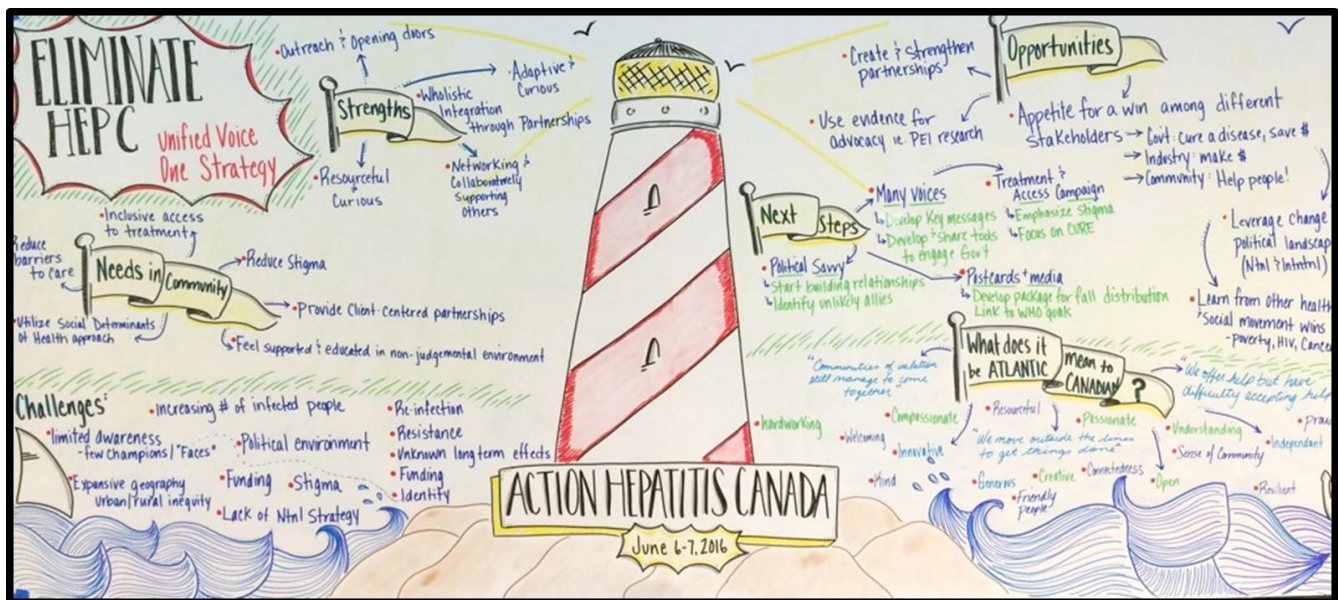


AHC Atlantic Members Meeting Dalhousie University, Halifax, NS June 6-7, 2016

This was the second face-to-face members meeting of the AHC, the first in Atlantic Canada. All ten AHC Steering Committee members were in attendance, and 14 of our 18 Atlantic Member groups, along with other local allies and those with lived experience.

Meeting Objectives:

- To ignite a unified hepatitis C response among AHC Atlantic region membership;
- To identify opportunities for potential collaboration and strategic action in hepatitis C advocacy moving forward;
- To facilitate networking among like-minded advocates.



Executive Summary

The Atlantic members of AHC were clear that our work should be focused on the elimination of hepatitis C. We discussed the challenges and advantages of working with the hepatitis community in the Atlantic region specifically, outlined goals, and possible tactics and messaging. In the end we identified a few key ways that we could collaborate on advocacy efforts and also strengthen the advocacy capacity of the individual members:

Political Savvy: build capacity for our members to engage with their federal and provincial politicians, offering templates and toolkits.

Many voices: although the Hep C community is diverse, the AHC can work to unify those many voices around a clear ask for next steps. One ask that we can agree on is to follow through with their commitment with WHO to eliminate viral hepatitis by 2030 – the federal government needs a strategy to support the P/Ts in meeting this target.

Treatment and access campaign: several suggestions came out of ways that we could capture the interest and attention of our political targets. There was agreement that we need to find a way to make the need visual rather than vague, and humanize the need.

