

# Hepatitis C: Awareness, Testing & Cure



A Series by:

*Real World Health Care*  
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Hepatitis C affects 2.4 million people in the U.S. It is a disease with tremendous stigma attached to it.

***Hepatitis C: Awareness, Testing & Cure*** is a recently published series of articles that spotlights the organizations and efforts dedicated to fighting the stigma as well as the disease.



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# May Is Hepatitis Awareness Month

This month, [Real World Health Care](#) focuses on [Hepatitis C](#), a viral disease that affects 2.4 million people in the U.S. and infects about 50,300 new people each year, according to the Centers for Disease Control and Prevention (CDC). For some, hepatitis C is a mild illness lasting a few weeks. However, most people who get infected with the hepatitis C virus develop a chronic infection that can lead to life-threatening health problems like cirrhosis and liver cancer.

In this article, we'll shine a spotlight on two organizations committed to serving the hepatitis C community: National Viral Hepatitis Roundtable and Community Liver Alliance.

## What Is Hepatitis C?

Hepatitis is an inflammation of the liver, a vital organ that processes nutrients, filters the blood and fights infections. When the liver is inflamed or damaged, its function can be affected. While hepatitis can be caused by heavy alcohol use, toxins and certain medications or medical conditions, it is often caused by a virus.

Hepatitis C is a common type of viral hepatitis (along with hepatitis A and hepatitis B) and is spread through contact with blood from an infected person. Today, most people become infected with the hepatitis C virus by sharing needles or other equipment used to prepare and inject drugs. About half of those with hepatitis C do not know they are infected, according to the CDC.

There is no vaccine for hepatitis C, but it is curable. The best way to prevent hepatitis C is by avoiding behaviors that can spread the disease, such as injection drug use. Getting tested for the disease is important because treatments can cure most people in 8-12 weeks. CDC recommends one-time hepatitis testing of all adults 18 and older and of all pregnant persons during every pregnancy. Regular testing is recommended for those with risk factors such as injection drug use.

## NVHR: Giving a Voice to People with Viral Hepatitis

The [National Viral Hepatitis Roundtable](#) (NVHR) is a national coalition working to eliminate viral hepatitis in the U.S. and improve the lives of those affected through advocacy, education, and support to national, state and local partners.

One of NVHR's key tenets is to amplify the voices of people who have lived experiences with viral hepatitis. To that end, NVHR launched [#Voices4Hep](#) in November 2019. This network of 200+ patients, providers and community

advocates provides a way to connect, gain support for local initiatives and access resources.



*Daniel Raymond*

"Receiving a diagnosis of hepatitis C can be an emotional and isolating experience," said Daniel Raymond, Director of Policy at NVHR. "Often, people aren't sure who they can talk to, especially because of the misunderstandings and stigma surrounding the disease. Voices4Hep gives people in the viral hepatitis community a forum for sharing their stories in a way that will be respected and will help them transcend any internalized shame around being sick."

Voices4Hep also seeks to inform policy makers about the need for leadership, resources and reform. To that end, Voices4Hep members participated in a [2021 Viral Hepatitis Policy Summit & Hill Day](#), hosted by NVHR and partner organizations in February. More than 100 advocates from around the country participated in the virtual event, making it the largest one ever.

The Voices4Hep network also will be active during Hepatitis Awareness Month by sharing patient stories and building awareness through social media – a campaign designed to inspire the hepatitis C community to take action around treatment access and affordability.

"Treatment coverage under Medicaid can vary considerably from state to state," Raymond said. "Patients also face treatment barriers in terms of the extent of liver damage required to initiate treatment, how long they have abstained from controlled substances, and even the type of doctor they must see for treatments. These roadblocks aren't based on best evidence or guidelines, but unfortunately they persist."

To follow Voices4Hep during Hepatitis Awareness Month, visit NVHR's [Facebook](#), [Twitter](#), and [Instagram](#) feeds, and use the hashtag #Voices4Hep.

