Patient No More

Timothy Brown—a.k.a. “the Berlin Patient”—is the Man Who Once Had HIV. Recovered from a deadly form of leukemia and now virus-free, Brown embodies the hopes of scientists and millions of people living with the virus. Brown’s road to a cure is unlikely to be traveled by others. But his journey provides critical proof of a concept that just may lead to the end of AIDS-by offering clues for how to develop a safe, affordable cure for all.

June 1, 2011 By Regan Hofmann

To walk past Timothy Brown on the street, you’d hardly know that his body contains secrets capable of ending one of the worst plagues in recorded human history. But Brown, the man known as “the Berlin Patient,” is arguably scientific proof that we can cure AIDS.

The Berlin Patient is not a German, but rather, an American whose life was saved, ironically, by a German living in America. Brown is a 45-year-old man originally from Seattle who moved to Berlin in 1991. It was in that famed European center of upheaval that he discovered, in 1995, he was living with HIV and where he was diagnosed with acute myeloid leukemia (AML) in 2006.* Multiple treatments for his AML, including chemotherapy and two stem cell transplants (using cells harvested from the German donor), have allowed him to survive against unthinkable odds—and to be cured of HIV.

Brown might not be alive and he certainly wouldn’t be HIV-free had his path not crossed that of Gero Hütter, MD, a German hematologist at the University Medicine Berlin. Hütter had the foresight, when administering a stem cell transplant to Brown to cure his AML, to try injecting stem cells harvested from a donor who had a certain genetic mutation that made his immune system impervious to HIV. HIV uses the cells of the immune system in its replication process. If it can’t enter the immune cells, it can’t survive. Hütter’s theory was that if you took all the immune cells out of a person living with HIV and replaced them with immune cells that couldn’t be infected with the virus, then HIV could be eradicated.

Hütter was right; Brown is the first person to have HIV cleared from his body. But while the process Brown endured cannot be universally applied, Brown’s case taught scientists much about how HIV works and how to produce a similar outcome without the risks of a stem cell transplant.

Which is why after four years of being known anonymously as the Berlin Patient, Brown has come forward to talk about the importance of finding a cure for AIDS.

When we first spoke (when he was still in Germany, about six months ago), Brown was

understandably concerned about stepping into the spotlight. He has no desire for fame and wants nothing more than to get on with a regular life. But he also wants people to pay attention to and accurately understand the scientific insight gleaned from his case—insight that could lead to a cure for the millions of us who are not HIV-free. Brown knows the misperception that a cure has already been found would devastate efforts to raise funds for cure research, and he expressed concern about the recent press coverage of his case. Too many media outlets oversimplified his story, which he fears could lead to false hope for HIV-positive people. And too few highlighted the exciting research that has since sprung from what was learned in his case, research that is ready for fast tracking and human trials but that lacks necessary funding. (For a highlight of this research, read "From Mice to Men," POZ October/November 2010.)

Brown also wants the world to know that what he went through, and is still recovering from, is not something he'd wish on his worst enemy. A stem cell transplant like Brown's presents many challenges: finding the right donor, a $250,000+ price tag and the possibility of massive infection—and death. Brown paid dearly for his survival with physical and emotional stress and some enduring side effects. Thankfully, he is moving slowly, and steadily, back to a place of good health.

As a young man, Brown decided, after a brief stint in college, to head to Europe. Landing in Barcelona, he traveled with friends to Berlin, where he met another young man and fell in love. Just days after Brown returned to Spain, his boyfriend joined him. But roommate squabbles drove the couple back to Germany.

Berlin's architecture entranced Brown, who worked at Café Adler, near Checkpoint Charlie, the best-known Berlin Wall crossing point between East and West Berlin. During the Cold War, the famous café was frequented by journalists who covered the historic fall of the wall in 1989. "Berlin was really beautiful, particularly after the wall came down and the country was reunited," Brown says in a voice that is somewhat halting as he is still recovering from neurological damage from his extensive treatment. "I liked the fact that there weren't lots of police in Berlin. It was a free-for-all."

The nightlife reflected this. And Brown was caught up in the pervasive feeling of newfound freedom. Young, in love, and living in a city that embodied a new openness, Brown lived, worked and played hard. "I remember one disco in particular. There was so much fog from the fog machines that you couldn't see the person next to you. It was like dancing in space."

But his days of carefree joy ended abruptly one day in 2004 while riding to work on his bike. Brown was suddenly overcome with fatigue. He arrived at work late, and when he went out again at lunch on his bike, he had to stop, sit on a park bench and call his partner to come get him. "I knew something was really wrong," he said. Brown was also on treatment for HIV but had no health issues resulting from the virus. The first doctor Brown visited did blood work and sent him to an oncologist who did a bone marrow test and determined Brown had AML. That doctor sent Brown to the hospital where he met Dr. Gero Hütter.

From that point forward, Brown found himself engaged in a series of painful and dangerous treatments. He received chemotherapy, which initially kept the cancer at bay. But when it returned, Huetter recommended a stem cell transplant. There were more than 100 genetically compatible donor candidates—a very unusual thing—so Huetter wondered if he could attempt to cure not only Brown's AML but also his HIV.

Huetter thought that rather than simply injecting regular stem cells to fight the AML, he could hunt down a donor who had a particular genetic mutation, called the "CCR5-delta32 deletion." This genetic "defect" (in this case, an advantage) causes a body to produce CD4 immune cells that lack a receptor known as CCR5. In order to bind to the CD4 cells of the immune system, enter them and replicate, most strains of HIV must find two receptors on the surface of the cell: CD4 and CCR5. No CCR5 receptor? Then no docking and no HIV replication. (Though some strains of HIV can bind to CD4 and another receptor, CXCR4, Brown's virus was using CCR5 to infect his cells.) Hütter's plan was to replace all of Brown's immune cells with ones that would cure him of AML and stop HIV replication—thus curing him of HIV.

