Building Political Partners Toward HCV Elimination

National Viral Hepatitis Roundtable (NVHR) Presentation

July 11, 2018
National Viral Hepatitis Roundtable (NVHR)

NVHR is a national coalition working together to eliminate hepatitis B and C in the United States of about 500 members.

- **Vision:** a healthier world without hepatitis B and C in the U.S.
- **Our coalition includes:**
  - community-based, advocacy, and grassroots groups
  - healthcare providers
  - health departments
  - other government and industry partners
National Viral Hepatitis Roundtable (NVHR)

Values: NVHR’s work will be guided and informed by our beliefs and commitment to:

– **Participation** – we value the lived experience of people affected by hepatitis B and hepatitis C and provide meaningful opportunities for their involvement in education and advocacy efforts

– **Inclusiveness** – we are strong together and we respect people, value diversity, and are committed to fighting for racial and social justice

– **Intersectionality** – we understand the relationships between our work and various social structures and inequities and commit to addressing overlapping and interdependent systems of discrimination and disadvantage

– **Health equity** – we believe everyone affected by hepatitis B and hepatitis C deserves access to health care services, including nonjudgmental harm reduction services

– **Stigma elimination** - we believe in ending prejudice and discrimination against people affected by hepatitis B and hepatitis C and the communities disproportionately impacted by these viruses
HEPATITIS C: THE STATE OF MEDICAID ACCESS PROJECT
Hepatitis C: The State of Medicaid Access - Overview

• One of NVHR’s top priorities is ensuring that public and private payers end all restrictions to treatment access.
• This project examined Medicaid reimbursement criteria for available direct-acting antivirals (DAAs) for all 50 states, in addition to the District of Columbia and Puerto Rico.
  – Focuses on liver damage, sobriety and prescriber restrictions.
  – Highlights successes in access expansion as well as ongoing challenges since 2014.
  – Providing a first-time national assessment of Medicaid Managed Care Organization (MCO) coverage.
Hepatitis C: The State of Medicaid Access - Findings

• Access to HCV treatment has improved, primarily in reduction/elimination of liver damage (fibrosis) restrictions.
• Access restrictions related to sobriety and prescriber limitations have decreased to a far lesser extent.
• While there are some MCOs with low levels of restrictions, many follow their states’ fee-for-service (FFS) Medicaid restrictions, and others impose more restrictions.
• Transparency about criteria has increased dramatically from 2014 to 2018.
NVHR Advocacy Engagement

• Patient and Community Voices in the Media
  – Advocates can share their own stories and experiences and advocate for less restrictive HCV Medicaid policies by changing the conversation narrative. NVHR and CHLPI can provide support.

• Clinicians Can Help Hold Payers Accountable
  – Share information about restrictions with advocacy groups
  – Submit testimony to state’s P&T committees or DURBs, meet with state Medicaid officials to share clinician perspective
  – Clinicians have led many of the most successful efforts to expand access, including in Pennsylvania and Rhode Island most recently
FEDERAL AND STATE ADVOCACY
Policy Priority Initiatives

NVHR advocates at the federal and state levels for increased access to hepatitis B and C prevention, testing, treatment, and care. Our priority public policy initiatives include:

• Lift all restrictions on access to HCV treatment in the criminal justice system, including developing policy solutions to address the high cost of treatment in state prisons.

• Expand access to syringe service programs, to link people who use drugs with HBV/HCV screening/testing and treatment.

• Increased funding for CDC/DVH to coordinate with community groups on the ground to implement screening and prevention programs, and conduct surveillance efforts via the Viral Hepatitis Prevention Coordinator Program.

• Protect Medicaid and the Affordable Care Act and urge states to expand Medicaid where needed.

• More information about NVHR’s Policy work: [www nvhr org policy](http://www.nvhr.org/policy)
Federal Public Health Advocacy

• NVHR developed a fact sheet for community members to use in federal and state level advocacy, “Dual Epidemics: Opioids and Hepatitis C.”
  – Incorporates the National Academies’ recommendation that state and federal agencies expand access to syringe service programs to combat both the opioid and hepatitis C crises.

• NVHR submitted a letter to the President’s Commission on Combating Drug Addiction and the Opioid Crisis to urge inclusion of the National Academies’ recommendations on syringe access in the Commission’s Final Report to the President.
The Eliminating Opioid-Related Infectious Diseases Act

- Over the last several years, hepatitis C (HCV) infections have increased by nearly 300 percent and are directly tied to injection opioid use.
- The bill amends the Public Health Service Act to require the Centers for Disease Control and Prevention (CDC) to expand its grant program for combating hepatitis C infections to include other infections associated with injection drug use.
- Allocate resources to states and provide the organizations of impacted communities with the tools needed to combat the rise of HCV infections.
- Passed the U.S. House of Representatives on June 12, 2018.
Federal Appropriations and Funding

• NVHR is committed to supporting creative strategies - legislative, administrative, and regulatory - to secure additional federal funds to fight the hepatitis C epidemic.

