A Tale of Two Diagnoses

For seven months, Gary Steinkohl believed he was cured of HIV.

November 3, 2015 By Casey Halter

In July 2012, the world was told that two HIV-positive men with lymphoma, who had recently undergone chemotherapy and stem cell transplants, had stopped taking their antiretroviral medications and for months showed no signs of HIV in their blood.

The findings—which were presented in Kuala Lumpur at the 7th International AIDS Society Conference from a study led by Harvard University—were heralded by the mainstream media as a major step toward a cure, one of the holy grails of HIV research.

However, the scientific community was cautiously optimistic that the men could be included in the tiny club of cured individuals, which so far only has one member. That person is Timothy Brown (a.k.a. "the Berlin Patient"), a former lymphoma patient who underwent a similar HIV cure study in 2009—with at least one major difference. The stem cells harvested for Brown's transplant came from a donor with a genetic mutation (called CCR5-delta-32) that protected themselves from HIV; in other words, any existing virus could not enter Brown's newly created immune cells.

As it turns out, the two men didn't join Brown in the cure club. In December 2012, news came out that they had both experienced a viral rebound—their HIV was detectable again. The men, known as "the Boston Patients," have remained anonymous until now. One of them, Gary Steinkohl, has decided to share his story.

Steinkohl was first diagnosed with non-Hodgkin lymphoma in 2006 and had his first autologous stem cell transplant in 2007, meaning that the stem cells were harvested from his own body; he was his own donor. About two years later, he started to develop myelodysplastic syndrome (MDS), which is when the bone marrow is not functioning correctly to produce healthy blood cells. To treat his MDS, he had a second transplant in 2010.

Both Boston patients had received transplants from donors whose stem cells are normal and therefore susceptible to HIV. After the successful transplants, doctors couldn't find HIV in the men. But to find out whether any virus remained and would replicate, the men agreed to an experimental treatment interruption. In other words, they stopped taking their HIV meds for the study. Unfortunately, the virus eventually was detectable.

POZ recently spoke with Steinkohl to find out what it was like to go through this experience.

How did it feel to believe that you were HIV negative?

It was emotionally beyond comprehension. To envision myself after 30 years of being HIV positive suddenly being HIV negative was both exhilarating and also so scary. HIV had become a part of me. It was who I was. My identity, my personality, my drive and the decisions I made in my life.

The emotional layering that happened during the early stages of the HIV struggle—the challenge of shame, ostracization and separation—all of that was coming back up. I have described it to people I know as a comparison to A Tale of Two Cities.

The father character in that book has a phrase in there, “Recall to life.” I was like, “If I become HIV negative, I am recalled to life, but I’ll never forget what I’ve been through.”

Tell us about your HIV diagnosis.

I was first diagnosed with HIV in January 1985. An ex of mine died a couple of years after that, in a hospital where they wouldn’t touch him and would leave his food out in the hallway.

Unfortunately, many people now believe that if you get HIV that it’s a manageable disease. The reality is that the virus still has a negative effect on your life and your health. The domino effects are incalculable.

I tell people that I’ve had two rounds of cancer, the cancer led to a transplant, and then I needed a transplant again to treat the effects of long-term chemo. Plus, the impact on your kidneys, liver and emotional health is painful.

What was it like stopping your HIV treatment for the study?

That first morning, I woke up thinking, “I am not taking meds this morning and I may never take them again for the rest of my life.” That continued for approximately seven months.

That period of time was like a roller coaster. The doctors told me that the general framework for people who went on HIV drug holidays was that in eight to 12 weeks the virus would be detectable.

In the early stages, I was doing blood tests every week and every week it was undetectable. Then the appointments were stretched out a little longer, like once every two weeks.

After about the fifth month of being off meds, I started to feel more and more absorbed in thinking, “I’m HIV negative now.” I know it was my hopefulness talking, but there was nobody who could tell me differently.

And then the HIV became detectable.

I remember the day exactly. I started to feel ill with flu-like symptoms. I know this was self-protection talking, but I didn't really think it was HIV. I had spent some time in the country that summer and I found a tick on me, so I was like, "Oh, this could be Lyme disease."

But within about 48 hours, I started feeling really bad. I took a taxi to a hospital, checked in, told my whole story to the doctors there and told them to run some blood tests. Then I went home, and a few days later, the call came: I was HIV positive.

What was the aftermath of the study like for you?

It was emotionally devastating. I went back on HIV meds immediately. My viral load was well over 1 million, so it took several months for the meds to bring it down to undetectable.

I was sad for the community, and myself, but the follow-ups with the study team were wonderful. They told me that I had helped change medical knowledge and that they had discovered so much new information with my case. I felt warm about that, but it didn't take away from my personal sadness.

Why did you decide to talk about your experience now?

I felt it was important for the community, and I wanted to invite people in similar scenarios to participate in HIV research. The cure is a holy grail, and we need to be actively participating in the search for it.

At one point, I thought I would write my story, but I'm not a writer. I was also cautious about who might do an appropriate article. Some things came up and some things never worked out, but I knew that reaching out to POZ was always an option.

How is your health now?

The lymphoma is in remission. Whether those in the cancer field would call me cured or not, I'm beyond the five-year time frame. Everything else is stable. My HIV viral load is undetectable and my CD4s are good, especially for someone who had two bone marrow transplants.

Would you participate in another HIV cure study?

Yes. All I can say to everyone reading is get involved. Do your part. I'm sad for my personal net result, but knowing that this is not the be-all end-all toward a cure is still progress. It's like the tortoise and the hare story—slow, steady progress.

For more information about the current state of HIV cure research, check out the October 2015 POZ feature, "The Cure for HIV is Not Around the Corner."