## Community Liver Alliance: Expanding Services Nationally

The Community Liver Alliance (CLA) was established in Pittsburgh in 2013. Originally focused on the greater Pittsburgh community, CLA has grown to become a national organization and today serves the liver disease community from coast to coast. It is dedicated to supporting local communities through liver disease awareness, prevention, education and research.

"CLA provides support and education to those experiencing liver illnesses, their caregivers and health professionals," explained Suzanna Masartis, Chief Executive Officer, Community Liver Alliance. "The vision also includes educating the community at large on liver wellness and advocating to government representatives to ensure that issues surrounding liver disease, screenings, education and research funding are recognized and supported."

Like many organizations over the past year, CLA pivoted to virtual events and services, focusing on those that would be the most meaningful and provide the most value to the community. For example, it expanded its Hepatitis C Virus (HCV) Coalition into new states while continuing to focus heavily on Central Appalachia, a seven-state region hard-hit by the opioid crisis. A Central Appalachia hepatitis elimination summit is in the planning stages for Summer 2021.



*Suzanna Masartis*

CLA also has taken its provider education program virtual, allowing it to train many more health providers nationwide than would be possible with in-clinic visits. Provider training is crucial, said Masartis, to help reach the World Health Organization's goal of 80 percent viral hepatitis elimination by 2030. That goal is not attainable, she said, without allowing primary care providers to screen and treat for the disease – a practice currently limited to specialists.

"We're working diligently to increase the number of primary care providers who can screen and treat those with hepatitis C," said Masartis. "We're excited about empowering primary care doctors to make a real difference in their patients' lives, and they are excited to embrace this new way of serving their patients."

The CLA is conducting a month-long campaign for Hepatitis Awareness month in May to provide information about viral hepatitis A, B, C, D and E. Their objective is to educate the public on viral hepatitis risk factors, available treatments and therapies, encourage screening, promote linkage to care and provide patient and provider resources through print, radio and social media.

To connect with CLA during Hepatitis Awareness Month, visit its [Facebook](#) and [Twitter](#) feeds. You can also join the CLA's [Knock Knock Challenge](#), a fun awareness campaign designed to raise money to knock out liver disease.

## **Hepatitis C: An Epidemic within a Pandemic**

Both Masartis and Raymond pointed to the unique challenges faced by those with hepatitis C and substance use disorder during the COVID-19 pandemic. A National Institutes of Health-funded study found that people with substance use disorder are more susceptible to COVID-19 and its complications. In addition, liver patients fare far worse with COVID-19 than other populations, according to the CDC and health researchers.

"The pandemic has created socially isolated environments that are ripe for drug use, relapses and overdoses," said Masartis. "With the rise in drug usage, we expect to see viral hepatitis increase among this cohort."

In the early days of the pandemic, many hepatitis C patients were afraid to visit clinics for screening and treatment, leading to delays in diagnosis and care, and increasing the incidence of costly emergency department visits, according to Raymond. Moreover, he said that treatment costs – even small copays – have been challenging as people lost their jobs or were furloughed.

"On top of these factors, many health services providers previously dedicated to hepatitis elimination were redirected to COVID-focused work," said Masartis. "We saw treatment centers and harm reduction initiatives like syringe services reduce their availability or close down, further exacerbating the difficulties patients face in accessing care."

A [survey](#) supported by NVHR, HepVu and key partner organizations supports Masartis's concerns, finding that:

- Nearly two-thirds of community-based organizations providing viral hepatitis services have received inadequate or no funding to adapt services during COVID-19.
- More than half (52 percent) of community-based organizations had to furlough or lay off staff or reduce operations due to COVID-19.
- The percentage of community-based organizations offering hepatitis B/C screening dropped by nearly 60 percent.

"Hepatitis C has long been underfunded," concluded Raymond. "Immediate, ongoing and long-term investments in public health infrastructure and workforce are necessary to ensure that viral hepatitis programs can continue to provide critical services into the future if we are to achieve viral hepatitis elimination in the United States."

