

FOR IMMEDIATE RELEASE [26 JULY 2019]

National Viral Hepatitis Roundtable to Host First Hepatitis C Patient Summit

Patient Advocates to Demand Inclusion in the Response to the Epidemic

ATLANTA, GA: On July 29th and 30th, the National Viral Hepatitis Roundtable will hold a first-of-its-kind hepatitis C Patient Summit in Atlanta, GA. The meeting, scheduled to coincide with World Hepatitis Day, will bring together national partners and 100 patient advocates from across the country to share their stories, learn new advocacy skills, and identify opportunities to improve hepatitis C prevention and care.

The timing of the conference aligns with the development of national and state-levels strategies to eliminate hepatitis C. The viral infection, for which a cure is available, can cause liver disease and cancer. Fatalities associated with hepatitis C have surpassed those of all of the other 60 reportable infectious diseases combined. This trend, along with dramatically increasing rates of new hepatitis C cases driven by the opioid epidemic, has elicited national attention to the issue. Congress approved \$11m last year to address the infectious-disease consequences of the opioid epidemic. Though interest is growing at the national-level, resources needed to eliminate the virus are in short supply, and patients are often left out of the planning process. The patients organizing next week hope to address this issue.

“The patient voice has long been left out of the response to the hepatitis C epidemic, and it’s time to put an end to that practice,” claims Lauren Canary, the new director of the National Viral Hepatitis Roundtable, who until recently worked on viral hepatitis at the Centers for Disease Control and Prevention. Her hope is that patients will serve in an advisory role to inform elimination efforts.

Patient advocates attending the summit will also learn how to engage with lawmakers in their state to draw attention to policies that may be hindering elimination efforts. Many state policies limit access to hepatitis C prevention and treatment, functionally interfering with the public health response. Because most new infections of hepatitis C are driven by unsafe injection drug use, states that lack legislation to permit the establishment of syringe services programs and the legal possession of drug paraphernalia are limited in their ability to prevent new infections. Many state Medicaid programs also restrict curative therapy to those with the most advanced stages of liver disease and/or to those who can demonstrate abstinence from alcohol and drug use. The result is a burgeoning epidemic among young people, pregnant women, infants, and marginalized groups.

“Elevating patient voices is an important first step in addressing the systems-level stigma that is interfering with the public health response to this epidemic” according to Canary. The summit aims to be the first, but “certainly not the last”, opportunity for patient advocates to have their voices heard, she says. For more information about the National Viral Hepatitis Roundtable, readers are encouraged to visit www.nvhr.org.

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