The Hep 10

Meet 10 fierce HCV advocates who are raising awareness about the virus and making sure everyone has access to care and treatment.

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We're living in an exciting, hopeful era for curing hepatitis C virus (HCV), with powerful new drugs on the market and more to come. These drugs are making treatment shorter and easier to take, and they're boosting cure rates to nearly 100 percent. But prior to this optimistic moment, some folks—with and without a history of hep C—have been on the front lines of the fight against this disease for years. They provide lifelines for newly diagnosed people as well as those living long-term with the virus. They start support groups, help patients understand the latest science and advocate for their best options in an imperfect world, and they push drug makers and law makers to invest in testing, care and treatment for those living with the virus.

In a word, they're hep superstars, mavericks who've been working hard, often with little credit, to get the word out about HCV to an underinformed public and to make sure that everyone has the best access possible to care and treatment. Often they've had to tear down walls of stigma, bias and misinformation as they insisted that everyone has a right to quality care. It hasn't always been easy. Nor will it get easier in an era when effective treatment is available but high prices threaten to hold it back from all who need it. From the Pacific Northwest to the Bay Area to New York City, these advocates do a lot of one-on-one caregiving and counseling on a daily basis. They also head to their statehouses and to DC, where they demand continued support. Here, we salute them. Meet 10 inspiring individuals around the nation working to make hep C a thing of the past.

Orlando Chavez
Oakland, CA
Senior peer educator
Oasis Clinic

Orlando Chavez got involved in hep C activism when he came to the Oasis Clinic a decade ago for treatment: "Everyone else had written me off, doctors would not treat me, and I wasn't getting the right information to make an informed decision." He cleared the virus with interferon and ribavirin but, he says, "once I saw how many others were perishing for lack of knowledge, I knew I had to get involved.” His top priority at Oasis is pushing for fair and affordable access to care and treatment. He says that Oasis’s nonjudgmental harm-reduction approach helped him gradually stop using drugs completely and quit cigarettes. “More traditional approaches fit me like tight shoes,” he says. “Good for a few miles—then come the blisters!” To HCV-positive folks, he says, “Don’t freak out; you’re part of a very big family. Find a support group and get educated. We all deserve a cure.”

Ryan Clary
San Francisco, CA
Executive director
National Viral Hepatitis Roundtable

In 2006, HCV advocates asked Ryan Clary to share strategies and lessons he’d learned from years in HIV grassroots organizing. “Seeing the shamefully inadequate resources for hep C, I decided it was time to join the fight,” he says. Since then, he’s helped lead successful efforts to change the U.S. Preventive Services Task Force’s hep C testing recommendations and to ensure that Medicare covers HCV testing at no extra cost to patients. His top goal going forward? “Ensuring that everyone—and I mean everyone—who has hepatitis C knows their status, is linked to care and has access to the cure.” He urges HCV-positive folks to speak up to help create change: “Being an activist starts by telling your story. Speak out, demand change and hold our leaders accountable.”

Alan Franciscus
Sacramento, CA
Founder and executive director
Hepatitis C Support Project

After a 1996 HCV diagnosis, “I realized there was no one out there educating people and providers,” says Alan Franciscus, one of the pioneers of hep C activism. So he started a support group, which included those who had both hep C and HIV. “The more I did, the more need I found,” he says. So he started hcvadvocate.org, set up national training workshops and printed educational publications. “It’s an honor to educate people with hep C and those providing services to them,” he says. His top goal going into 2015 is to help people access powerful but costly new hep C drugs. As for him, a third try at HCV treatment—pegylated interferon plus ribavirin—lasted a grueling 70 weeks. “It was worth it because I was cured,” he says. “I’ve regained my physical and emotional health. Everyone should be able to experience that freedom.”

Jules Levin
New York, NY
Founder and executive director
National AIDS Treatment Advocacy Project

Jules Levin tested positive for HIV in 1987 and then for hep C a decade later. “I realized HIV/HCV coinfection was going to be a big concern but wasn’t getting any attention,” he says. Though he cleared his own hep C in 2002, he devoted his life to helping people living with HIV and/or HCV, playing a key role in getting hep C incorporated into the federal Ryan White CARE Act for people with HIV/AIDS. He's a pioneering coinfection advocate whose National AIDS Treatment Advocacy Project site is widely read for the latest news from medical conferences. "Get treated, don't delay too long, and get rid of the virus," is his advice for folks with hep C. He also wants everyone to become an activist. "After all these years of waiting," he says, "we can finally cure people with 12 weeks of interferon-free, tolerable therapy. But we must get the federal government and the states to invest in testing and linkage to care and treatment."