## **A Message from Our Sponsor**

If you or someone you know has hepatitis C and needs financial assistance to afford treatment copays, the HealthWell Foundation may be able to help. Visit our [Hepatitis C Fund](#) page to learn more about the fund and determine eligibility.

## **Additional Resources**

[Centers for Disease Control and Prevention Viral Hepatitis Information](#)

[Webinar: Building COVID-19 Vaccine Confidence in the Viral Hepatitis Community](#)

# The Importance of Being Tested for Hepatitis

The editor-in-chief of Hep magazine urges everyone to know their hepatitis status.

By Oriol R. Gutierrez, Jr, editor-in-chief, Hep magazine

I remember the first time I was tested for hepatitis C virus (HCV). It was shortly after I tested HIV positive in 1992. I found out I was living with HIV the day after my 22nd birthday. After the initial shock, I soon started seeing an HIV specialist for my health care. He recommended that I get tested for a whole bunch of other things, which included hep C.

Not only was I new back then to HIV and HCV, so was testing itself. The first HIV test was introduced in 1985 and the first test for HCV was in 1990. I got a confirmatory HIV test, which came back positive. My HCV test came back negative. I was not living with hep C. In those days I was grateful for any good news, so I celebrated being HCV-free.

However, I did not take being HCV negative for granted. Although I had never gotten a blood transfusion or used injection drugs, I was a sexually active gay man. That alone put me in a risk category for hep C. Studies over the years have only further supported the fact that HCV can be sexually transmitted. Getting tested regularly for hep C became routine for me.



*Oriol R. Gutierrez Jr.*

## A Reason to Test for Hep C

In addition to being gay, I am also Latino. I had no real understanding when I first tested for HCV just how much being a person of color also gave me a reason to test for hep C. Now as editor-in-chief of Hep magazine and [HepMag.com](http://HepMag.com), I am all too aware how people of color continue to be disproportionately affected by viral hepatitis, especially hep C.



Statistics from the U.S. Department of Health and Human Services Office of Minority Health tell a stark story. In 2017, compared with whites, African Americans were 1.5 times as likely to die from viral hepatitis and Latinos were 70 percent more likely. In 2018, compared with whites, African Americans were almost twice as likely to die from hep C and Latinos were 40 percent more likely.

Of course, viral hepatitis is broader than hep C. The two other common viral causes of hepatitis are hep A and B. While hep A is often associated with food and isn't generally deadly, hep B is a killer. Although African Americans had similar hep B case rates compared with whites in 2016, they were 2.6 times more likely to die from hep B than whites.

## **A Cure for Hep C**

For decades, both hep B and C had no cure. That changed for hep C in the 1990s with the introduction of combination therapies that cured the virus. The initial cures were harsh for most people, but newer cures became available starting in 2014 that are highly effective and easier to take. Researchers are getting closer to a hep B cure, but are not there yet.

Hep B does have effective treatment which, until there is a cure, must be taken for the rest of the patient's life. The same is true for HIV. Since I'm already taking HIV treatment, I didn't want another such situation. To that end, years ago my doctor recommended that I get vaccinated against hep B. Unfortunately, my immune system didn't respond, so I'm still susceptible to hep B.

The prime suspect for my inability to respond favorably to the hep B vaccine is HIV. The interconnections of HIV with viral hepatitis keep rolling on. Most importantly, people living with HIV in the United States often have coinfection with hep B and C. About a quarter of those with HIV also have hep C and about 10 percent of people who have HIV also live with hep B.

## **Routine Testing Should be Standard**

There are more than three million people living with hep C nationwide and over one million with hep B. There are also more than one million who have HIV across the country. Too many people, regardless of their demographics, are unaware of their viral status. Routine testing for all these conditions should be standard. Treatments and the chance at a cure make testing worthwhile.

As I mentioned, both HIV and hep B have effective treatments and hep C even has an easy-to-take cure. Nonetheless, access to treatment or a cure remains far from affordable for countless people in need. Whether it's no health insurance or inadequate health insurance, cost doesn't have to get in the way of saving lives. Organizations like the [HealthWell Foundation](#) can help underinsured individuals living with hep C cover the cost of their medication treatments or insurance premiums through their [Hepatitis C Fund](#).

