Coming Out as Cured

Marc Franke is part of an exclusive circle of people cured of HIV after a stem cell transplant.

June 26, 2023 By Liz Highleyman

Marc Franke, 54, remains free of HIV a decade after receiving a stem cell transplant to treat leukemia from a donor with a rare mutation that makes immune cells resistant to the virus. Dubbed the Düsseldorf Patient, Franke lives in a nearby small city in Germany with his husband, Ingo, and their dog, Motte.

Franke is either the second person to be cured using this procedure, after Timothy Ray Brown (the Berlin Patient), if counting from the date of his transplant in February 2013, or the third, after Brown and Adam Castillejo (the London Patient), if counting from when he stopped antiretroviral therapy in late 2018. A Southern California man (the City of Hope Patient) and a woman treated in New York City have since joined the exclusive club.

But Franke's doctors—Björn Jensen, MD, and Guido Kobbe, MD, at Düsseldorf University Hospital—were cautious about declaring a cure, and he has not gotten the same extensive media coverage as the other four cases. Franke decided to go public this year when a report about his case was published in Nature Medicine. After POZ covered the news in February, he offered to tell us more.

How did you find a donor with the CCR5-delta32 mutation, which blocks HIV from entering immune cells?

I saw a documentary about Timothy on TV at the end of 2012. I don't remember if I asked my doctors about searching for such a donor or if they mentioned it. They found five matching donors, and one had the gene defect. Only 1% of the Caucasian population has two copies of the mutation, from the father and mother. I was so happy because I knew it was a little needle in a big haystack. It was like winning the lottery.

What was it like being treated for leukemia and undergoing the transplant?

No one who hasn't gone through it can imagine how hard it is. I had my first chemotherapy in 2011, and they thought they could cure my leukemia. I met Ingo before the leukemia diagnosis. I was chatting on [the dating app] Gay Romeo at the hospital because I had time to kill. He didn't care if I had HIV. He visited me the next day, then he came every day. I went through chemo so well because I wanted to have my normal life back and get to know Ingo better. The power of love guided me through all of this.

But the chemo didn't cure me, and I got the transplant on Valentine's Day in 2013. My donor was female, so it was easy to tell that it worked. Special chemo and T cells from the donor got rid of all my male immune cells. It was a very risky year after the transplant. So many things went wrong. I got hepatitis and had to take cortisol to save my liver. Because of the cortisol, I got diabetes and had to inject insulin. Then my hip broke, so I needed a new hip. I had problems with my brain, a strange encephalitis, and I had to go to intensive care for several weeks. And I have graft-versus-host disease [when the donor cells attack the recipient's body], which gives me dry eyes. If you see me now, you think, Oh, everything is fine, but everything is not fine.

You had the opportunity to meet your stem cell donor. What was that like?

In Germany, it's not a problem to meet your donor, but you have to wait a year to get in contact. My donor, Anja, contacted me at the beginning of 2014, but at that time, my constitution was not so good, and I was not in the mood to answer, so I answered her half a year later. We chatted on the telephone for hours, and I told her she was very, very special for me. They had told her that her body has a special kind of immunity, but they didn't tell her she was donating to a person with HIV hoping for a cure.

After she contacted me, she was diagnosed with breast cancer, and on the first day of her chemo, she got my letter. She said it made her feel that if something went wrong with her chemo, her cells had helped another person. When we first met in person, she visited me in the hospital after my hip replacement. I didn't feel so good after the operation, and she had no hair and was wearing a wig. So we decided to meet again when everything was fine. In 2016, we got together with our partners at a little restaurant in Cologne on the Rhine. And when I celebrated the 10th anniversary of my transplant on Valentine's Day this year, she was a guest of honor.

How did you and your doctors decide to stop antiretroviral treatment?

A year after stopping immune suppression therapy in 2017, Dr. Jensen thought it might be the right moment to stop the antiretrovirals. Several tests were done to look for any hint of HIV. They found [virus] fragments and tested to see if it could be reactivated. They took samples from my gut and lymph nodes because they thought there might be a reservoir. All of this took much time. But I was 100% sure that if Dr. Jensen said to me, "You're ready to stop treatment," I was ready.

Why did you recently decide to go public with your cure?

My case was first presented as a little paper at the 2016 CROI [Conference on Retroviruses and Opportunistic Infections] before I stopped HIV treatment. Then it should have been presented together with the London Patient at CROI 2019, but an Indian newspaper broke the press embargo, and all the focus was on Adam, and they forgot me. At that time, I thought, Well, let Adam be the focus, and I could have a normal life.

I got my transplant sooner than Adam but stopped HIV treatment later because my doctors wanted to be 100% sure. Dr. Jensen is not one for publicity—he cares about me, not about his fame. In 2019, it was just three or four months after stopping the antiretrovirals. I didn't want to be the person who had to say six months later, "Sorry, it didn't work." But 10 years after the transplant, I think I can say I'm cured. In 2021, I had my first interview for a Dutch newspaper, but I didn't show my face and only gave my first name.

Have you met any of the other people who were cured?

I didn't meet Timothy because I was not ready to go out with my story, and then he was dead. [Brown died in September 2020 due to a recurrence of leukemia.] In 2021, I was on stage with Adam at the Power of Love, a big meeting for the HIV community in Utrecht [in the Netherlands]. I have talked with Paul [Edmonds, the City of Hope Patient] on Zoom. Paul, Adam and I have a WhatsApp group, The Three Musketeers, where we exchange information.

What do you hope to accomplish by going public?

One of the reasons to come out with my story is to support HIV science and get more people to become donors. [Franke recommends Aidsfonds.org and DKMS.org.] Many people think that if you donate stem cells, you get a needle in your back and it will hurt a lot, but now, nearly 90% can be done via apheresis [removal of stem cells from the blood]. Another reason is to fight HIV stigma and get rid of the pictures that are still in our minds from the beginning of the '80s, when people were dying like flies. I was a teenager then, so that had a big influence on my life.

I want to focus on cure research because I think scientists have learned so much about HIV and its reservoirs from stem cell transplants. They could see in detail how a new immune system responds to HIV. But the procedure the five of us went through is not suitable for people without leukemia or lymphoma. I hope that in the near future they can recreate this [CCR5-delta32 mutation] via CRISPR or something else—that they can make some gene magic so they have a one-shot therapy that can help people with HIV all over the world.

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