

# Building Political Partners Toward HCV Elimination

National Viral Hepatitis Roundtable (NVHR) Presentation

July 11, 2018

# National Viral Hepatitis Roundtable (NVHR)

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**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)

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**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

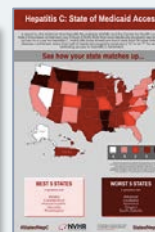
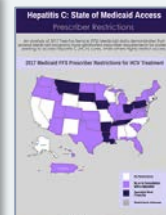
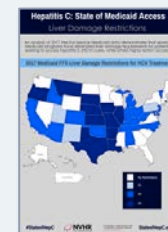


# HEPATITIS C: THE STATE OF MEDICAID ACCESS PROJECT

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# 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

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- **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

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- 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

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# 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

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- 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

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- 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

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- 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

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- Reported cases of HCV infection increased about 3.5-fold from 2010 through 2016.<sup>1</sup>
- Most new HCV infections occur among young, white persons who inject drugs and live in non-urban areas.<sup>2</sup>
- Certain groups are disproportionately dying with these infections: people 55–64 years old and American Indians/Alaska Natives from HCV.<sup>1</sup>
- Hepatitis-C related liver complications were among the leading causes of death for African Americans aged 45-64 in 2014<sup>2</sup> while African Americans continue to be denied access to HCV treatment at higher rates than other ethnicities.<sup>3</sup>
- Latinx/Hispanics also have higher rates of hepatitis-C related deaths compared with whites.<sup>4</sup>

<sup>1</sup> *Commentary | U.S. 2016 Surveillance Data for Viral Hepatitis | Statistics & Surveillance | Division of Viral Hepatitis | CDC.* (2018). *Cdc.gov*. Retrieved 9 May 2018, from <https://www.cdc.gov/hepatitis/statistics/2016surveillance/commentary.htm>

<sup>2</sup> *Hepatitis C Disproportionately Affects the African American Community* CDC. (2018) *Cdc.gov*. Retrieved 9 July 2018, from <https://www.cdc.gov/hepatitis/blackhistmnth-hepc.htm>

<sup>3</sup> *Sims et al, 2017. "Racial Disparities in Hepatitis C Treatment Eligibility."* Retrieved 9 July 2018, from <https://www.ncbi.nlm.nih.gov/pubmed/28611273>

<sup>4</sup> *Wollitski, 2016. "Hispanic Heritage Month: Opportunities to Address Hepatitis C Among Hispanic Populations"* Retrieved 9 July 2018, from <https://www.hhs.gov/hepatitis/blog/2016/10/11/opportunity-to-address-hep-c-in-hispanics.html>

# Fighting HCV Criminalization

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- 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.



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# 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)

**HEALTH EFFECTS OF HEPATITIS C OUTSIDE OF THE LIVER**  
Hepatitis C: It's About More than Liver Disease

The effects of the hepatitis C virus (HCV) on the liver are well-known. For example, chronic HCV infection can lead to long-term liver damage and increased risk of liver cancer.

But up to **74%** of HCV-infected patients have symptoms outside the liver!

It is important to recognize these health effects because they may play a role in diagnosis, treatment, and the overall wellbeing of an infected individual.

**WHAT ARE SOME COMMON EFFECTS OF HCV OUTSIDE OF THE LIVER?**

Depression and anxiety  
Heart disease  
Diabetes  
Skin conditions  
Kidney disease  
Cancer  
Pain and fatigue

Eye, eye and mouth  
throat conditions  
muscle, tendon, and vascular system disorder  
Numbness or tingling  
Reproductive health issues

Health effects of HCV can appear in many parts of the body. Some have distinct features that are easy to identify, while others are hard to diagnose and often get overlooked. It can be difficult to recognize that these symptoms are associated with HCV.

**HOW DOES HCV AFFECT OTHER PARTS OF THE BODY?**

HCV can live in the body for many years, causing long-term inflammation and constant stress on the immune system. Over time, this produces problems across multiple body systems.

The virus invades cells in the body other than liver cells. Even though HCV usually infects liver cells, there is also evidence that it affects other cell types including those found in the brain and immune system.<sup>1,2</sup>

Some health conditions are associated with HCV, but the reasons are unknown. For example, the risk of heart disease is higher among HCV patients than the general population, and researchers are still working to understand why.<sup>3,4</sup>

**WHY IS THIS IMPORTANT?**

HCV-related effects on other parts of the body can be an early indicator of HCV infection. Chronic HCV infection may not have noticeable impacts on the liver for many years. However, patients may experience earlier symptoms in other parts of the body that could be related to HCV.