In the United States, the month of May is Hepatitis Awareness Month and May 19 is Hepatitis Testing Day. Increasing knowledge of all kinds of viral hepatitis is an overall goal. However, raising awareness about both hep B and C is a specific goal. Everyone should get tested for viral hepatitis, but especially people living with HIV and people of color. Get tested today!

*Oriol R. Gutierrez, Jr. is the editorial director of Smart + Strong, a health care information company. He is the editor-in-chief of Hep magazine and HepMag.com, which focuses on hepatitis and liver health, as well as POZ magazine and POZ.com, which chronicles the HIV/AIDS epidemic. Both publications are published by Smart + Strong.*

# Hepatitis C: Fighting the Stigma as Well as the Disease

Warren Hall has grown accustomed to the fear and trepidation in the voices of people who have been diagnosed with hepatitis C. As National Manager of Support Services for the American Liver Foundation (ALF), Hall regularly speaks with callers to the ALF helpline and participates in live chat sessions to educate people about the viral disease and answer their questions.



*Warren Hall*

"Sometimes, people are looking for a basic understanding of hepatitis C and how it affects the liver," Hall said. "They may not be exactly sure what hepatitis C is – they just know it's something they don't want. It's important to educate them that if left untreated, hepatitis C can cause significant liver damage."

In many cases, Hall and his team at ALF address issues beyond the medical and physiological ones. He said hepatitis C, along with other liver diseases, carries a stigma that can lead to a range of emotions, from denial to embarrassment and even hopelessness.

"Liver diseases in general are often associated with what some consider poor lifestyle choices, like excessive use of alcohol," he said. "In the case of hepatitis C, the most common associations are injectable drug use or unsafe sexual practices."

Hall likened the hepatitis C stigma to the negative stigma attached to HIV and AIDS in that virus's early years. He pointed to 1980s and 90s advertisements for HIV testing that were alarmist and accusatory – casting dispersions on the gay community – and contrasted them with today's advertisements for HIV treatments showing happy, smiling people going about their daily lives, confident in their ability to treat their disease.

## **"What Will People Say?"**

Hall is quick to point out that, just as a teetotaler can contract a liver disease (for example, nonalcoholic steatohepatitis or NASH), so too can someone contract hepatitis C without ever having used IV drugs or practiced unsafe sex. In fact, most baby boomers – who represent 75 percent of hepatitis C cases in the U.S. – contracted the disease from a blood transfusion conducted before hepatitis C was discovered in 1989.

Younger people, however, are also at risk. Recently, troubling increases in the rate of new hepatitis C infections related to injection drug use have occurred among young people in some parts of the country, according to the Centers for Disease Control and Prevention (CDC).

Hall said that, while baby boomers tend to question how they got hepatitis C, many younger people who reach out to ALF's Support Services don't. Instead, they express fear over friends and family finding out.

"Their fear isn't necessarily connected to the health aspects of the disease," Hall said. "It's connected to the stigma of the disease. They worry about what people will say or what will happen when their parents, spouse or friends find out. They also worry that it's something they'll have to live with for the rest of their lives."

The best way to counteract the perceived stigma, Hall said, is speaking matter-of-factly about hepatitis C and creating an action plan for starting and completing treatment – regardless of the way someone contracted the disease. This approach is particularly effective for people who have been diagnosed recently and aren't experiencing any symptoms.

"We are positive and encouraging, never harsh or accusatory," he said. "We are cure-focused, not cause-focused and let them know that not only can hepatitis C be treated, it can also be cured within a matter of months. They can take care of it and nobody needs to know. That usually provides a sense of relief and gives them peace of mind moving forward."

