moving forward:

- Through the member surveys, we learned that we need to be more aware of staff turnover and organizational memory when it comes to our broader membership's involvement with AHC, clearly communicating more often the role(s) our members can play in our collective work.
- We have received feedback that participation in our Speak UP letter writing campaign to provincial/territorial Health Ministers was lower than anticipated because the template letter wasn't a good fit in each province and territory. When writing to the provinces and territories, our communications are going to have to be more tailored to each one specifically, which will likely require increased input from our members working in that region.

NEXT STEPS

During our Strategic Planning Session, a renewed mission was established and priorities identified:

- AHC is going to be stepping more fully into a role of providing **community accountability** on our government's commitments to the WHO target of eliminating viral hepatitis as a public health threat by 2030.
- An important tool in this work will be the **Elimination Blueprint** on which we have been working on with CanHepC. We will be taking a leadership role in the community endorsement and dissemination of that document in 2019.
- To allow us to do this work most effectively, we are **restructuring our governance model** to better reflect our priorities and the strengths of our Steering Committee members.
- We will be leveraging Federal/Provincial/Territorial elections, and releasing a **2020 Report** aligned with the WHO 2020 elimination targets, to monitor our progress and hold our governments accountable.



MEMBERSHIP

Steering Committee

AIDS Committee of Newfoundland and Labrador
AIDS Saskatoon
Blood Ties Four Directions Centre
Canadian Association of Hepatology Nurses (CAHN)
Canadian HIV/AIDS Legal Network
Canadian Treatment Action Council (CTAC)
CATIE
Centre associatif polyvalent d'aide hépatite C (CAPAHC)
Gilbert Centre (ON)
Hep C BC
Peers Alliance (formerly AIDS PEI Community Support Group)
Positive Living Fraser Valley Society

AIDS Coalition of Nova Scotia (ACNS)
AIDS Moncton
AIDS Saint John
AIDS Vancouver Island
All Nations Hope Network (Saskatchewan)
Ally Centre of Cape Breton
ANKORS (BC)
Atlantic Interdisciplinary Research Network
for Social and Behavioural Issues in Hepatitis
C and HIV/AIDS (AIRN)
Calgary Liver Unit, Viral Hepatitis Clinic
Canadian Aboriginal AIDS Network (CAAN)
Canadian AIDS Society
Canadian Association of Nurses in HIV/AIDS
Care
Canadian Liver Foundation
Canadian Society for International Health
(CSIH)
Carefirst Family Health Team
Central Toronto Community Health Centre
(Queen West CHC and Shout)
Coopérative de solidarité SABSA
CUPS Clinic (Calgary)
Dopamine (Montreal)
Elevate NWO
Halifax Sexual Health Centre
Healing Our Nations
Hépatites Ressources
Hep'd Up (PEI Native Council)
Hep NS
Lookout Society (BC)
Lower Mainland Purpose Society
Mainline Needle Exchange (Halifax, NS)
Manitoba Hepatitis C Support Community Inc.
Northern Healthy Connections Society
Nova Scotia Hemophilia Society
Pacific Hepatitis C Network (PHCN)
Pender Hep C Support Society
Prisoner's HIV/AIDS Support Action Network (PASAN)
Programme National de Mentorat sur le VIH-Sida et
Hépatites Virales, CHUM UHRESS Saint-Luc
Realize
Sanguen Health Centre
Sandy Hill Community Health Centre – Oasis Program
Saskatchewan Infectious Disease Care Network
Sexual Health Centre Lunenburg County,
Sheet Harbour Sexual Health Centre
Sidaction Mauricie
St. Stephen's Community House, Corner Drop-In
Street Health Centre Kingston
Toronto Community Hep C Program
– South Riverdale CHC
– Regent Park CHC
– Sherbourne CHC
Vancouver Island Persons Living with HIV/AIDS Society
(VPWAS)