

September 27, 2023

The Honorable Charles Schumer  
Majority Leader  
United States Senate  
Washington, DC 20510

The Honorable Kevin McCarthy  
Speaker  
United States House of Representatives  
Washington, DC 20515

The Honorable Mitch McConnell  
Minority Leader  
United States Senate  
Washington, DC 20510

The Honorable Hakeem Jeffries  
Minority Leader  
United States House of Representatives  
Washington, DC 20515

Dear Speaker McCarthy, Majority Leader Schumer, Minority Leader McConnell, and Minority Leader Jeffries:

On behalf of the 70 undersigned organizations representing patients, providers, and public health organizations, we urge Congress to adopt legislation to eliminate hepatitis C and deliver better outcomes for hepatitis patients living in rural communities. These communities are disproportionately impacted by hepatitis C, seeing infection rates that are often estimated to be twice as high as those in urban areas. Fortunately, hepatitis C is curable with an 8-to-12-week oral therapy that is highly tolerated and over 95 percent effective. This epidemic does not have to continue in our most vulnerable communities, and passing legislation to eliminate hepatitis C will ensure that all Americans can know their hepatitis status and be connected to a low-cost cure.

At least 2.4 million people in the United States are chronically infected with hepatitis C, a “silent killer.” Chronically infected individuals may be asymptomatic for years while the virus damages their liver. Left undetected and untreated, hepatitis C may progress to cirrhosis, liver cancer, and potentially even death. Liver transplantation is the only rescue therapy available to those who develop complications related to cirrhosis, but is an expensive and limited option. Every year, one of every five people on the waiting list for liver transplantation dies or becomes too sick to undergo the transplant. Diagnosis and treatment of hepatitis C can avoid all those downstream consequences—for every one million people cured of hepatitis C in ten years, 34,000 cases of liver cancer, 2,500 liver transplants, and 24,000 deaths can be prevented.

Rural areas bear the brunt of the hepatitis C epidemic due to risk factors such as opioid use and limited or no access to health care services. The highest rates of opioid prescribing occurred in states with the highest rates of acute hepatitis C infection.

- Twenty two percent of the 35,000 people infected with hepatitis C in Wisconsin live in large metropolitan areas. 5,000 infected individuals lived in one county without a qualified provider who had prescribed HCV therapy in the past year.<sup>1</sup>
- A 2021 North Carolina surveillance report links hepatitis C infection to wealth disparity and poverty, which are more commonly seen in rural communities. Additionally, county level statistics from North Carolina demonstrate significantly higher rates of hepatitis C in rural counties, some of which do not have state funded hepatitis C programs.<sup>2</sup>

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6383161/>

<sup>2</sup> <https://epi.dph.ncdhhs.gov/cd/stds/figures/2021-Hep-AnnualReportFinal.pdf>

- Similarly, a May 2023 Missouri surveillance report with data from 2017 – 2021 shows that the top 10 counties for hepatitis C diagnosis are all rural with one exception<sup>3</sup>. Infection rates in Florida tell a similar story.
- In 2020, heavily rural West Virginia had one of the highest rates of hepatitis C in the country, with the highest burden of acute HCV falling on white males with drug use as the most common risk factor according to a 2022 surveillance report.<sup>4</sup>

It is clear from state reporting that rural populations incur a disproportionate share of the hepatitis C burden, underscoring the urgency for action.

While rural communities have a higher incidence of hepatitis C, they often have the fewest resources and health care providers to combat the disease. Overcoming stigma for drug use affects people seeking health care in the first place, while lack of access to care itself is often a barrier. One study in southern Illinois demonstrated that, for some people, the closest specialty health care facility was in a neighboring state.<sup>5</sup> Similarly, in West Virginia where hepatitis C rates are increasing, access to care is a challenge because there are so few specialists available.<sup>6</sup> The hepatitis C elimination plan would invest in infrastructure to educate providers, including primary care physicians, qualified public health professionals, and pharmacists, across the country on hepatitis C risk factors while providing resources for a hepatitis C rapid diagnostic that would quickly inform a potential patient of their status to enable a test-to-treat model. This infrastructure and education would also help providers identify cases of other diseases among their rural patients including hepatitis B, HIV, and STIs; all of which share some of the same risk factors as hepatitis C. Hepatitis C treatment works best when other co-conditions are well-managed, so it is important that patients are made aware and steps are taken to link them to care. This will not only improve the overall health of the rural community, but also ensure the best chance of success for the HCV plan.

Congress can address these challenges in our rural communities, save the lives of many Americans with hepatitis C, and reduce the significant health costs associated with treating patients with liver cancer and liver transplants by supporting the national plan to eliminate hepatitis C. This plan will:

- Support the development of point-of-care diagnostic tests to enable a test-to-treat model;
- Broaden access to curative hepatitis C medications, primarily through an opt-in national subscription model; and
- Expand infrastructure needed to reach, test, and treat all affected individuals.

