

Community Leadership on the Path to HCV Elimination in New York State

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HCV Community Work to Date

Feb 2013: NYS advocates begin organizing annual HCV Advocacy Days coordinated by VOCAL NY.

Jan 2014: HCV Testing Law Implemented.

Fall 2014: VOCAL NY and ACT UP/NY picket AASLD/EASL Symposium in response to restrictive treatment guidelines, calling out Gilead executives in a public session.

2015: HCV Elimination discussion paper released

2015-2016: Established a statewide coalition, and raised HCV awareness across the state via regional town halls to bring attention to the state of the epidemic and the unique issues in each region of NY.

HCV Community Work to Date

2016: Coalition wins Drug Utilization Review Board removal of disease prognosis and sobriety restrictions for HCV treatments under Medicaid fee-for-service plans. Managed Care plans and private insurers follow.

2016: Expanded AIDS Drug Assistance Program coverage to include HCV treatment for people living with HIV.

2016-2017: Summit process engaged 94 stakeholders to draft 34 recommendations and Consensus Statement on HCV Elimination, signed by over 147 organizations, including county health departments. **HCV Elimination Campaign** launched, demanding State and pharma negotiate pricing for elimination.

The Inspiration for Elimination

New York's bold plan to end the AIDS epidemic by 2020 offered insights and strategies that converged with efforts to eliminate HCV. Modeled after the End HIV/AIDS work, advocates developed an HCV discussion paper proposing that New York State commit to developing and implementing a parallel strategy to end its HCV epidemic.

The timing of the paper's release nicely coincided with the Governor's efforts to establish an End HIV/AIDS task force, and sparked discussion between community and DOH/DOHMH on HCV elimination.

Advocates Proposed 6 Strategies to End New York's HCV Epidemic

1. Surveillance & Testing
2. Prevention
3. Access to Care & Treatment
4. Structural Determinants of HCV Related Health
5. Targeted Public Investment
6. Political Leadership

NYS HCV Elimination Summit

Between May 2016 and February 2017, a broad committee of 94 NYS stakeholders—state and local government representatives; epidemiologists; physicians; harm reduction and social service providers; and community advocates—worked together to build consensus on the opportunity for statewide HCV elimination.

Five working groups were established:

- Prevention
- Testing & Linkage
- Care & Treatment Access
- Data, Surveillance & Metrics
- Social Determinants of Health



Consensus Statement on HCV Elimination

New York State (NYS) faces a growing hepatitis C epidemic with a rising death toll. Given the availability of new highly effective, well-tolerated curative treatments, we can no longer settle for a low cure rate that perpetuates the high fiscal and human costs of inaction. The committee that organized the NYS Hepatitis C Elimination Summit, along with the other providers, community-based organizations and individuals living with and affected by hepatitis C that sign this consensus statement, call on Governor Andrew Cuomo, the NYS Legislature, and industry partners to make a joint commitment to hepatitis C elimination, and for appointment of a formal NYS Hepatitis C Elimination Task Force.



Five Community Pillars of HCV Elimination

1. Enhance HCV prevention, testing and linkage to care services for people who inject drugs, people who are incarcerated, men who have sex with men, and other populations disproportionately impacted by HCV infection.
2. Expand HCV screening and testing to identify people living with HCV who are unaware of their status and link them to care.
3. Provide access to clinically appropriate medical care and affordable HCV treatment without restrictions, and ensure the availability of necessary supportive services for all New Yorkers living with HCV infection.
4. Enhance NYS HCV surveillance, set and track HCV elimination targets and make this information available to the public.
5. Commit NYS government and elected officials, public health professionals, HCV experts, and industry partners to leadership and ownership of the NYS Plan to Eliminate HCV alongside community members living with and affected by HCV.

Regional HCV Listening Session Key Findings

- A lack of syringe exchange programs, especially in rural counties
- A need for expansion of peer/outreach services
- A need for mobile units, especially in rural areas
- A need for education on the severity of HCV, and info on new, non-interferon based treatments
- Issues with stigma from healthcare providers and community members
- A lack of treatment providers- hard to get in and easy to get kicked out of treatment due to drug use and/or behavioral issues.
- Issues experiencing stigma at Expanded Syringe Access Programs (ESAP) pharmacies
 - Having very few syringe disposal points
 - Virtually no coalition building between agencies and networks doing local HCV work/services
 - Very little community understanding of what harm reduction is
 - Extremely limited transportation (getting to SEPs and screening/treatment appointments)



Recent HCV Community Victories!

- ✓ March 16, 2018, Governor Cuomo made a public commitment to eliminating hepatitis C in NYS
- ✓ Final NYS FY 19 Budget includes \$5 million in new funding for hepatitis C (\$10 million over 2 years)
- ✓ July 2018, NYS Medicaid prescriber restrictions removed
- ✓ October 11, 2018, Governor Cuomo announced the formation of the Hepatitis C Elimination Task Force



NYS Hepatitis C Elimination Campaign Steering Committee

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Annette Gaudino – Treatment Action Group (TAG)

Reed Vreeland – Housing Works

Ronni Marks – HCMSG

Mike Selick – Harm Reduction Coalition