## **Hepatitis C Screening**

While there is currently no vaccine to prevent hepatitis C infection, highly effective treatment options are available. However, because hepatitis C initially has few noticeable symptoms, at least half of those infected don't know it. That's why the CDC says it's critical for everyone at risk for hepatitis C to get screened, including:

- Everyone born from 1945 through 1965
- Anyone who has ever injected illegal drugs
- Recipients of blood transfusions or solid organ transplants before July 1992, or clotting factor concentrates made before 1987

- Patients who have ever received long-term hemodialysis treatment
- People with known exposure to hepatitis C, including:
  - Health care workers after needlesticks involving blood from a patient with hepatitis C
  - Recipients of blood or organs from a donor who later tested positive for hepatitis C
- People living with HIV
- People with signs or symptoms of liver disease (e.g., abnormal liver enzyme tests)
- Children born to mothers who have hepatitis C

## Financial Assistance for Hepatitis C Treatment

Hall said that while the stigma associated with hepatitis C can keep people from seeking treatment, the cost associated with treating the disease can also be a deterrent. He brings up the issue of treatment costs in virtually every patient interaction and shares financial assistance resources.

"We don't want people to get excited about the cure, only to be shocked and put off by the cost," Hall said. "We make them aware of various assistance options."

One such option is provided by the sponsor of *Real World Health Care*, the HealthWell Foundation. HealthWell's Hepatitis C Fund provides up to \$30,000 in financial assistance to qualifying individuals to help pay for insurance premiums or medication copayments for the treatment and management of hepatitis C.

"The financial aspect of treating hepatitis C should never get in the way of getting cured," concluded Hall. "Your health is too important."

# Get Tested, Get Cured: Hepatitis C Infections Rising Among 20-39 Year-Olds

Viral hepatitis is a serious, preventable public health threat that puts people who are infected at increased risk for liver disease, cancer and death.

The World Health Organization (WHO) has called for a 90 percent reduction in new hepatitis infections and a 65 percent reduction in deaths by 2030. Unfortunately, rates of hepatitis C cases – one of the three most common hepatitis viruses – nearly tripled between 2011 and 2018. Today, an estimated 2.7-3.9 million people in the U.S. have hepatitis C, with about 57,000 acute infections diagnosed in 2019. Two-thirds of cases now occur among people aged 20-39, the age group most impacted by the opioid crisis.

"We are on the wrong road to hepatitis C elimination," said Lorren Sandt, executive director of [Caring Ambassadors](#). "Concurrent with the nation's opioid crisis, we are now facing a syndemic of continued spread of hepatitis C among people who inject drugs."

## Barriers to Hepatitis C Elimination

Caring Ambassadors is a non-profit organization dedicated to eliminating viral hepatitis and specifically hepatitis C. Sandt co-founded the program in 1999, when hepatitis C research and treatment were in their infancy. Standard western therapy was successful in less than 28 percent of those treated.



*Lorren Sandt*

Today, effective clinical interventions have reduced morbidity and mortality associated with viral hepatitis. Accurate diagnostic tests detect hepatitis C infections years before symptoms develop. And hepatitis C therapeutics, such as direct-acting antiviral (DAA) therapies, can cure hepatitis C infections with an efficacy rate greater than 95 percent.

Despite these significant medical advances, Sandt remains concerned. "We are facing dual challenges of a public health infrastructure that is not funded to support elimination and a general public that is hesitant to get tested," she said. "Until recently, it's been very difficult for people with hepatitis C to access treatment unless they have significant cirrhosis and demonstrate continued sobriety – two factors that have created significant disparities for younger adults."

Sandt noted that treatment costs can also be a barrier to starting treatment.

"We encourage everyone who has tested positive for hepatitis C to take advantage of assistance programs available through the pharmaceutical companies supplying the therapies as well as through organizations such as the HealthWell Foundation's [Hepatitis C grants](#) that provide up to \$30,000 of medication copay or insurance premium assistance for qualifying individuals," Sandt said.

