

Las Cruces cyclist receives ground-breaking MS therapy

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(Photo: Robin Zielinski — Sun-News)



LAS CRUCES >> Las Cruces resident Michael Barrow, a U.S. Border Patrol agent and member of the Zia Velo Cycling team, first noticed changes in the way his body was responding in 2010. After completing a 100-mile bike race in Las Vegas, Nevada, his skin was numb — not normal, even after such a grueling exercise.

"I was showering off and I was wiping myself with a towel and I felt like I wasn't touching myself directly," Barrow said. "I felt like I was touching myself through my shirt."

Barrow went to see a doctor, but no one could tell him the cause of the numbness. Eventually Barrow's sense of feeling came back. Six months later, in 2011, while mountain biking with his family, he began to lose vision in his left eye. Barrow was soon diagnosed with the beginning stages of multiple sclerosis, an unpredictable, often disabling disease, in which the immune system attacks the brain and spinal cord. There is no known cause nor cure for MS, which can be managed with medications that only slow the progress of the disease, according to the [National Multiple Sclerosis Society](#).

Five years into Barrow's struggle with MS — in which two MS medications had stopped helping his condition — he is now one of the first few hundred people with MS to have received hematopoietic (blood cell-producing) stem cell transplantation, or HSCT, in the United States. HSCT is a new, not-yet-FDA-approved therapy being studied as an approach to halting the progress of MS. HSCT was developed by stem cell researcher [Dr. Richard Burt](#), of Northwestern University in Chicago, the only place in the country that offers treatment, and only to patients accepted into the study.

Results of the ongoing international [clinical trial](#) published by Burt and colleagues in the Jan. 20 [Journal of the American Medical Association](#), show that HSCT could be the first MS therapy to reverse disability.

HSCT is a procedure that involves storing stem cells taken from a patient's own blood or bone marrow and depleting the rest of the patient's immune cells using

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chemotherapy. The stored stem cells are then reintroduced via an intravenous infusion, producing new cells that repopulate the body over time. The goal being the new immune cells no longer attack myelin (the protective covering of nerve fibers) or other brain tissue, and therefore, stop the progression of MS, according to the National MS Society.

Barrow was accepted into Northwestern University's stem cell transplant program in January, after meeting with Burt and an MS specialist in person and explaining his struggle with the disease.

"Usually you have to wait a couple of weeks to hear back," said Liz Barrow, Michael's wife. "With us, we found out that day."

Michael Barrow, 37, said he was selected along with five other patients for treatment on a "compassionate," off-study basis because he didn't quite fit study criteria, which among other things, requires patients to have relapsing-remitting MS, to have had two MS medications fail and to have had two flare-ups (an attack of a symptom or relapse of symptoms) in the past year.

"My last two (flare-ups) were like 14 months apart, so I was just out of study (requirements)," he said.

Fortunately, Barrow was accepted for treatment anyway.

"(The doctors) looked at me and they said they felt really strongly that (the procedure) was going to work for me because of where I was with the disease — still early and still doing well," he said.

The idea to enter the trial study began with Barrow's own investigation of the procedure in September, while preparing for his Bike MS race in Albuquerque. He happened upon a blog posted by someone who had participated in the study. In his desperation to live a long, healthy life with his wife, 2-year-old daughter Olivia and a son on the way, he became passionate about researching HSCT and learning everything he could about the trial therapy.

Before the treatment, Barrow said his outlook was dim and that if the disease progressed much further, he might not have been able to work or been confined to a wheelchair.

In 2013, an attack caused Barrow to lose balance and strength on the left side of his body. He went through infusion therapy and switched medications, but MRI results showed that more lesions were forming on his brain. In 2014, he had another attack and more lesions formed. The most recent MRI showed he had a total of 26 brain lesions.

"For the last five years, even though things were going pretty good, for the most part, I just felt like it was going to come to an end," Barrow said. "I just thought, 'I'm having too many lesions to just keep getting lucky. At some point one of these things is going to get a leg or an arm and everything's going to come to an end.' (After HSCT therapy), I suddenly felt like it's not going to."

Liz Barrow said making the decision to do the procedure caused her to think about their family's future.

"That was a huge thing for me — that hurdle of realizing that I have to accept that he has MS, that I'm married to him and that I'm having his children and that hopefully, our life is going to go on and we can raise them."

While Michael Barrow said the study will go on for five more years, recent results have given patients hope. According to an [article](#) published on Healthline.com, 80 percent of study participants remained relapse-free four years after treatment.

Barrow said he's experienced a tingling sensation in his feet at night since he was first diagnosed with MS.



