An Exception to the Rule

Loreen Willenberg may be the first person to be cured of HIV without a bone marrow transplant, but there's more to this elite controller.

February 15, 2021 By Kate Ferguson

A few months ago, Loreen Willenberg stood on the cusp of launching the website for her landscape design business. You could say the moment marked a return to her roots. In 2007, Willenberg, now age 66, walked away from her career as a landscaper and dedicated herself full-time to HIV research and advocacy. True, she had taken on this work for deeply personal reasons and found it immensely satisfying. But eventually, the pull of her innate and instinctive passion for working with the earth became too insistent to ignore.

Willenberg possesses a creativity that demands expression and an artistic flair for working with plants in natural or manmade environments. While immersed in the HIV world, she began to feel the exquisite torture of being torn between two great loves. The new website aimed to help resurrect her original passion.

"I have another way to be of service to others, which is to do the work of plants," Willenberg says. "Working as a landscape designer keeps me grounded, and sharing my knowledge of horticulture and my passion for nature gives me great joy, which I hope my work reflects."

Loreen WillenbergCourtesy of Loreen Willenberg

In 1992, at age 38, Willenberg tested positive for HIV. She was living in Placerville, California, a small town in the foothills of the Sierra Nevada with a mining history and a notorious reputation for the hang-’em-high style of vigilante justice meted out during the Gold Rush. It wasn’t exactly a welcoming environment in the fearsome early days of the epidemic.

In her search to find a doctor she could trust, she called an AIDS education group hotline in San Francisco, which referred her to Bruce Cohn, MD, a physician in private practice in Sacramento, about an hour’s drive southwest of Willenberg’s home. Over the next few years, Cohn regularly tested and retested her blood. Each time, her CD4 T-cells—white blood cells that fight infection in the body—were high, and she remained in good health. While this was obviously great news, it

was also perplexing. She wasn't on treatment (effective treatment didn't even exist until 1996), and most people in her situation would have seen declines in CD4 cell counts.

Cohn soon introduced her to the term "long-term nonprogressor," which is used to describe people who remain healthy without antiretroviral treatment despite years of living with HIV. "One day, scientists are going to want to study you," he told her.

For the next few years, Willenberg's lab reports always reached the same conclusion: "Indeterminate. Results indicate long-standing immunity or early phase seroconversion," and "demonstrates a high level of immunity."

"I began to wonder if I was indeed immune to HIV," she says.

Willenberg spent the next three years in limbo. Her life was an emotional roller coaster. Burdened by a feeling of dread that any day she'd get sick and die, Willenberg bought every book she could find on HIV/AIDS. A subscription from her sister added POZ to her reading list. The magazine eventually changed her life.

One day while reading an issue of POZ, Willenberg laid eyes on a small advertisement soliciting participants for a research study in Boston. Individuals were required to have been HIV positive with no symptoms of illness for more than seven years and never to have taken antiretroviral meds. "I was on the phone the next day. I was actually crying when I called my doctor," she says. "I told him, 'Oh my God, I think they're looking for me!'"

She hoped she could finally get answers to nagging questions such as "Why don't I get sick like everyone else?" and "What's different about me?"

"I was also very curious about whether or not there were other people in the world like me," Willenberg recalls. "But how I was going to find them eluded my grasp." A scientific study offered a possible solution—this was years before the advent of social media—and she hoped that connecting with others would relieve the crushing loneliness that haunted her.

Before any of that could pass, Cohn had to ship 10 vials of Willenberg's blood to the Boston research group for review. Shortly thereafter, Willenberg and Cohn received a letter confirming that the samples had been received and explaining that an assessment was underway. Willenberg didn't understand most of the medical jargon in the letter. But one part was crystal clear. It stated that she fit the profile of some "elite controllers" who had never had a detectable viral load despite repeatedly showing positive results on ELISA and Western blot assays (at that time, the two tests were routinely administered to confirm an HIV diagnosis).

Willenberg exhaled. This was the first time she had heard herself described this way. But, more important, now she knew there were other people like her.

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In early February 2005, a research fellow from the Boston study called Willenberg to share a genetic discovery. Willenberg carried the genetic marker HLA-B*5701, which some call the Northern European descent gene. In Willenberg, the gene triggers a brisk response by her immune system, which continues to suppress HIV. She was asked to travel to Boston—on her own dime—to donate fresh blood samples.

Short on money, Willenberg reached out to different organizations for funding. Unsuccessful in her efforts, she learned about several other HIV research projects closer to her home. “Within two months, I was enrolled in three studies,” she says.

The trio of investigations were underway at the University of California at Davis. Two were headed by Richard B. Pollard, MD, an investigative physician, and the third was led by Barbara Shacklett, PhD, a primary investigator. For Shacklett’s gut tissue studies, Willenberg underwent colonoscopy procedures over a six-year period. Researchers took blood, saliva and tissue samples from her genital area and upper and lower intestines.

In December 2005, Shacklett called to say no HIV had been found in Willenberg’s lower intestines, a site that usually harbors the virus.

“It would seem that I’m both an extrovert and an introvert, comfortable and excited by the opportunity to have my cells placed under a microscope in order to be studied with an aim to help others,” Willenberg says. “Yet I’m also able to withdraw into my private, quiet life to stay balanced and think about events.”