## **Bringing Hepatitis C Out in the Open**

Sandt called hepatitis C a "silent disease" and said increased awareness of the disease is crucial to eliminating it. She has spent years advocating for increased hepatitis C funding at the state and federal level, holding over 1,000 meetings with elected officials; training 150+ advocates to participate in "Hill Days;" sponsoring numerous roundtables with advocates, law enforcement, and legislators; and supporting the [Oregon Viral Hepatitis Collective](#) of key stakeholders in the fight against hepatitis C infection.

"Hepatitis-related illness kills someone in the world every 30 seconds," Sandt said. "Yet there is an alarming lack of funding and political will focused on prevention and treatment. We simply cannot eliminate this disease if we don't fund it."

Caring Ambassadors also supports public testing events, like the one they ran for 13 years straight at the annual Waterfront Blues Festival in Portland (prior to the COVID pandemic).

"We tested between 300-600 people each year at the Festival," Sandt said. "We always received great support from the musicians performing there, who would encourage people to get tested. We've worked with other musicians on awareness campaigns as well, including Grammy Award-winning blues musician Curtis Salgado, and Bruce Conte from Tower of Power. We are grateful for the support of the musician community, which has been hard-hit by this disease."

On World Hepatitis Day (July 28), Caring Ambassadors joined the World Hepatitis Alliance in its [Hep Can't Wait](#) campaign. The campaign's theme stresses that the world shouldn't wait to act on viral hepatitis, even during the COVID-19 crisis. In addition to a social media campaign, Caring Ambassadors recognized World Hepatitis Day by lighting up Portland's Morrison Bridge.





## **Patients Need to Advocate for Their Health**

Being out in the open about hepatitis C also means having frank conversations with care providers. Sandt encourages people to advocate for their own health and not get talked out of getting tested and treated. Caring Ambassadors offers a tool to help: [Hep C Discussion Point™](#), a private online questionnaire designed by medical experts that generates a customized list of topics for people to use as a guide in talking with their doctor about their hepatitis C health care.

Another patient tool, [My Choices©](#), is designed to help those with hepatitis C recognize and act upon what they can control in their health care journey to achieve optimal healing. The tool contains elements of a guidebook, health planner, journal and activity book and promotes an integrative approach to health and medicine.

"When we launched My Choices, about 70 percent of those with hepatitis C weren't eligible for treatment," Sandt explained. "We needed to encourage that 70 percent to make meaningful lifestyle and wellness choices that would keep them alive until the cure came. Today, people turn to My Choices for goal tracking, self-advocacy and empowerment, often working on one issue or section at a time if they're not quite ready to tackle everything. It's important to remember that your holistic health and wellness need to continue even after you're cured."

## **Integrating Hepatitis C into Medical Care**

In addition to raising awareness about hepatitis C among patients and the public at large, Caring Ambassadors strives to raise visibility for the disease among the medical community. They have worked with health systems, hospitals and community clinics, teaching professionals at all levels – administrators, physicians, nurses, social service providers and outreach workers – how to integrate hepatitis C into their practices.



"Our training covers everything from what Hepatitis C is, how to test for it, and how to diagnose it, to care protocols, care resources, and even how to apply the correct billing codes," Sandt said. "We also focus health provider training on harm reduction measures for patients who use injectable drugs. We want providers to have the knowledge and tools they need to create micro-elimination projects within their clinics and systems."

## **Listen to Their Stories**

Get tested. Get cured. It's a simple message that bears repeating, according to Sandt, and one that has inspired people impacted by the disease to speak out on their behalf. Caring Ambassadors, in partnership with StoryCorps (an initiative dedicated to preserving and sharing humanity's stories in order to build connections between people and create a more just and compassionate world), has collected dozens of powerful stories from everyday people impacted by hepatitis C, along with reflections from artists, musicians and poets.

"We invite everyone to listen to these inspirational stories of personal empowerment and take from them what they need to start taking control of their own lives," Sandt concluded. "Now is not the time to wait."

## **Additional Hepatitis C Resources**

U.S. Department of Health and Human Services. Viral Hepatitis National Strategic Plan: A Roadmap to Elimination. Accessed 6/14/21.

American Liver Foundation