hep

As Long as I Live

HIV advocate Lepena Reid is living free of hepatitis C.

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Lepena Reid tested HIV positive in 1988, after spending the early ’80s caring for friends and others living with the retrovirus as well as working with AIDS organizations.

“I didn’t start medications until about 15 years later,” says Reid, a 63-year-old advocate living near Tampa. “The reason was because many of the friends I saw were on [older drugs], and they were dying.”

Reid didn’t begin taking HIV meds until 2002, when she ended up in the hospital with pneumonia. HIV aside, the worst health problem she’d experienced before that was an occasional cold. “I always ate healthy and exercised spiritually,” she explains. “I always had my belief in my faith. I just had that will to live.”

In 2003, Reid went to the hospital for a biopsy and was diagnosed with hepatitis C virus (HCV). Reid didn’t start HCV treatment until a year later, when her doctor put her on an interferon regimen, which required weekly injections.

“I got prepped for it,” Reid recalls. “There was a time before beginning treatment that you got a lot of tests to see if your body would even sustain the interferon.”

Reid’s doctor warned her that the hep C treatment could make her weak. Interferon was known to cause side effects ranging from mild to severe. Common side effects include cough, runny nose, depression, moodiness and flu-like symptoms.

In recent years, direct-acting antivirals (DAAs) have emerged, replacing interferon as a standard treatment for people with hep C. These medications tend to be safer, more tolerable and highly effective with a shorter treatment duration. In addition, people who take DAAs are more likely to be cured of HCV.

“After I got the injections, I was very weak, achy and irritable,” Reid says. “My blood levels began to be very low.”

As a result of her low red blood cell count, Reid was told she’d need a blood transfusion. Because she resisted, her doctor prescribed her Procrit, an injectable medicine used to treat anemia.

“It was really a hard regimen on the body,” Reid says of interferon. “I tried to stay with it for about eight months. But I couldn’t take anymore, and I stopped.”

Over the years, Reid’s doctor kept a close watch of her hepatitis. As new treatments came out in 2014, Reid’s doctor suggested she’d be a good candidate for Harvoni, one of the first DAAs approved by the Food and Drug Administration.

Harvoni combines 90 milligrams of ledipasvir and 400 mg of sofosbuvir into a single tablet. This interferon-free treatment can vary from eight to 24 weeks, depending on a patient’s viral load, genotype, prior treatment experience and the presence of cirrhosis.

Reid was at first hesitant to take the drug because of the horrific experience she’d had with interferon. However, after talking to others who’d taken Harvoni and been cured, she opened up to the idea.

So once again, Reid was prepped. She received infusions of iron to get her blood levels up. In August 2015, she started on a three-month, one-tablet-daily regimen of Harvoni. “When I went back for my first lab work, it showed extremely good progress,” she says. “That was a great sign.”

In October 2015, as Reid was finishing up her treatment, she received a call informing her that she was cured of hep C: Her last lab results showed no signs of HCV.

“It just seemed incredible,” she says. “At that point, I said, ‘If we could just get some news like this about HIV, what a time it would be.’ It was a huge celebration and relief.”

Reid’s test results continue to show that she is hep C–free. “Here is a medication that really did what it said it was going to do, and it really wasn’t hard,” Reid says. “It was miraculous.”

Her hope is that everyone living with hepatitis C can be cured one day, but she knows access to treatment remains a concern for many people.

“Science is coming through with amazing advancements,” Reid says. “My hope for the future is that we see the same thing with HIV. These pills are nothing like HIV, where you have to continue with them for the rest of your life.”

As for her HIV, Reid has experienced some physical changes—she has gained weight. By her count, she’s put on 20 pounds in the last two years.

In 2018, Reid and her doctor switched her to a single-tablet HIV regimen to reduce her pill burden. At one point, she had been taking three pills daily.

After the switch, Reid gained weight. She told her doctor and started doing research. She spoke with other people in the HIV community who shared their own experiences with weight gain.

She learned that one component of the tablet—tenofovir alafenamide (TAF)—was associated with weight gain. In addition, the pill contains an integrase inhibitor, another possible culprit.

“I really eat healthy,” she explains. “I don’t drink alcohol, smoke or none of those things. My diet hadn’t changed, but my weight was increasing.”

Her new weight has made her feel uncomfortable and larger overall. “I’m very disappointed with my appearance right now,” she says. “When I look at myself and how my clothes fit on me, I don’t feel good about it.”

Nevertheless, Reid has kept up her wellness habits. She regularly eats vegetables, makes her own juices and walks twice a day. She doesn’t eat seafood but does sometimes enjoy chicken. Even so, she still hasn’t lost any weight and considers her belly a problem area.

After observing no decrease in her weight, her HIV specialist recently switched her to a different single-tablet regimen that does not include TAF but does contain an integrase inhibitor. Although she hasn’t shed any pounds yet, she is optimistic about the future. “I hope I can go back to my doctor soon, and they’ll do something else because these 20 pounds are just not comfortable for me,” Reid says.

What’s more, Reid is very worried about developing dementia, as she has a family history of the condition. She also knows HIV can affect brain function and lead to HIV-associated neurocognitive disorders.

Otherwise, Reid isn’t too concerned about her health and remains active.

Despite the ongoing COVID-19 crisis in the United States, Reid continues to facilitate support groups for women living with HIV, albeit via telephone. She also crafts red ribbon earrings—to raise awareness and support for HIV-positive people—as well as other jewelry as a member of Common Threads, a crafting collective of women living with HIV.

Reid plans to continue celebrating life—whether she’s spending time at the beach, crafting, skydiving, laughing or advocating for people living with HIV.

“I’m still alive,” Reid says. “If you’re alive, you have a possibility to do and create, and that’s what I want to continue to do as long as I live. I’m doing the best each and every day that I can for myself and my community.”