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Paying It Forward

Hepatitis C activist Shirley Barger is fighting so everyone can access treatment.

September 5, 2016 By Tim Murphy

Shirley Barger—a retired computer expert and a dyed-in-the-wool San Franciscan since she moved to the Bay Area at the height of Flower Power in 1968—was cured of hepatitis C virus (HCV) in 2013.

Now 67 years old, she feels great. “I know people who’ve been cured who say they feel 21 again. I wouldn’t go that far,” she laughs. “But I feel better than I have in a long time. Clearing hep C really lifted me up emotionally.”

Yet putting HCV behind her doesn’t mean she has stopped advocating for others with the virus. She continues to cochair the San Francisco Hepatitis C Task Force, which she has done for the past three years. However, it does mean she now has the energy to enjoy things like local museum hopping. “I just went to the new SF MOMA [San Francisco Museum of Modern Art],” she says. “It’s quite a beautiful showcase for art.”

That’s just one way that life without hep C has helped Barger reconnect with a city she moved to as a teen from North Carolina after both her parents died. “My friends and I were fascinated with what was happening in San Francisco,” she says. “I came for the summer but ended up staying. There were lots of people on the street, and Haight-Ashbury was pretty wild, full of young people, concerts, antiwar rallies—and lots of drugs.”

Barger rented a cheap room, sold indie newspapers on the street and cleaned rooms at the YMCA to make money. Like many young people in the city at that time, she also dabbled in drugs, including experimenting with needles three times, which is how she thinks she got hep C.

In time, she landed a job processing medical claims, went to college and became one of the first people to code and administer computer systems in the 1970s, working for San Francisco City College until her retirement three years ago.

By the early 2000s, Barger was experiencing constant fatigue and joint pain. A doctor ran a battery of tests on her but didn’t even ask about HCV. Barger knew someone with the virus, so she said to the doctor, “Well, as long as you’re testing me for pernicious anemia, how about hep C, too? And the doctor said, ‘Oh, you wouldn’t have that,’ but I asked her to test me for it anyway.”

Sure enough, Barger had HCV. The assumption that she “wouldn’t have that” is all too common among doctors with regard to middle-age patients who don’t appear to be active drug users.

“I had to educate myself,” she says. “I bought a couple of books and decided that I had every possible symptom of cirrhosis [advanced liver disease]. Then I got tested for my genotype, viral load and disease stage and found out that I actually wasn’t really that sick.”

She started going to meetings at the Hep C Support Project led by esteemed local hep activist Alan Franciscus. “It was like finding your tribe,” she recalls. “Several people there were on treatment.” The meetings motivated Barger to undergo treatment herself: 48 weeks of interferon and ribavirin.

It was horrible. “Exhaustion that just kept building, lots of aches and pains, night sweats,” she recalls. “I felt like I was 95 years old. Pushing the grocery cart was really hard. Thankfully, I didn’t have a job that required physical labor, and I could work partly from home. My colleagues were really helpful.”

On top of all that, she found out six months after treatment that her viral load had rebounded. The treatment had failed. “I cried when I found out,” she says. But that didn’t stop her from trying treatment again in 2007. “I got sick the first night and stayed sick the entire time, plus I had serious anxiety because they didn’t put me on an antidepressant first.” Once again, the treatment failed.

Fast-forward to 2013, by which time the new HCV protease inhibitor drugs had come along and were already showing remarkable success, curing people fast and without horrible side effects. Barger went into a trial for a drug that turned out to be Harvoni.

“I was assigned to 12 weeks of the drug,” she recalls. “I felt very good all the way through except for a mild headache, and I actually thought the drug wasn’t working because it didn’t feel strong enough.”

But after the first week, her viral load dropped from around 3.5 million to 151. “I couldn’t believe it,” she says. Then she reached undetectable, where she has remained, and she’s felt younger and healthier ever since.

Now hep C–free, Barger has even more energy to fight for people still living with the virus. Issues of concern to her include expanding HCV testing and increasing access to the new hep C drugs by lowering their costs.

As a member of a special committee formed to tackle both hepatitis B and C in San Francisco, she has pushed for comprehensive policy changes. “We’ve got a number of medical providers and community organizations trying to come up with a plan to really address the disease here in a coordinated fashion,” she says.

She’s proud that the city has added a $500,000 line item to its budget over the next two years to do just that. “That’s paying for a viral hepatitis coordinator from the department of health,” she says, “who’s coming up with campaigns to educate people via screenings, such as pilot projects at certain pharmacies.”

Getting hep C treatment to everyone who needs it remains a big challenge. “There are still restrictions from various insurers,” she says. “If you get two denials, sometimes the third appeal will work. Medi-Cal [California’s Medicaid] has removed restrictions on paper, but many people on it still have managed care and are not getting treatment in a speedy fashion. The fact that the treatment is a cure that will save a lot of money down the line is not necessarily taken into account when plans decide not to cover it.”

All that red tape doesn’t stop Barger from making the following her first message to the newly diagnosed: “Get treatment! It’s worth it. You might have symptoms right now that you don’t know are symptoms, such as foggy thinking and fatigue. Check with support groups online and see what services might be offered in your state.”

And once you’re on treatment or cured, says Barger, pay it forward. “Consider advocating for others, join groups and talk to legislators,” she says. “We can lick this together!”