HCV treatment improves many health conditions. Clearing HCV from the body can relieve health conditions affecting multiple parts of the body, in addition to the liver.<sup>5,6</sup>

**WHAT SHOULD I TAKE?**

Providers	Advocates
<p><b>DEMANDS</b> that HCV is chronic disease that acts the whole body.</p> <p><b>DEMANDS</b> that patients occur side the liver.</p> <p><b>DEMANDS</b> that patients occur side the liver can be slow cause of use for HCV tests.</p> <p><b>DEMANDS</b> that certain get conditions</p> <p>outside the liver can lead to early HCV diagnosis and may be indicators for HCV treatment.</p> <p><b>COORDINATE</b> care so that providers across specialties can work together.</p>	<p><b>EDUCATE</b> others about the effects of HCV beyond the liver.</p> <p><b>EDUCATE</b> policymakers to endorse strategies that increase access to HCV treatment.</p> <p><b>INCREASE</b> awareness about the wide-ranging clinical needs of HCV patients.</p> <p><b>DEMANDS</b> that HCV be recognized as a systemic health condition deserving of more attention and resources.</p>

1. Journal of Hepatology. 2015;62(5):1033-1041. 2. Journal of Hepatology. 2015;62(5):1033-1041. 3. Journal of Hepatology. 2015;62(5):1033-1041. 4. Journal of Hepatology. 2015;62(5):1033-1041. 5. Journal of Hepatology. 2015;62(5):1033-1041. 6. Journal of Hepatology. 2015;62(5):1033-1041.

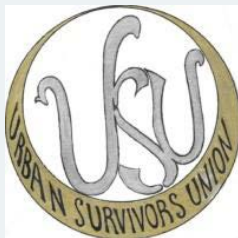
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For information about specific HCV conditions outside of the liver, visit:  
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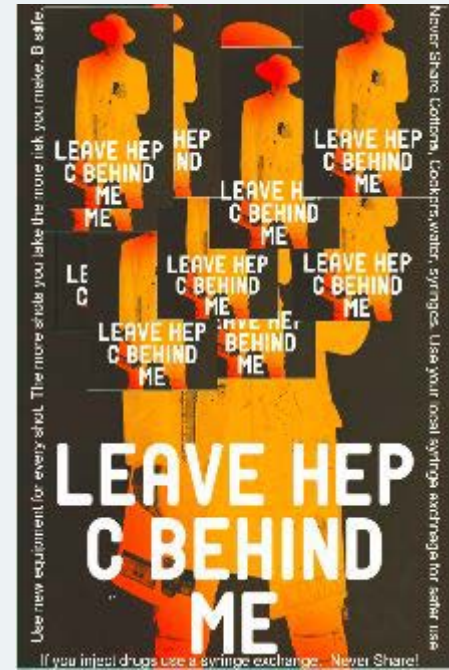
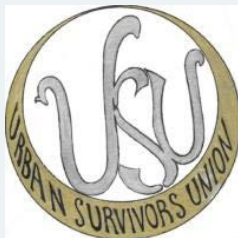
# More than Tested, Empowered

- 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

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## **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

# Pharmacy Working Group

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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](http://www.nvhr.org/programs/pharmacy)

# More Than Liver Disease Project

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- 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

## HEALTH EFFECTS OF HEPATITIS C OUTSIDE OF THE LIVER

*Hepatitis C: It's About More than Liver Disease*

The effects of the hepatitis C virus (HCV) on the liver are well-known. For example, chronic HCV infection can lead to long-term liver damage and increased risk of liver cancer.

But up to **74%** of HCV-infected patients have symptoms outside the liver.<sup>1</sup>

It is important to recognize these health effects because they may play a role in diagnosis, treatment, and the overall wellbeing of an infected individual.