• FY2019 Senate and House Appropriations
  – Requests increased funding for the Division of Viral Hepatitis (DVH) at the Centers for Disease Control and Prevention (CDC) totaling $134 million, an increase of $95 million more than the FY2018 enacted level.
  – Increased funding is crucial as the opioid epidemic continues and disproportionately impacts those living with hepatitis C.
Engaging Key Stakeholders

- Reported cases of HCV infection increased about 3.5-fold from 2010 through 2016.¹
- Most new HCV infections occur among young, white persons who inject drugs and live in non-urban areas.²
- Certain groups are disproportionately dying with these infections: people 55–64 years old and American Indians/Alaska Natives from HCV.¹
- Hepatitis-C related liver complications were among the leading causes of death for African Americans aged 45-64 in 2014² while African Americans continue to be denied access to HCV treatment at higher rates than other ethnicities.³
- Latinx/Hispanics also have higher rates of hepatitis-C related deaths compared with whites.⁴

Fighting HCV Criminalization

• Laws criminalizing hepatitis single out people living with viral hepatitis for especially harsh treatment under our criminal legal system. Laws criminalizing viral hepatitis target the same behaviors as HIV criminal laws: sex, exposure to bodily fluids (blood or saliva), and needle-sharing. **Often, the laws include situations where there is no real risk of disease transmission.**

• Just like HIV criminal laws, laws criminalizing hepatitis are unscientific, overly harsh, and discriminatory. Criminalizing someone’s health status should never be the solution to a public health challenge.

• 13 states have laws that criminalize hepatitis.

• Opportunity to partner with HIV advocates and harm reduction groups to fight these laws while working to expand access to syringe services.
NVHR Programs
Program Department Overview

- Capacity-Building, Technical Assistance, and Coalition-Building
  - Support for groups conducting screening in community-based settings
  - Templates and EMR support for implementing routine screening
  - Webinars, Fact Sheets & Online Resources

- More than Tested, Empowered

- Working Groups for HCV Treaters and Pharmacists

- Hepatitis C – it’s about More than Liver Disease

- Mini-Grants
  - Technical assistance and $10K of financial support

- NVHR Hepatitis C Patient Summit (2019)
More than Tested, Empowered

- A Novel Project to Meaningfully Engage Drug Users in HCV Work
- Key Accomplishments in Year One:
  - Engaging individuals who use drugs in defining the solution
  - Developing and disseminating culturally appropriate HCV education materials
  - Expanding Access to HCV Services for Individuals Who Use Drugs
  - Expanding Services available at Syringe Exchange Sites
  - Reducing Stigma and Barriers for Specialists to Treat Active Users
  - Strengthening the National Network
Meaningful Engagement of People who Use Drugs

- Almost every person involved in USU’s part of the project identified as a person that uses drugs.
- “Grant Parents” – NVHR considering the harm reduction groups as true partners and providing technical assistance.
- Planning, implementing, evaluating the program.
- Every person involved in USU’s part of the project was paid – Focus group facilitators, focus group attendees, interviews, survey participants, video team.
- Paying people is about showing people you believe their time is valuable.
NVHR HCV Treaters Workgroups

NVHR HCV Treaters Advocacy Group – Chaired by Dr. Stacey Trooskin
• A multidisciplinary group for clinicians sharing best practices for providing HCV treatment. The focus for 2018 is expanding treatment access in Medicaid programs.
• Activities include developing tools to track progress, identifying champions, and supporting clinicians in key states who wish to pursue further advocacy
• 30 minute calls, monthly every third Thursday, and/or email communication

NVHR HCV Telehealth Group – Chaired by Dr. Andy Talal
• A multidisciplinary group working to share models and strategies around the use of telehealth to improve access to HCV care.
• 30 minute calls, monthly
NVHR created the Pharmacy Working Group to help community pharmacies and clinical pharmacists expand awareness, screening, vaccination, linkage to care, and treatment for hepatitis B and C.

Goals of the Pharmacy Working Group:

- Support for all states up to the highest level of pharmacy integration/scope of practice for pharmacists.
- Provide a forum for relationship-building and sharing of best practices among multidisciplinary group of partners (pharmacists, advocates, health departments, industry partners, etc.).
- Elevate the role of pharmacists and pharmacies in the hepatitis community through program and advocacy work.
- Create a repository of resources, available at: www.nvhr.org/programs/pharmacy
More Than Liver Disease Project

• Raise awareness about HCV conditions that occur outside the liver
• Facilitate discussion with the public health community about these conditions
• Change the conversation about HCV, emphasizing the need to characterize it as a systemic condition
• Broaden NVHR coalition to expand the number of groups working to eliminate HCV in the U.S.
More Than Liver Disease Project Activities

- Development of fact sheets
  - Overview of EHMs
  - Kidney disease, lymphoma
  - Fatigue, depression, chronic pain
  - Diabetes, heart disease
  - Skin conditions
- Engaged new partners
- Webinar
Hepatitis C Project Booster Mini Grants

- Seven $10,000 grants were awarded in 2017
- Four $10,000 grants were awarded in 2018
- One-year projects, support from NVHR and fellow grantees
- Intended to enhance the capacity of NVHR member organizations to conduct hepatitis C education, testing, and linkage to care in their local communities and then disseminate those best practices nationally
- Build relationships with grassroots organizations, learn from their experiences to inform national work and share national learnings with local partners
- Diverse groups have participated representing correctional services, homeless services, primary care providers, etc.
Patients not engaged enough in advocacy work

NVHR is planning a HCV Patient Summit in early 2019 to address need for greater patient engagement and leadership in the HCV field.

- opportunity for 100 patients recently or currently living with HCV who have not had experience engaged in other advocacy programs to come together to develop shared goals.
- emphasize recruitment of individuals from disproportionately impacted and marginalized communities to ensure the demographics of attendees are representative of the demographics of the HCV epidemic.

- [http://nvhr.org/program/PatientSummit](http://nvhr.org/program/PatientSummit)