As the year drew to a close, Willenberg received another call from Boston. Funds were now available to fly her there. A light snow fell the night she made her first trip to the historic city.

Now introduced to the scientific research community in earnest, Willenberg crossed paths with Bruce Walker, MD, the Harvard University researcher heading up the study. He was genteel, soft-spoken and very approachable, she says.

“Dr. Walker and his colleagues actually took me under their wing, and I became their student,” she recalls. “That I sit here 15 years later able to speak knowledgeably about their research is due in part to the generosity of their knowledge-sharing with me.”

A lifelong lover of learning, Willenberg found herself armed with a new sense of purpose, especially after Walker told her how important elite controllers are to HIV research. She was surprised to learn how few such individuals exist and how difficult it is for researchers to find them.

Determined to locate more elite controllers and advocate for them, Willenberg launched the Zephyr LTNP Foundation Inc. (LTNP stands for “long-term nonprogressor.”) Awareness of the existence of others like her “offered a sense of connectedness and helped release me from the hidden feeling I had carried deep inside that I was a freak of nature,” she says.

In mythology, Zephyr is the god of the West wind, a warm, light breeze that ushers in spring.

Willenberg adopted the moniker. “People would email me or call me and say, ‘I need to speak to Zephyr,’ and I’d say, ‘I’m here, how can I help?’” she says.

As an advocate, Willenberg views herself as a “Mama Bear.” Essentially a one-woman outreach operation, Zephyr referred dozens of elite controllers to several studies conducted by national research organizations.

But to do this important work, Willenberg retired in 2007 from the landscape design business she’d reestablished in 2004. “When you get a tap on your shoulder for some important purpose, you don’t walk away from it; that’s what the advocacy was about for me,” she says. “There’s not a day that’s gone by that I haven’t thought of my friends who we lost in the early days of AIDS.”

Loreen WillenbergCourtesy of Loreen Willenberg

She also enjoyed taking part in a worldwide effort. “A little-known fact about research on HIV controllers,” she says, “is that there are 22 different countries that started cohorts studying HIV controllers. And the only reason I know that is because I was reading the scientific literature.”

Willenberg began devouring study findings in 2005. “The researchers always answered my request for a copy of their PDFs, so I have thousands of them,” she says.

After findings from studies Willenberg had participated in began to be published, she gave scientists permission to use her real name whenever her data were presented at conferences. Sacrificing her privacy was a way to bring attention to elite controllers, a group of people making a valuable contribution that Willenberg believes will one day lead to a cure for HIV.

“I hope the researchers can translate their recent groundbreaking discovery about the immune

systems of exceptional elite controllers to improve the quality of life for people living with HIV and AIDS wherever they are," she says. "In an ideal world, removing the burden of taking medications to survive would be the best translation."

(Researchers have recently discovered a new mechanism that helps to explain why HIV in elite controllers does not produce new virus. Click here for details on these findings.)

Loreen WillenbergAri Michelson

Working for the Zephyr Foundation allows Willenberg to speak at community events, where she answers questions about elite controllers; she also offers counseling sessions to elite controllers who have reached out to her for advice.

“Women especially would call me to say that their doctors were pressuring them to start meds, even though they’re in a unique class,” she says. “This push to put everybody on meds who’s positive for HIV is one of the heartaches that I’ve experienced in working with this community because these doctors were actually calling these women ‘medicine deniers’ and saying that they were being obstinate in their refusal to begin medications because they think we’re flukes.”

Adds Willenberg, “By the way, three out of five women who called me about this were African American.”

She found the work intense and all-consuming but very satisfying. “I learned that my capacity to love people was greater than I could have imagined prior to being in the spotlight as a person living uniquely with HIV,” she says. “Although I appreciated life before HIV, these past 28 years have made me realize that life is the greatest gift and something for which we need to be grateful.”

But eventually, Willenberg experienced another epiphany and realized it was time to disengage from advocacy work. Two years ago, she deactivated all her social media.

“Now, I’m kind of just wanting to go back to my old love,” Willenberg says. “What I’m most proud of is my legacy of trees, planted years and years ago in people’s gardens [redwoods that are 80 to 100 feet tall now], and the two associate degrees I earned at 63 years of age.”

But advocacy is also woven into Willenberg’s DNA. “I was profoundly touched to learn my efforts to connect members of the HIV controller community to the study in Boston helped the researchers make their recent discovery,” she says. “The wish in my heart is that in my lifetime with what they learned about my case and those of the other 63 elite controllers, that this can be translated into a way to help other people’s immune systems evolve to the point where HIV in the body is destroyed, leaving individuals with no trace of the virus.”

Earlier this year, Willenberg collaborated with colleagues on an article soon to be published in a peer-reviewed journal. “What I’d like people to know about me is that I’m a person who cares about others,” she says. “When I think about my life, the one true purpose has been to be of service in the world—to do good deeds.”

Of course, this includes Willenberg’s goal to reconnect people to the joy of nature during these challenging times. “There’s nothing like the fragrance of a rose,” she says, “to help you feel that all is right in the world.”

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