### WHAT ARE SOME COMMON EFFECTS OF HCV OUTSIDE OF THE LIVER?

<p>Depression and anxiety</p> <p>Heart disease</p> <p>Diabetes</p> <p>Skin conditions</p> <p>Kidney disease</p> <p>Cancer</p> <p>Pain and fatigue</p>	<p>Dry eyes and mouth</p> <p>Thyroid conditions</p> <p>Immune, lymphatic, and vascular system disorder</p> <p>Numbness or tingling</p> <p>Reproductive health issues</p>	<p>Health effects of HCV can appear in many parts of the body.</p> <p>Some have distinct features that are easy to identify, while others are hard to diagnose and often get overlooked.</p> <p>It can be difficult to recognize that these symptoms are associated with HCV.</p>
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### HOW DOES HCV AFFECT OTHER PARTS OF THE BODY?

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The virus invades cells in the body other than liver cells. Even though HCV usually infects liver cells, there is also evidence that it attacks other cell types including those found in the brain and immune system.<sup>2,3</sup>

Some health conditions are associated with HCV, but the reasons are unknown. For example, the risk of heart disease is higher among HCV patients than the general population, and researchers are still working to understand why.<sup>4,5</sup>

### WHY IS THIS IMPORTANT?

HCV-related effects on other parts of the body can be an early indicator of HCV infection. Chronic HCV infection may not have noticeable impacts on the liver for many years. However, patients may experience earlier symptoms in other parts of the body that could be related to HCV.

HCV treatment improves many health conditions. Clearing HCV from the body can relieve health conditions affecting multiple parts of the body, in addition to the liver.<sup>6,7</sup>

## Hepatitis C: It's About More than Liver Disease

### B-CELL NON-HODGKIN'S LYMPHOMA

#### What is it?

A type of cancer that affects the immune system. It occurs when there is an abnormal increase in the number of B cells (a type of immune system cell) produced by the body.

#### How common is it?

~2% of HCV patients will develop this condition.<sup>4</sup> It is more likely to occur in individuals who have a blood disorder called mixed cryoglobulinemia (see page 1).

Although this condition is rare, it is very serious and can be fatal.

#### Symptoms

Some symptoms include:

- Swollen lymph nodes (often in the neck, groin, or armpit)
- Fever, chills, and/or night sweats
- Weight loss
- Fatigue

#### Diagnosis

Diagnosis is made through a procedure where a section of lymph node tissue is removed from the body and examined under a microscope.

Additional tests may be performed to determine how advanced the cancer is.

#### Complications

This type of cancer can lead to death if it is not treated. Survival rates depend on factors such as how aggressive the cancer is, how advanced it is when identified, and the patient's age.

If detected early, however, treatment can be very successful.

#### Treatment\*

- HCV medications are a key part of treatment for HCV patients with this condition.<sup>5</sup>
- Patients with advanced stages of cancer may also need chemotherapy to treat their cancer either before or during HCV treatment.
- Early HCV treatment can also help prevent this type of cancer from developing.

\* All treatment should be done in consultation with a licensed healthcare provider.

1. Sordani, David, et al. "Hepatitis C-associated mixed cryoglobulinemia: a crossroad between autoimmunity and lymphoproliferation." *Rheumatology*, vol. 46, no. 8, 2007, pp. 1294-42.

2. Zignego, Anna Maria, et al. "HCV and lymphoproliferation." *Journal of Immunology Research*, 2012, doi:10.1155/2012/278924.

3. Maccioni, Anna C, et al. "The relevance of renal impairment and associated conditions among HCV-infected persons in the Chronic Hepatitis Cohort Study (CHC3)." *Digestive Diseases and Sciences*, vol. 61, no. 7, 2016, pp. 2082-95.

4. Del Missi, Ligorio and Silvio Foraccesi. "Hepatitis C virus and risk of lymphoma and other lymphoid neoplasms: A meta-analysis of epidemiologic studies." *Cancer Epidemiology, Biomarkers & Prevention*, vol. 15, no. 11, 2006, pp. 2079-85.

5. Sorensen, Steen and Gøtzge, Søren. "Hepatitis C-associated B-cell non-Hodgkin lymphoma: clinical features and the role of antiviral therapy." *Journal of Clinical and Translational Hepatology*, vol. 3, no. 2, 2015, pp. 134-9.

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<http://nvhr.org/program/HCVMoreThanLiverDisease>

# Hepatitis C Project Booster Mini Grants

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- 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.

# NVHR Hepatitis C Patient Summit

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- 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>