Dec. 15, 2019, 3:04 a.m.

"Even if my symptoms weren't bad, my feet would just always get numb and tingly and they'd feel wet," he said.

Since he received the new treatment, Barrow said he no longer has this feeling at night.

Barrow, who started treatment in Chicago on March 2, was released from Northwestern Memorial Hospital, where he was kept in a sterile room, on April 16 and returned home on April 20. He currently does physical therapy in the pool at Southwest Sport and Spine, where his heart rate is closely monitored. He also gets blood work done each week and continues to stay in touch with doctors at Northwestern. Due to the treatment he received, his white blood cell count is still low, making him more susceptible to illness. Until his immune system is back up to speed, he has to avoid germs and people who might be contagious for three months after treatment, he said.

"When he's in large crowds, he's had to wear a mask — like when he rode on the plane ride home," Liz Barrow said.

While certain days are more difficult than others, Michael Barrow said he feels "ahead of the game" as far as his recovery goes and is already riding his mountain bike again.

"People who have (gotten this treatment) really feel like it's a cure," he said. "The trial is 10 years old and there's people 10 years out, and then five years out, and it's like a 90 percent success rate of halting the disease."

However, researchers have found that HSCT only works on people with relapsing-remitting MS who have had the disease for 10 years or less. People with secondary-progressive MS or those who have had the disease for more than 10 years did not show improvements, according to study results published on the National MS Society website.

Barrow said he is fortunate to have been accepted for treatment at Northwestern when several obstacles, such as insurance and high travel expenses, could have stood in his way.

"Because it's in the trial phase, a lot of insurance companies aren't too quick to jump on it," he said.

But Barrow's insurance did ultimately come through, he said.

"Every year a pill comes out. If this one was \$55,000, the next one is probably going to be \$65,000," he said. "Once (people with MS) get this (treatment), they're not on medication anymore and insurance companies are starting to catch on."

Through a [gofundme campaign](#), Barrow and his wife were able to raise more than \$10,000 for lodging, food and travel expenses. Barrow said he got support from people he had never met before, as well as encouraging words from members of his cycling team, some of whom were previously unaware he had MS.

"There's so many people who were so supportive, and I just felt like they were with us the whole time," Liz Barrow said. "I've never felt anything like that before."

Michael Barrow said only time will tell whether the procedure will stop the progress of his condition. He said he still has fears about having another attack.

"Right away you have people asking, 'Well how do you know when it's worked?'" he said. "The problem is, MS has so many symptoms, any little overtraining (symptom) or anything like that — you could say 'Oh, is that a symptom?' I think there's going to be a little fear for many years. ... They say for the first two years, you still feel a lot of stuff, but after two years, you're feeling great."

As part of the study, Barrow will visit Northwestern in October for a six-month checkup. After that, he will visit every April for the next five years.

Barrow, who is on medical leave from work, said his goal is to be aggressive in the recovery process by keeping active. By mid May, he was riding up to 140 miles per

week with his cycling team, Liz Barrow said.

The Barrows plan to continue to help raise awareness about MS by participating in Walk MS and other awareness events.

"I just think the more we talk about it, the more people will be interested in (the therapy), and the more lives that could be saved," Liz Barrow said. "We think years from now, this will just be a normal doctor's visit."

Michael Barrow said he will also continue to post updates on his progress in his blog at hsctnotwithoutafight.wordpress.com.

"If it goes smoothly, it's meant to be, and everything just kept dropping into place," he said. "Even if (I only gain) 10 years, no one else really gets on medications that give them 10 years," he said.

Liz Barrow said since he has participated in the study, the waiting list for getting into the program at Northwestern has increased to a six to 12-month wait.

The study, led by Burt, continues to recruit participants at sites at Northwestern University, Rush University Medical Center in Chicago, the University of Sao Paulo in Brazil, Uppsala University in Sweden, and Sheffield Teaching Hospitals NHS Foundation Trust in the United Kingdom, according to the National MS Society.

Alexia Severson may be reached at 575-541-5462.

Common symptoms of MS:

- **Fatigue**
- **Numbness or tingling**
- **Weakness**
- **Dizziness and vertigo**
- **Spasticity, or feelings of stiffness and muscle spasms**
- **Vision problems**
- **Bowel problems**
- **Bladder problems**

Who is affected:

Anyone can develop MS, however ...

- **More than two to three times as many women as men develop MS.**
- **Genetic factors may increase risk of MS.**
- **Environmental factors, such as low Vitamin D and cigarette smoking may increase risk of MS.**
- **More than 2.3 million people are affected by MS worldwide.**

— **National Multiple Sclerosis Society.**



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