Postcards and media: A plan was developed take the ideas from the Many Voices group and the Treatment and Access Campaign group and combining them into a postcard campaign for Fall 2016.

Meeting Notes

• Ignite a unified Hep C Response
 • Identify opportunities for potential Opportunities
 • Facilitate Networking

What does Hepatitis C look like in Atlantic Canada?

- It is a problem
- #'s are rising... under reported?
- Systematic treatment is needed

Gerri Hirsch

What is RECAP Model?

- Open doors!
- Don't forget about NB
- Model set in innovative primary care

Lisa Frechette

What are the research & Advocacy opportunities?

- Eliminate Hepatitis C!
- Be present: Be a voice!
- Communicate & Advocate together
- Infectious disease issue, not liver issue

Lisa Barrett

HOT TOPICS

- Cure available but access to it is not equitable
- Canada has the potential to lead the world in curing Hepatitis C

Adam Cook

• Age Cohort Screening
 • Treatment Eligibility
 • Pricing

AGENDA: National Hepatitis C Strategy

LIST OF PARTICIPANTS

Jaime Smith	Facilitator
Kim Martin	Graphic Recorder
Jennifer van Gennip	AHC Admin
Adam Cook**	CTAC
Carla Densmore*	HepNS
Geri Hirsch	Canadian Assoc. of Hepatology Nurses (CAHN)
Susan Kirkland	AIRN
Caroline Ploem	AIRN
Shannon Pringle	AIDS Coalition of NS
Debbie Warren	AIDS Moncton
Luc Malenfant	AIDS NB
Julie Dingwell	AIDS Saint John
Christine Porter	Ally Centre Cape Breton
Janet MacPhee	Northern AIDS Connection Society
Julie Thomas	Healing Our Nations, NS
Vania MacMillan	Pictou County Sexual Health Centre
Natasha Tousenard	Mainline Needle Exchange
Cybelle Rieber	PEI AIDS Coalition
Dawne Knockwood	Hep'd Up on Life, PEI
Lisa Frechette	RECAP Clinic for Hep C and Harm Reduction Management
Dr. Lisa Barrett	Clinician investigator at Dalhousie University
Sharon Oldford	Research Scientist
Karen Pitts	HepNS
Alex MacDonald	HepNS
Betty Ann Hines	Hep C Community Member
Katie Hines	Hep C Community Member
Jeanette Rogers	Hep C Community Member
Melisa Dickie**	CATIE (ON)
Ed Bennet*	CAAN (ON)
Daryl Luster**	PHCN (BC)
Lesley Gallagher*	CAHN (BC, SK)
Laurence Mersilian**	CAPAHC (QC)
Satori Soden*	Hep C BC (BC)
Patricia Bacon**	Bloodties (Yukon) (AHC Chair)
Sandra Chu*	Canadian HIV/AIDS Legal Network (ON)
Claire Checkland	AHC Policy Analyst (ON)

*AHC Steering Committee Member

**AHC Exec Member

There were presentations to:

- Give an introduction to the AHC and the main issues our work is focusing around currently (Jennifer and Claire)
- Set the scene of hepatitis in Atlantic Canada specifically (Geri Hirsch)
- Share about the RECAP model for HCV treatment/harm reduction in NB (Lisa Frechette)
- Share research endeavors and opportunities for advocacy that tie in with that work (Dr. Lisa Barrett)
- Discuss some of the “Hot Topics” in hepatitis C work today (Adam Cook)

The second day opened with an invitation to describe what being Atlantic Canadian means to you. Answers included:

- Hard working
- Welcoming
- Innovative
- Kind
- Compassionate
- Resourceful
- Passionate
- Friendly
- Creative
- Generous
- Open
- Understanding
- Resilient
- Humorous
- Sense of community
- Independent
- Proud
- “We offer help but have difficulty accepting help”
- “We move outside the lines to get things done”
- “Communities in isolation still manage to come together”

Through small group discussions about the context and challenges we face in our work with the hepatitis C community, and the needs that our work is addressing, all groups came to the same vision/common purpose that our organizations share for our hepatitis C work: **the elimination of hepatitis C.**

One of the messages that was well-noted was that a “National Strategy” doesn’t always adequately consider the provinces and territories on the periphery of our country, the 3 coasts, and that we need to carefully consider any messaging around requests for a National Strategy; if we do not advocate for a flexible strategy that allows each province and territory to address our own unique challenges and opportunities, we may be given a one-size-fits-all solution that does not meet our needs.

