Positive Empowerment

Building a coalition of advocates, Gloria Searson uses a holistic approach to change the way people think about hepatitis C.

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Gloria Searson has never let her circumstances define her. Instead, she has always found a way to turn them into opportunities to help and educate those within her community. That’s precisely what she did when she learned she was living with HIV and hepatitis C virus (HCV).

“Hep C scared me more than HIV,” explains Searson, 58, an advocate, health care provider and social worker. “They say 30 years is the progression of HCV with no HIV. I’ve lived almost half my life with both. I had to learn how to do it well or else it would have been a horrible half of my life.” Today, she is hep C–free, and her HIV viral load is undetectable.

While in rehab in 1991 for a six-and-a-half-year addiction to crack cocaine, she tested HIV positive. “I think that HIV and that death sentence—as it was considered back then—was my get-woke moment.”

Her main priority at the time was remaining drug-free, so she didn’t initially address her HIV diagnosis. She also didn’t want to discuss her HIV status with anyone because she felt the virus was a by-product of her addiction.

Searson joined the recovery program Narcotics Anonymous (NA) in an effort to overcome her substance dependence. However, about a year into living with HIV, her sponsor told her that NA wasn’t really working for her because she hadn’t addressed her virus.

“My sponsor challenged me,” she recalls. “She said, ‘If you don’t deal with your HIV, you’ll probably relapse in a year or two. It’s something that you have to deal with.’ She also felt like I was someone who could do something about being HIV positive.”

Searson would have to leave her Brooklyn neighborhood to learn how to take care of her HIV and to get accurate information about the virus because “information wasn’t funneled into Black communities,” which was something her sponsor understood.

That’s why Searson’s sponsor sent her to Stand Up Harlem—a now-defunct organization that provided housing to homeless people and people with addictions who were also living with HIV. She credits the organization with helping her turn her life around and accept her status. “It was the first time I had said out loud that I have HIV to another human being," she says. "From there, I just moved forward."

She spent the subsequent years learning about HIV and educating those around her. This included stints at the former advocacy organization People of Color in Crisis, the People with AIDS Health Group and the National AIDS Treatment Advocacy Project (NATAP).

"Not only did I get the science, but I also had the ability to interpret it and give it back to the people like me who didn't come from a science or health and wellness background," she says. "I realized that I could beat HIV because I watched the science over the years." And she was right. She's been virally suppressed for 20 years.

In 1997, Searson found out that she also was living with hep C. It was her involvement in the Women's Interagency HIV Study (WIHS), an ongoing investigation into the progression of HIV in women, that led to her HCV diagnosis.

During this time, Kathryn Anastos, MD, the key study investigator at WIHS's Bronx, New York, site, began testing participants for hep C. Data had shown that a large number of women with HIV and those who had a history of substance use or partners who did were at risk for HCV.

Searson believes that she contracted HIV and hep C around the same time, but no one tested her for the latter virus until the study.

Searson also remembers seeking help from her HIV provider after learning she had HCV. However, she was referred to a hepatologist—a specialist who handles viral hepatitis and diseases related to alcohol—who instead advised her to return to her regular physician. Her HIV doctor eventually told her that she would live only 30 more years with hep C. And that was the extent of the information she received.

"Because I worked for Jules Levin at NATAP, I knew the science," she says. "I couldn't sit still with that information. I changed doctors and did some other things to just move the agenda forward to make sure that everybody with HIV got tested for hep C."

Although treatment options were scarce, especially for African Americans and women, Searson continued to learn more about hep C. It wasn't until 2004 that she noticed new types of treatment were being developed that potentially could help a person's liver get better.

"I knew the data was saying that people with HIV were going to progress more quickly with their hepatitis," she explains. "So I went on treatment and had a horrible experience. It was the only time that I ever got sick with either illness." She became even more frightened of hep C but also more diligent in confronting it.

Then, in 2009, she noticed that researchers were developing new HIV treatments, which she believed meant that a more effective drug to treat hep C was on the horizon. Consequently, that same year, she decided to form the Coalition on Positive Health Empowerment (COPE), a nonprofit organization based in Harlem that provides services that tackle chronic liver-related diseases and other conditions that affect the liver.

As new medication emerged in the pipeline, Searson wanted to empower folks to advocate for themselves and to rethink treatment. But she also realized it wouldn’t be a walk in the park.

“I knew I couldn’t do it by myself,” Searson says. “I had to build a coalition of people—providers, policymakers, advocates, drug treatment counselors and patients. We needed to get together and change the way people thought about hep C.”

COPE uses a peer-led model, among many others, to integrate HIV and hep C into chronic, manageable diseases. The organization uses a holistic approach to understand the social needs of patients.

COPE employs 12 peer workers as part of a testing and outreach team, has a network of 48 providers, offers an HCV/HIV support group and has linked 268 individuals to care and helped cure 147.

According to Searson, who splits her time between Connecticut and New York City, it’s the best job that she has ever had. Although the organization struggles to secure funding from all levels of government, her private donations remain intact.

“It shows me that at least they’re willing to support my efforts because they know the value of what I do,” she explains. “Maybe I have something to contribute to what the city, state and federal governments are trying to do with this population. That’s what I’m trying to do with COPE.”

One of her goals is to focus not only on folks currently engaged in risky substance use but also on addiction survivors who may not want to discuss hep C or talk about their past.

“I want them to come in, stop hiding and stop feeling shame or guilt,” she says. “If it means I have to share my story to empower them, I will. I always say that I have to walk the walk because our community is tough on us. Could you imagine if I didn’t look well and I was talking about all of this? It would be hard for them to buy into what I’m saying.”

In 2014, Searson was cured of HCV after taking one of the newer direct-acting antivirals. “With medicine now, you have to pick something that fits into your lifestyle,” she explains. “Treatment is a commitment for life. You do the best you can. Sometimes you have to switch, just like in relationships, because it didn’t work out.”

She also encourages those struggling with adherence to recognize their worth. “We’ve got to try,” she says. “I don’t think we’ve come this far to let something knock us down, especially when there are things we can do about it. Get rid of the shame and guilt. Go take care of it. It will be gone.”