Besides these components, the plan would also accelerate research to find a safe and effective vaccine for hepatitis C, so that the next generation of Americans will be protected from this serious disease. The White House requested a mandatory authorization—an investment of \$12.3 billion—for five years. This investment will be offset by \$7.2 billion in savings, primarily by the reduced spending on care for hepatitis C progression and drug costs in the Medicaid program, for a net cost of \$5.1 billion. This will provide incalculable benefit to the millions of lives that will be saved, particularly among our most vulnerable populations who are disproportionately affected by this virus. We have seen a similar approach taken by the state of Louisiana that has made a great deal of impact in reducing the number of people with hepatitis C. When the program launched in 2019, Louisiana estimated that more than

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<sup>3</sup> [Missouri Viral Hepatitis Epidemiological Profile, 2017 – 2021 \(mo.gov\)](https://mo.gov/health/epidemiology-and-prevention/communicable-diseases/hepatitis-c)

<sup>4</sup> [https://oeps.wv.gov/hepatitis/documents/data/Summary\\_2020\\_Acute\\_HBV-HCV.pdf](https://oeps.wv.gov/hepatitis/documents/data/Summary_2020_Acute_HBV-HCV.pdf)

<sup>5</sup> <https://www.sciencedirect.com/science/article/pii/S0955395922003462#bib0052>

<sup>6</sup> <https://hepvu.org/judith-feinberg-hepatitis-c-appalachia/>

39,000 people on Medicaid or in the prison system had hepatitis C. As of June 2023, 14,345 people have been treated with direct acting antivirals.<sup>7</sup>

This plan provides a blueprint to save lives and reduce federal healthcare spending, particularly in rural health care settings where hepatitis C is endemic, and care is not readily available for many people living with the disease. The time to act is now before hepatitis C progresses to more costly and complicated liver diseases for many Americans, particularly in rural communities. We cannot leave our most vulnerable behind. We stand ready to work with you to eliminate hepatitis C for all Americans and respectfully request that Congress develop and pass legislation to authorize this hepatitis C elimination plan immediately.

Sincerely,

American Association for the Study of Liver Diseases  
Access Support Network  
American Association of Colleges of Pharmacy  
American College of Gastroenterology  
American Dental Association  
American Diabetes Association  
American Liver Foundation  
Arapahoe County Public Health  
Asian Liver Center at Stanford University  
Association of Schools & Programs of Public Health  
Breadcrumb Analytics  
California Hepatitis C Task Force  
Caring Ambassadors Program  
Center for Health Law and Policy Innovation  
Central City Concern  
Central Outreach Wellness Center  
Choice Health Network  
Clary Strategies  
Coalition for Global Hepatitis Elimination  
Community Education Group  
Community Liver Alliance  
ekiM For Change  
El Punto en la Montaña  
End Hep C SF  
Evergreen health  
Facente Consulting  
Full Circle Recovery Center  
Gastroenterology & Hepatology Advanced Practice Providers  
Global Liver Institute  
H.E.A.L.S of the South

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<sup>7</sup> <https://ldh.la.gov/assets/hepc/prod/>

Hawai'i Health & Harm Reduction Center  
Hawaii State Rural Health Association  
Hennepin Healthcare  
Hep B United  
Hep Free Hawai'i  
Hepatitis B Foundation  
Hepatitis C Association  
HIV Alliance  
Hope on TTaPP  
Institute for Healthcare Improvement (IHI)  
International Association of Hepatitis Task Forces  
Kentucky Rural Health Association  
Mid South Liver Alliance  
MoNetwork  
Montefiore Medical Center  
NASTAD  
National AIDS Treatment Advocacy Project (NATAP)  
National Consumers League  
National Harm Reduction Coalition  
National Rural Health Association  
National Viral Hepatitis Roundtable (NVHR)  
New York Recovery Alliance  
NEXT Distro  
Project ECHO: Hawai'i Learning Groups  
Rady Children's Hospital/UCSD  
Robert G Gish Consultants LLC  
SF Hep B Free - Bay Area  
Smoky Mountain Harm Reduction  
Sonoran Prevention Works  
Southwest Recovery Alliance  
The AIDS Institute  
The American Correctional Association  
The Bonnie Morgan Foundation for HCV  
The Hepatitis C Mentor and Support Group-HCMSG  
The Porchlight Collective SAP  
Thomas D. Boyer Liver Institute  
Treatment Action Group  
Utah Hepatitis Coalition  
Will Rodgers Liver Health Foundation