Brown had little to lose by being a guinea pig. He might not survive the treatment, but he certainly wouldn't survive without it. There was no additional risk to the experimental stem cell treatment and, if it worked, Brown could potentially recover from two life-threatening conditions. Of the decision, Brown said, "I wasn't really worried about my HIV. I was worried about the cancer." It didn't really sink in that his survival could be linked to that of tens of millions of others.

Hütter found a donor with the double CCR5-delta32 deletion (the genetic mutation is inherited, and when it's inherited from both parents, it's considered a double deletion and makes the person immune to HIV) and set up the transplant. To prepare Brown's body to receive the new stem cells, Hütter administered massive chemotherapy to wipe out Brown's existing immune system. Devoid of an immune system for several weeks while waiting for the transplant, Brown faced considerable risk of contracting a deadly infection. There was also the risk that his body would not accept the donor cells. But he survived the transition period and the transplant, and Brown's health began to return. But, 13 months later, the AML returned and Brown underwent a second transplant with the delta-32-deleted stem cells.

Brown's mother Sharon flew repeatedly from America to sit beside him while he endured the procedures. Brown never knew his father, so his mom and his now ex-partner were his support team. "It's really important to have emotional support when going through things like this," he says. "Especially with HIV since the stigma is so bad. You need people to put their arms around you and tell you they love you."

Brown's former partner cared for him throughout his treatment—for four years. The fact that the AML returned resulted in a much longer recovery. "I couldn't walk and had to wear diapers," Brown says. "I was very incontinent so my partner had to clean up after me a lot.

"I'm very appreciative of that, but he got another relationship and he didn't want to continue to [take care of me] anymore," Brown says. "There was talk of whether or not I'd have to go to a

[nursing] home. I didn't want to do that. I visited a couple. One really shocked me. The people were much worse off than me." Faced with a choice of going into a home or trying to take care of himself, which he couldn't do, Brown decided to come back to the United States.

News of Brown's astounding duel recovery was first shared at the 15th annual Conference for Retroviruses and Opportunistic Infections (CROI) in Boston in 2008. Interestingly, very few people noticed the potentially world-changing poster hanging at the far end of the exhibit hall. The story of the first man potentially cured of AIDS barely made a ripple in the scientific community, let alone the global press. Early news of Brown's cure was cautiously mentioned in a few medical journals—and in POZ and on AIDSmeds. Though the data were astounding, there was talk about whether residual HIV, particularly a form of the virus that targets the CXCR4 receptor, hiding in reservoirs in Brown's body could emerge and replicate. And then there was the question of whether or not the procedure could, or should, ever be replicated in people with HIV who were not facing life-threatening cancers such as leukemia and lymphoma. Few were sure how Brown's case would influence scientists' ability to develop a cure that could be had by all.

It wasn't until December 8 of 2010 when the medical journal Blood reported that Brown had been free of HIV medicines for three and a half years while maintaining normal CD4 counts—and still had no trace of HIV—that word spread more widely that a man had apparently been cured of HIV. The article in Blood reported that the team monitoring the patient said, "Our results strongly suggest that cure of HIV has been achieved in this patient." And yet, the news remained cautiously optimistic.

Several false starts for an AIDS cure have led the scientific and investment communities, the government and the media to be extremely wary of focusing on or discussing an AIDS cure. Until the case of the Berlin Patient, the word "cure" was uttered by few in the last 15 years. The widespread suspicion that an AIDS cure is not possible has led to a focus on developing and refining prevention and treatment protocols. Further undermining the focus on the cure is the grave misconception that modern treatments have rendered HIV a "manageable" condition and as a result a cure is less needed. This is a misconception because the drugs remain toxic with debilitating side effects and long-term health risks, and because HIV itself causes health problems long term.

Funding for cure research has suffered greatly from these misconceptions. Few people are aware that AIDS science is poised on the brink of a breakthrough. For proof of the disbelief in an AIDS cure, consider that in 2010, Time magazine named "PrEP," or pre-exposure prophylaxis, which is the practice of taking existing HIV drugs to prevent infection, as the No. 1 medical breakthrough of the year—the same year in which a man had been cured of HIV.

Brown hopes coming forward will help change this. He has helped enough in offering his body as a proving ground for a concept that opened scientific horizons. But amazingly, he doesn't want to stop there. He wants to be a public advocate for an increased focus on—and more funding for—the cure for AIDS.

Today, Brown lives in San Francisco with some wonderfully supportive friends. He is looking for a doctor, and to form a new life. It’s not easy to know whom to call for medical help. An oncologist? An infectious disease specialist? He no longer has cancer, and he no longer has HIV. But as his body heals from years of living with the virus and battling cancer and enduring life-threatening treatment, he needs medical and emotional support.

Brown has started to work out at home with the help of an exercise video. He is trying to regain his strength, and weight, drinking lots of protein shakes (“My favorite is hazelnut,” he says). He’d like to resume work as a translator or go to law school.

When asked what it feels like to be leukemia-free and to be the first person cured of HIV, he smiles, slowly, almost as if he doesn’t believe his own story, and says, “It’s really great. I hope what I’ve gone through will help lots of people.” I get the sense that it’s strange for him, after his many brushes with death, to consider how to rebuild his life. Like for so many of us with HIV who thought we’d die, the future feels delicate. But for the moment, his heightened appreciation for life enables Brown to enjoy the small and simple things. Like a dog on his lap, and the warm California sun on his face.

*This article has been revised to reflect the following correction: Timothy Brown was diagnosed with acute myeloid leukemia (AML) in 2006 not 2004.

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