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Advocacy in Action

Ryan Clary, executive director of the National Viral Hepatitis Roundtable, sits at the helm of U.S. efforts to end the epidemic.

March 5, 2018 By Casey Halter

Eleven years ago, Ryan Clary, a longtime HIV/AIDS advocate for the likes of Project Inform and the San Francisco AIDS Foundation, pivoted his professional focus to ending the hepatitis C virus (HCV) and hepatitis B virus (HBV) epidemics in the United States.

Clary, 48, is now the executive director of the National Viral Hepatitis Roundtable (NVHR), where he leads a small but determined staff of health policy experts across the country dedicated to pushing policymakers, public health officials, medical and health care providers and the media to more aggressively address the nation’s liver disease crisis.

“The need is so great, and the resources are so few,” says Clary. “I just felt that there was a real opportunity for me to bring the skills and experience that I had developed in HIV advocacy to try to make an impact.”

His strategy for ending the HCV and HBV epidemics is to apply the grassroots tactics he and other HIV advocates used to combat that crisis—like empowering the voices of people living with HIV to communicate directly with their elected officials—to what has become one of America’s most urgent public health concerns.

His work has played a major part in shaping the national conversation around viral hepatitis. Today, NVHR is at the forefront of U.S. advocacy efforts both to end viral hepatitis and to better address the needs of people living with hep B and C.

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Under Clary’s leadership, NVHR has become well known for pressing top government officials to make good on the promise to end the hepatitis epidemic by 2030—a goal originally set by the World Health Organization.

“Not only are we not moving toward elimination—we’re barely even managing the epidemics,” Clary says, pointing to recent statistics from the Centers for Disease Control and Prevention showing that the number of new reported hep C cases has nearly tripled over the past five years. “It’s so poorly funded that we’re going backward.”

In an attempt to keep the government on course, NVHR hosts regular hepatitis action days on Capitol Hill for liver disease advocates to share their concerns. The group also lobbies lawmakers year-round to step up their hepatitis elimination efforts on behalf of their constituents.

NVHR recently joined 60 other advocacy organizations in sending a letter to President Trump directly, urging him to allocate hundreds of millions of dollars for hepatitis elimination.

“Our biggest challenge this year will continue to be protecting the health care system and the safety net,” Clary says. “We could get a massive infusion of hepatitis-specific funding, but if there is no health care safety net, then it won’t matter.”

With this concern in its sights, NVHR joined thousands of other health care and policy organizations nationwide to fight the Republican-led proposal to repeal the Affordable Care Act—a move advocates estimated would have potentially left nearly 32 million people uninsured, while imperiling the health of nearly 5 million Americans living with hep B or C.

NVHR is also engaged in an ongoing fight to peel back Medicaid and insurance restrictions on new direct-acting antiviral treatments for HCV, a battle Clary says he’s been waging since cures were first introduced to the market in 2013.

“Stigma is huge,” says Clary. “I feel like stigma is one of the key drivers of the restrictions to treatment access that a lot of Medicaid programs have put in place. So that’s also one of our top policy priorities.”

To shed light on these restrictions, the group collaborated with Harvard Law School’s Center for Health Law and Policy Innovation to produce a report grading the Medicaid programs of all 50 states on HCV treatment accessibility.

The report showed that more than half of state Medicaid programs continue to impose discriminatory restrictions on hep C cures—such as requiring individuals with hep C to meet severe liver damage criteria or abstain from substance use for six months before they can access treatment.

It’s a policy battle NVHR will fight until all hep C treatment restrictions are revoked nationwide—and one that the group appears to be winning state by state.

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Further, Clary points out that NVHR isn’t just dedicated to top-level political advocacy. Under the Californian’s leadership, the group is also devoted to community organizing and draws from his experience with the on-the-ground work that helped mitigate the impact of the HIV epidemic.

“I’m a firm believer that the people who are most impacted by any issue should be leading the advocacy efforts around that issue,” says Clary. “What we’re seeing is a growing movement among people living with hep C who are angry at the lack of response to their health needs. That is going to lead to a lot of change."

Part of this work revolves around hepatitis education. To that end, NVHR regularly hosts webinars for patients and providers that cover topics such as hep C considerations among pregnant women and the realities of living with viral hepatitis today.

From these grassroots discussions spring targeted actions. One such recent example is the initiative "Hepatitis C—It's About More Than Liver Disease," which aims to raise awareness about HCV-related health conditions that occur outside the liver, such as kidney disease, depression, skin problems and lymphoma.

The end goal, says Clary, is not only to bring greater medical attention to patients with secondary medical issues but also to help make a stronger case for why liver disease patients should be granted access to early-stage treatment.

There's also NVHR's grant-building and research work, which helps fund and coordinate hepatitis and harm reduction advocacy groups across the country to expand their efforts on the ground. This includes giving seven $10,000 mini grants to U.S. community-based organizations to expand hep C education and increase testing and linkage to care in their local communities and disseminate those best practices nationally.

NVHR is working on a far-reaching pilot project this year with Seattle's Peoples Harm Reduction Alliance, the Atlanta Harm Reduction Coalition and the Urban Survivors Union in North Carolina to help address increasing HCV rates among people who inject drugs.

"We're looking for gaps in testing, gaps in access to treatment and gaps in prevention," Clary explains. "NVHR's role is serving as a convener. We help write the grant and get it funded, and then we provide mechanisms for our partners to communicate and share strategies and lessons learned."

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As for what's in store for NVHR in 2018, Clary says the organization will continue to push for expanding hep C prevention, testing and treatment access, while also joining other health care advocates to protect the nation's fragile health care infrastructure.

The group will also continue to ramp up its advocacy on behalf of at-risk and underserved communities, such as people of color, injection drug users and prison inmates—all of whom are at the heart of the crisis and are often overlooked.

"Any policies that are furthering the potential for more health disparities and discrimination—they're going to have an impact on our ability to ensure that we're addressing hepatitis C meaningfully in this country," says Clary.

"We're proud to be joining in partnership with an overall social justice movement to improve the lives of the communities we serve.” Go to NVHR.org to learn how to get involved.

Editor’s note: After a long tenure, Clary resigned his position as NVHR executive director effective February 28, 2018. The transition to a new executive director is in the hands of the NVHR executive committee.
