



## Stem cell transplant reduces Culver woman's MS symptoms

Lacey Miller participating in Chicago study

By Tara Bannow • The Bulletin Apr 14, 2017 0

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“Even on the days when it was like, ‘This sucks. This is really hard,’ it was like, ‘I’m doing this for him so he can have a mom who can run down to the park with him and do things with him.’” — Lacey Miller,

Lacey Miller will probably never forget her son's first birthday, at least not for the usual reasons. She threw him a party at a park near their home in Culver. Throughout the whole thing, she couldn't walk and could barely see, merely moving was a challenge.

“I just kind of sat there and everyone cleaned up and they got me back to the house,” she said.

Miller has a form of multiple sclerosis, a disease that disrupts communication between the brain and the rest of the body. The symptoms — numbness, difficulty concentrating, blurred vision and fatigue — come in cycles and tend to worsen over time.

When she was diagnosed in 2012 at age 27, Miller's symptoms weren't so bad: little things like numbness

## about her treatment

in her legs and blurry vision. It wasn't until three years later, when she became pregnant with her son, that things went downhill fast. She had to be induced into labor early because she had so much trouble walking. After that, there was vertigo, vision loss and walking became more difficult. Her worsening symptoms culminated in an emergency room trip following her son's first birthday party.

"I was going to be in a wheelchair in probably a year," she said.

Internet exploration brought her to a study at Northwestern University in Chicago that is further exploring the idea of, in a sense, resetting the immune systems of multiple sclerosis patients. Multiple sclerosis develops when a person's immune system attacks the protective covering of nerve fibers in the central nervous system, making it difficult for the brain to communicate with the rest of the body.

Miller applied to join the study in June 2016 and was approved in September. She started her testing and treatment in early January, embarking on what would be months of grueling treatments and travel.

Through it all, Miller thought about her now-18-month-old son, Emmerick.

"Even on the days when it was like, 'This sucks. This is really hard,' it was like, 'I'm doing this for him so he can have a mom who can run down to the park with him and do things with him,'" she said.

'That's a win'

A handful of prominent studies in recent years have raised hope that a procedure called hematopoietic stem cell transplantation can prevent further disability among patients with multiple sclerosis.

A [study](#) on 25 multiple sclerosis patients published last month gave further hope. Three years after undergoing stem cell transplants, disability symptoms in nearly 80 percent of the patients had not worsened, according to the study, published in the *Journal of the American Medical Association Neurology*. At five years, nearly 70 percent of the patients' symptoms still had not worsened.

Dr. Linda Griffith, an author on the study and a medical officer at the National Institute of Allergy and Infectious Diseases, which sponsored the study, said being able to halt existing symptoms is a big advance.

“To us, that’s a win if they don’t get worse,” she said. “We have no notion of being able to cure MS here and make it go away. It’s not going to go away. It’s a bad disease. But medical investigators are really thrilled and excited when they can find that the disease isn’t getting worse.”

Dr. Richard Burt, a professor of medicine and chief of immunotherapy at Northwestern’s Feinberg School of Medicine, found similar results in a 2015 [study](#) he and his team published in the *Journal of the American Medical Association*. Five years after undergoing stem cell transplants, only 10 percent of multiple sclerosis patients had worsened symptoms.

“The majority got better and stayed better,” he said. “That’s a paradigm change.”

## Creating hope

The stem cell transplant procedure involves extracting a patient’s bone marrow stem cells using a long needle and using chemotherapy and other toxic medications to clear out the rest of the cells. In multiple sclerosis patients, the patient’s own stem cells are then put back into the body.

“It is now immature, just like if you were a child again and your immune system was learning all over again what’s it’s supposed to be reacting against versus not,” Griffith said.

While it sounds exciting, Griffith cautions the research is far from conclusive. She hearkens back to the hype around early studies that showed the procedure could be helpful for breast cancer patients. It ultimately wasn’t.

What needs to happen next, she said, is a randomized study that compares groups of multiple sclerosis patients who either receive the transplant or the medications typically used to treat the condition, following them over time.

## Not for everyone

Burt, the first doctor to perform these stem cell transplants for multiple sclerosis patients in the U.S., performed the procedure on Miller.

