Sharing the Hope

Paul Edmonds is one of a handful of people cured of HIV and cancer after a stem cell transplant.

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Paul Edmonds, 68, of Desert Hot Springs, California, is one of only five people to be cured of HIV after a stem cell transplant for cancer treatment from a donor with a rare genetic mutation called CCR5-delta32 that prevents the virus from entering cells.

Edmonds is the oldest person—and the longest living with HIV—to receive this type of transplant. His case was first presented at the 2022 International AIDS Conference. At the time, he chose to remain anonymous and was known as the City of Hope Patient. Today, his leukemia is still in remission, and he remains free of HIV three years after stopping antiretroviral therapy.

The stem cell transplant procedure Is too risky for most people living with HIV who do not have cancer and are doing well on antiretroviral treatment, but the handful of functional cures offer clues for researchers working to develop more widely applicable approaches.

You were diagnosed with HIV in 1988. What was it like living with HIV in the early years of the epidemic?

It was very scary. Around 1980, people began getting sick with what was called the “gay cancer.” People were afraid of each other. It was very stigmatizing. There were many nights of marches and protests to get the government to do something. I received an AIDS diagnosis because of my low T-cell count. At the time, most people were living no longer than two years after diagnosis.

My husband, Arnie House, who I met in 1992, is also HIV positive. We’ve taken care of each other over the years, accompanying each other to doctor appointments, collaborating on healthy diets and exercise regimens and discussing the pros and cons of different medications. I tried almost every drug that came out, including AZT, but the side effects of the early meds were awful. I tried to stay strong, live day-to-day and not allow myself to think about the worst-case scenario. I started combination treatment when it became available in the mid-1990s, and my HIV viral load stayed undetectable for many years.

How did you find a stem cell donor with the rare CCR5-delta32 mutation?

I was diagnosed with acute myeloid leukemia (AML) in 2018. I think I was diagnosed early because I saw my HIV doctor every three months, and he saw my bloodwork plummet suddenly. I felt like I had been here before with a near-fatal diagnosis. I was referred to City of Hope, which pioneered stem cell transplants for people with HIV.

I had heard of Timothy Ray Brown, the Berlin Patient, who had the same type of leukemia and was the first person cured of HIV after a stem cell transplant from a donor with the CCR5-delta32 mutation. My doctors at City of Hope told me from the beginning that they would look for a donor with the mutation. They searched the Be the Match donor registry and found someone within a month. But first, my cancer had to go into remission, which took three rounds of chemotherapy. By that time, the original donor was no longer available. Fortunately, they found a second donor with the same mutation. I felt as if I had won the lottery.

At the time, Brown was the only person who had been cured of HIV with this kind of transplant, but I had a lot of trust in my doctors. While I was in the hospital getting the AML in remission, the news about the London Patient [later identified as Adam Castillejo], a second person cured with a CCR5-delta32 transplant, came out.

What was it like receiving the stem cell transplant?

I got the transplant in February 2019. The transplant itself was a simple infusion. Unlike Brown, I received reduced-intensity chemotherapy and no radiation because of my age. I had heard from many people how difficult chemotherapy was, but it wasn’t as bad as I thought it could be—certainly not as bad as the years on early HIV meds. I started feeling good rather quickly, but I stayed at a hotel near the hospital because I lived too far away should something go wrong. Arnie and friends from across the country came to stay with me during these two months because I couldn’t be by myself. I have a great support system. I had only minor graft-versus-host disease [when donor cells attack the recipient’s body], with mouth sores and dry eyes. Overall, I’ve been very fortunate.

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

In March 2021, my AML was still in remission, and my HIV remained suppressed, so we decided to stop my antiretroviral therapy. We were planning to do so one year after the transplant, but then the COVID-19 pandemic hit. I wanted to wait until I got my COVID vaccine, and there was some talk early on that HIV meds might be offering some protection against COVID. This decision was completely mine. I felt no pressure to stop antiretroviral therapy until I was ready.

In the beginning, City of Hope sent someone to my house to do lab tests every week. Now I get my HIV viral load monitored every three months. Repeated tests have shown that I have no detectable HIV in peripheral blood cells [a marker of the latent viral reservoir] or gut biopsies from colonoscopies. A year and a half later, I still had not experienced viral rebound, and my doctors presented my case at the International AIDS Conference in July 2022.

How did you decide to go public with your cure?

In the spring of 2023, I appeared on Good Morning America and in The Washington Post, New York Post and ABC News. I had always planned to go public with my story if the stem cell transplant was successful. I grew up in a small town in Georgia and had a difficult time coming out as gay. I thought if I stayed anonymous, it would feel like going back into the closet—and I will never return to the closet. I remember how I felt when the news about Timothy Brown came out. For the first time, I felt like a cure for HIV might be possible. My story is too important to keep to myself. The researchers and people affected by HIV deserve to hear a story of hope and resilience.

What do you want to accomplish as one of the few people cured of HIV?

When I was diagnosed with HIV in 1988, I thought it was a death sentence. I never thought I would live to see the day that I no longer have HIV. But I've lived for half of my life with HIV. I'm still very connected to the community, and I feel like I always will be. I am going to be a strong advocate for HIV cure research. I also want to encourage people to sign up to be stem cell donors with Be the Match.

I've met two of the other people cured after stem cell transplants, Adam Castillejo [the London Patient] and Marc Franke [the Düsseldorf Patient]. We have Zoom get-togethers, and we were all together in public for the first time at the Hawai'i to Zero Conference in Honolulu last September. I sit on the community advisory board of RID-HIV, one of the 10 Martin Delaney Collaboratories for HIV Cure Research. I have been invited to join NMAC's HIV 50+ Strong and Healthy Program to advocate for people aging with HIV, and I will be attending the International AIDS Society conference in Munich this summer, along with Adam and Marc, and the U.S. Conference on HIV/AIDS in New Orleans in September.

I want researchers to study me and the others who were cured, like they did with Timothy Brown, so we can find a cure that’s accessible to all. We need to challenge stigma and ideologies that hinder progress and work as a global community, transcending borders to eradicate this virus.

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