

I Am the Berlin Patient: A Personal Reflection

Timothy Ray Brown

My name is Timothy Ray Brown and I am the first person in the world to be cured of HIV. While attending university in Berlin in 1995, I received a positive HIV diagnosis. I started out taking low-dose zidovudine (AZT), but the next year protease inhibitors hit the market and I, like many HIV-infected people at the time, lived a rather normal life and had a nearly normal life expectancy. That continued for the next 10 years. After attending a wedding in New York City and feeling exhausted the entire time, I flew back to Berlin, rode my bicycle about 10 miles to work (which I generally did weather permitting), and felt drained when I arrived. At lunch, I rode to a restaurant about a mile away and had to get off the bike halfway there. I called my boyfriend, Michael. He was unable to make an appointment for the next day with my doctor but made one with his HIV doctor.

I went there the next day and found out I had anemia, meaning that my red blood cell count was very low. He gave me red blood cell transfusions for the rest of the week and then, unable to resolve the situation, sent me to an oncologist, who at first said he did not think I had anything serious. However, he did a very painful bone marrow biopsy on me. I went back the next Monday for further treatment and the doctor informed me that I had acute myeloid leukemia (AML) and needed to be treated at a hospital. We chose one of the Berlin university hospitals near my apartment. He called there and got Dr. Gero Huetter on the phone who said "Send him in."

The next day I went to the hospital and was put on chemotherapy after having tubes put into my neck that extended into my heart. The doctors told me that I would need four rounds of chemotherapy treatments, each taking a week, with breaks of several weeks in between. I did the first round; that went well. The second round gave me fungal pneumonia, but that passed with antifungal treatment. During the third round, I got a dangerous infection. I was put into an induced coma. When I came out of that a day later, Dr. Huetter told me to go on vacation so I vacationed in Italy. Before the third chemo treatment, Dr. Huetter took a sample of my blood to send to the stem cell donor bank with the German Red Cross to look for matches for my tissue type in case I needed a stem cell transplant. This confused me because I thought this ordeal would end with the chemotherapy treatments.

Many patients do not have any matches; I had many matches, 267. This gave Dr. Huetter the idea of looking for a

donor who had a mutation called CCR5 Delta 32 on the CD4 cells making them nearly immune to HIV. CCR5 is a protein on the surface of the CD4 cell that acts as doorway for the HIV virus to enter into the cell. Take away this entryway and CD4 cells will not be infected and the person will not get HIV. His team found a donor with this mutation on the 61st attempt. The donor agreed to donate should it be necessary.

After my trip to Italy, my leukemia was in remission. The professor on the transplant ward pressured me to get the transplant, although he was unaware of the possible breakthrough with HIV. I talked with friends, family, and a transplant professor in Dresden. I said "No" to the transplant, thinking that it would not be necessary were the leukemia to remain in remission because I could continue to take my antiretroviral medication indefinitely. I did not need to be a guinea pig and risk my life receiving a transplant that might kill me. The survival rate for stem cell transplants is not great; normally it is about 50/50.

At the end of 2006, the leukemia rebounded. It then became clear to me that I needed the stem cell transplant to survive. I received the transplant on February 6, 2007, my new "birthdate." With Dr. Huetter's agreement, I stopped taking my HIV medication on the day of the transplant. (This is important because a continuation of antiretroviral therapy would have meant that no one would have known for a long time that I was cured of HIV.) After 3 months, HIV was no longer found in my blood. I thrived until the end of the year. I was able to go back to work and return to the gym. I began developing muscles that I had never had before because without HIV I no longer had the wasting syndrome. Unfortunately, after a trip to the United States for Christmas and being diagnosed with pneumonia while in Idaho, the leukemia was back.

My doctors in Berlin eventually decided on a second transplant using the same donor. I received the stem cells for a second time in February 2008. The recovery from that did not go well. I became delirious, nearly went blind, and was almost paralyzed. I eventually learned to walk again at a center for patients with extreme brain injuries. I have almost fully recovered about 6 years later. I continue to be tested for signs of HIV in my body with extremely precise tests.

While in recovery there was much talk about my case among medical scientists. I was not ready for publicity but, at the end of 2010, I decided that I would release my name and image to the media. I went from being the "Berlin Patient" to

using my real name, Timothy Ray Brown. I did not want to be the only person in the world cured of HIV; I wanted other HIV⁺ patients to join my club. I want to dedicate my life to supporting research to search for a cure or cures for HIV!

Shortly thereafter in 2010, I decided to move back to the United States. Regan Hofmann of *POZ Magazine* interviewed me. Pulitzer Prize winning author Tina Rosenberg interviewed me for *New York Magazine*. Jon Cohen, for *Science Magazine* among others, followed suit. I agreed to see Dr. Steven Deeks and be part of his SCOPE Study at San Francisco General Hospital. Dr. Deeks sent much of my blood and biopsy samples to the U.S. National Institutes of Health (NIH). I also participated in Dr. Jay Levy's study to look for a cure of HIV.

In July 2012, during the World AIDS Conference in Washington, DC, I started the Timothy Ray Brown Foundation

under the World AIDS Institute. We have worked together with medical scientists, institutions, and universities working on a cure or cures and vaccinations against HIV. The Timothy Ray Brown Foundation and the World AIDS Institute are starting the Cure Report, a guide to trials focused on curing HIV, vaccinating against HIV, and providing new information about HIV cure research. I will not stop until HIV is cured!

Author Disclosure Statement

No competing financial interests exist.

Address correspondence to:
Timothy Ray Brown
Las Vegas, Nevada

E-mail: tscma369@gmail.com