He cautions that only a specific subset of multiple sclerosis patients will benefit from the procedure.

They must have a common form of the condition called relapse-remitting, meaning symptoms come in waves that recur over time. He doesn't perform the procedure on people who have progressed to a later stage, as it would be too late to help them, he said. Imaging on their brain and spine must show new lesions, indicating the disease is active.

"It's frustrating because people learn about this on Facebook and want to get it," she said. "They're upset when we decline them."

Burt is confident, however, that he knows who his procedure can help and who it can't help.

"We developed this over many decades," he said.

When Miller, who is now 32, went in for testing with Burt, it was in the middle of an attack. She could barely walk into the office at Northwestern; her dad had to hold her arm for balance.

Although she was accepted into the study, getting her health insurance carrier on board proved to be a struggle and logistical issues delayed her ability to officially participate. Burt is still treating her under the study protocols, however, on what's referred to as a compassionate basis.

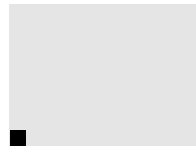
Miller's first trip to Chicago was a short one for pre-study testing: imaging to check the progression of her multiple sclerosis, among other evaluations. She flew back to Chicago on Jan. 21 for what would be a two-week trip. First, they gave her chemotherapy to kill her stem cells and suppress her immune system. That meant she lost her hair.

Then they put a long needle into her neck to remove the remaining stem cells. She still has a tiny, round scar where the needle went in.

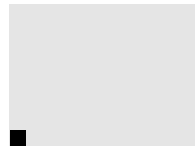
On Feb. 12, she flew back to Chicago again to have her stem cells put back into her body. She was discharged on March 1.

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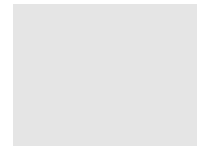
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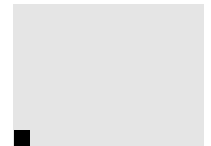
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Is Senate  
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Sometimes, Burt said his patients notice right away the so-called “MS fog,” the fatigue and inability to think clearly, is lifted once they finish the procedure.

Miller said that was the case for her. She noticed other things right away, too. Walking around downtown Chicago was much easier after the surgery than before. She no longer had to use a cane or wall

to guide her and she no longer had to stop and rest.

The other day, her fiance, Chris, asked her what the score of the basketball game was. She told him.

“He was like, ‘Can you see that?’” she said. “I was like, ‘Yeah! I didn’t realize — things are just so crisp and clear.’”

The near-constant numbness in her legs also isn’t as bad as it used to be.

“We were kind of joking the other day because my fiance touched my foot,” she said. “I was like ‘Oh my god, I can feel that!’ I hadn’t been able to feel my feet.”

No more drugs

Burt theorizes that in addition to helping people’s quality of life, stem cell transplants could also help them financially, a point he hopes to flesh out in his current research.

A 2015 [study](#) in the journal *Neurology* found multiple sclerosis drugs cost patients roughly \$60,000 per year. The price of the drugs increased annually between 1993 and 2013 at rates of five to seven times higher than the rate of prescription drug inflation, according to the study.

Miller, who works as a juvenile parole officer in Jefferson County, estimates she was spending about \$500 a month on the drugs after her insurance paid its portion. She had to quit one medication — a shot she gave herself three times per week — because it gave her flu-like symptoms. Not having to take

medications anymore was one of the main reasons Miller said she wanted to enroll in Burt's study.

"I'm kind of one of those people that I don't even like taking Tylenol," she said. "I'd rather just not take anything."

Miller isn't currently on any multiple sclerosis medications. She said she hasn't felt this good in years. She returned to work part time this week.

Burt routinely travels to medical centers around the world explaining the procedure in hopes other neurologists will perform the stem cell transplants on multiple sclerosis patients. The older ones tend to be more set in their ways, but he believes the technique will catch on among younger doctors.

The procedure is currently being performed in England, Sweden and Brazil, Burt said. A hospital in India recently expressed interest, too.

"At the end of the day, we want to help people throughout the world," Burt said, "and in fact this is spreading throughout the world."

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