In discussing how we move forward, together, four topics came forward to explore further: How to develop better **Political Savvy** for engaging decision makers, How to unify **Many Voices** around one message, How to develop an effective **Treatment and Access Campaign**, and the

possibility of a campaign that uses **Postcards and Media**. Breakout groups tackled these topics separately.

1. Building Political Savvy

Important to remember that you belong in Provincial House. You have a right to be there, although it can be intimidating.

It is a good idea to meet parliamentarians in their own environment.

When hosting a legislative breakfast/luncheon, etc.: Some lessons learned.

- Consider a pharmacy sponsor.
- Bring in voice of lived experience.
- Goal of raising awareness and have a SIMPLE ASK, such as for MPPs/MLAs to put pressure on the Minister.
- You have unlikely allies in the shadow cabinet and critics.
- Private Members Bills – many MPPs/MLAs are willing and it raises awareness. You can also go back to politicians and ask them why they did not vote for the bill when it fails.
- Marching on the street with signs is not always effective, depends on the issue.
- Hepatitis C is a huge issue with low political awareness.

Further Insights:

- Building relationships is much better than confrontation.
- Engagement is key with bureaucrats and MPPs/MLAs – lots of education needed as there are a lot of myths and stigma.
- Stay in touch, letting them know about progress. We are the harbinger of good news: There is a cure!
- Activism on World Hepatitis Day is difficult in July.
- We need a national plan to negotiate price with pharma.
- When looking for funding, work with multiple pharmas and do not let them attend the event. They will fund things that PHAC won't. What you do with the money is more important than where you got the money.

What AHC can do:

- Provide templates, and a good set draft to ask a representative to speak on hepatitis C – kept to 60 seconds.

2. Many Voices

Many voices, 1 strategy? Maybe Many voices, 1 goal, with asking for a National strategy to support the P/Ts in developing action plans to realize our WHO goals and commitments.

We need mechanisms for many voices to get together, and to create consensus out of the diverse hep C community. Many voices coming from many perspectives, but can we share a message on what to do next?

We want:

- Hold gov't's accountable to the WHO goals.
- Multisectoral strategies.
- Recognition of the different voices.

Next Steps:

- Ensure we have a unified voice, build consensus on key issues while respecting the many voices.
- Key messages that service providers can circulate (advocacy tools and updates on what everyone else is doing).

3. Treatment and Access Campaign

Some suggestions and ideas:

- In a campaign – don't name the disease, creatively capture interest because people seem to tune out HCV.
- Are there other government strategies we can look to? Australia?
- Consider the MMIW "red dresses" -> something visual
- Human rights angle, unethical.
- Need to emphasize wraparound care.
- Consider USA Gilead commercials – we need a human face.
- Can AHC develop a Nat'l Hep C Strategy? Could give more negotiating power.
- Cancer prevention angle
- Organ transplant angle
- Emphasis on CURE.
- Celebrity champions?
- Political champions?
- Consider the "1 in 12" campaign
- Health Equity issue
- Emphasize stigma
- Treatment access -> need education for health care providers
- "Getting to Zero"

4. Use of Postcard and Media

AHC to develop a Postcard Campaign: Postcards distributed for community members to submit to their MP. We want to hold the Federal Government accountable to what they signed on to (WHO goals).

Mailing to House of Commons = one address, no postage required. People can just fill in their name and MP's name and drop in the mailbox.

Call to Action for members: get this postcard out and have as many people as possible mailing them in.

Call to Action on the postcard for MP: tell the Health Minister that you support a National Strategy designed to support the P/Ts in doing what the Government of Canada has committed to do: elimination of viral hepatitis by 2030.

Consider a digital version as well.

Follow up: meeting requests? Phone calls? If receptive, ask for them to read a statement?

Timing: Early Fall 2016