Heather Lusk
Honolulu, HI
Director
The CHOW Project
Co-director
Hep Free Hawaii

Attending a global hep C conference in 1995 sparked Heather Lusk to do something about the disease. "I didn't get hep C, but I could have easily gotten it" due to past drug use, she says, "so I felt blessed and [knew] that I had to help fight this epidemic." Since then, she secured ongoing funds for HCV screenings in Hawaii and she launched Hep Free Hawaii's care coordinator program, which provides free medical case management for Honolulu residents living with hep B or C. She's dedicated to increasing access to testing and to treatment. "With a cure out there, people should know their status and have access to culturally competent care and life-saving meds," she insists. To those living with the virus, she urges, "Break the silence! Contact your local and national policy makers and let them know why hep is important. It sounds clichéd, but one person really can make a difference."

Michael Ninburg
Seattle, WA
Executive director
Hepatitis Education Project

Michael Ninburg became head of the Hepatitis Education Project in 2001 while he was a hep C patient. "There was clearly a need for the support and advocacy that the project provided, and there still is now, more than ever," he says. Since then, he counts legislative and policy advances among his successes, but not more than the achievement of "getting individuals tested, treated and cured." Ninburg himself was cured in 2009 in a clinical trial for the drug telaprevir (Incivek). "The side effects were terrible, but it worked," he says. To those with the virus, he advises: "Now's the time to get treated and cured. Treatment has come a long way the past year, now that interferon is out of the mix. Cure rates are approaching 100 percent. No one has to die from hepatitis C anymore—it's simply a question of making it a priority and allocating resources."

Lorren Sandt
Beavercreek, OR
Co-founder and executive director

Caring Ambassadors Program

A brother’s 1999 hep C diagnosis plunged Lorren Sandt into activism. Since then she helped create the first national coalition of HCV working groups, resulting in a 2009 merger of the National Hepatitis C Advocacy Council and the National Viral Hepatitis Roundtable. The coalition has published the Hepatitis C Choices book, now going into its fifth edition. Next year, she’ll focus on building new leaders in hep C policy through the Hepatitis Leadership Corps, with a goal of getting the Viral Hepatitis Testing Act signed into law. “Be an ambassador for your own health,” she urges people with hepatitis. “Educate yourself and advocate for your needs!”

Gloria Searson
West Haven, CT
President
COPE/Coalition on Positive Health Empowerment

Living with both HIV (undetectable since 1996) and hep C (currently undergoing treatment), Gloria Searson, MSW, helms the East Harlem–based COPE, which educates and links to care folks with liver-affecting illnesses including hep C. Her focus on HCV evolved out of her work in substance abuse, HIV and other social-justice challenges that create health disparities. She’s proudest that, at COPE, she and others have created “a coalition of advocates and patients fighting for access, education and quality care,” she says. She urges others living with HCV to “get educated and select what options will work for you. Go for the cure!” She says that, despite improved hep C treatment, there’s still much work to be done. “We need partnerships from grassroots groups all the way to every statehouse in the world!”

Susie Simon
Scotch Plains, NJ
President
Hepatitis C Association

Diagnosed with hep C in 1991, Susie Simon underwent years of failed treatments until finally clearing the virus in a clinical trial in 2013. A few years after her diagnosis, she got involved with counseling other newly diagnosed folks so that they “did not feel as frightened and alone as I did when I was diagnosed,” she says. At the Hepatitis C Association, she’s proud to have launched an HCV education program for use in substance abuse clinics throughout the country, which was funded by the U.S. government for a decade. “Don’t fear the new treatments,” she says. “They are easier than ever in terms of side effects and duration of treatment. So know your status and get tested. There’s a cure now for most people.”

Nancy Steinfurth
Denver, CO
Executive director
Hep C Connection

A former arts administrator, Nancy Steinfurth says, “I didn’t know what I was getting into,” when she took the helm of Hep C Connection. But since then, she’s gotten the Colorado legislature to twice restore crucial funding for hep C programs and to pass a law recommending that Colorado baby boomers get tested for the virus. Her top challenge going forward? “Working to expand access to hep C treatment through Medicaid,” she says. “We don’t want people to be as sick as they currently have to be to qualify.” Steinfurth does not have HCV, but she knows several middle-agers who do. “One passed away because she was too ashamed to seek treatment; one cleared the virus but is too ashamed to talk about it with anyone; and another one needs treatment but won’t give up beer,” she says. She urges folks in Colorado and beyond to call her group’s help line: 800.522.4372.