

## [Her aHSCT story](#)



### **Julie Eberhardt underwent aHSCT four years ago. Read about her journey and how she's doing today.**

by Vicky Uhland

In January 2016, Julie Eberhardt began having recurring headaches. Migraines run in her family, and her high-powered job as an attorney had caused more than one literal and figurative headache. But her doctor ordered an MRI just in case, and it was clear.

Less than two months later, Eberhardt woke up with vision issues. During an appearance in court, she realized her vision was so bad that she could not read the paper she was holding. After returning from court, a coworker noticed she was slurring her words. As the day progressed, Eberhardt began limping and feeling progressively numb on her left side.

“My symptoms went from zero to 100 miles per hour in less than 24 hours,” she remembers.

Eberhardt had another MRI in March 2016, which discovered lesions on her brain and spinal cord. She was diagnosed with MS and instructed to wait on starting any medications until another relapse occurred. Eberhardt didn't have to wait long, as she soon had another relapse that left her completely blind in one eye and numb on her right side. Altogether, Eberhardt had three relapses in six months.

“I was 29 years old when I was diagnosed,” she says. “My disease was progressing so quickly that my MS specialist said I needed to prepare myself to be wheelchair-dependent by the time I was 35.”

About seven months after her diagnosis, Eberhardt began taking Tysabri, but she was advised by her doctor that, due to concerns regarding the drug's side effects, she could only take the drug for a maximum of two years. This prompted her to join MS groups online and begin researching other treatments. A member of one of her groups posted about a new aHSCT trial conducted by Richard Burt, MD, at Northwestern Memorial Hospital.



**Julie Eberhardt refers to the end of her aHSCT journey as her new birthday.**

Burt has performed the procedure detailed in actress Selma Blair's documentary. His previous study of 110 people with MS, which was published in 2019 in the Journal of the American Medical Association, found that 79% of the study participants who had aHSCT had no evidence of disease activity after five years, compared with only 3% of the participants who took high-efficacy disease-modifying therapies (DMTs).

Eberhardt had never heard of aHSCT. None of her doctors or even her MS specialist had mentioned it. She did some quick research and called the intake number for the Northwestern study. She was told she didn't qualify, but Burt gave her a call anyway.

"He said, 'I can tell you right now that you're one relapse away from being in a chair, so I will treat you off-study,'" Eberhardt says.

But that meant she had to find a way to pay for the procedure. Burt warned her he'd never had an off-trial aHSCT approved by Eberhardt's insurer, Blue Cross and Blue Shield of Illinois. His team sent the insurance company a packet with information about his study, and Eberhardt included a personal letter.

“I gave them the financial breakdown of a ‘healthy year,’ when my only expense was Tysabri and the required testing that came along with it. That was about \$150,000 a year. When you take that into account, I told them aHSCT could pay for itself in less than a year and a half,” she says.

A few months later, Eberhardt got her insurance approval, and in January 2018, she underwent “every test under the sun to make sure my body was good to go” for aHSCT. Because she was also undergoing chemotherapy as part of the procedure, she had her eggs harvested — at an out-of-pocket cost of \$30,000.

Eberhardt then began the “mobilization” phase of aHSCT, which began with an overnight inpatient stay at Northwestern Memorial Hospital to receive her first dose of chemotherapy. Eberhardt was discharged the next day and sent home to inject herself with a drug called Neupogen for five days to stimulate stem cell growth.

Eberhardt then went through an eight-hour process similar to dialysis to harvest her stem cells. About 10 days later, she checked into Northwestern and underwent more chemotherapy to destroy her remaining stem cells. The chemo was so strong that her hair fell out.

On Feb. 19, 2018, Eberhardt’s harvested stem cells were infused back into her body.

“It only took about 20 minutes, but it was so emotional,” she says. “I was crying, saying this is me, my own cells, fixing myself. I like to call it my new birthday.”

Eberhardt remained in the hospital until her immune system rebuilt itself enough that she could go home, which ended up being nine days. During that time, she got more Neupogen shots to help her immune system rebuild itself faster by creating even more stem cells — and a bunch of painkillers.

Eberhardt’s doctors cautioned that her immune system was similar to that of a newborn.

“For the first three months I was home, I acted like a brand-new baby, being very careful in public settings.” She had weekly bloodwork for the first eight weeks post-procedure, then every two weeks for the next two months. She also took an antiviral, an antibiotic and a drug to prevent pneumonia for six months.

Eberhardt felt the effects of the aHSCT almost immediately. Her vision went back to 20-20. Her numbness disappeared, and her fatigue levels became normal enough that she could once again work full time. Four years post-procedure, her MRIs show no disease progression, and some lesions have shrunk or disappeared.

Eberhardt doesn’t view aHSCT as a cure for MS because she knows her symptoms could return. Instead, she thinks of it more as a remission.

“For me, the transplant was a lifesaver, a game changer,” she says. “It gives me the confidence to hope that MS is just going to be this thing that got me sick for a couple years, and I took care of it with aHSCT. It’s a reminder for me to continue to take care of myself because I got a second chance at life and I’m not going to waste it.”

## **Participate in an aHSCT clinical trial**

There’s currently one clinical trial on aHSCT and MS underway in the United States, called BEAT-MS. Researchers are recruiting 156 people at study sites in California, Colorado, Massachusetts, Minnesota, Missouri, New York, North Carolina, Ohio, Oregon, Pennsylvania, Texas, Virginia and Washington. There will also be a site in London.

BEAT-MS participants must meet specific criteria to participate and will be randomly assigned to receive either aHSCT or certain disease-modifying therapies. The objective is to compare the costs, safety and efficacy of the two treatments.

“We’ve already shown through other clinical trials that aHSCT is effective,” says BEAT-MS Principal Investigator Jeffrey Cohen, MD. “Now we want to place it in context. Our goal is to show whether aHSCT should be more widely used and become a more mainstream treatment approach covered by insurance.”

Cohen says the study is scheduled to last six years, with preliminary results expected in 2025 or 2026.

For more details about BEAT-MS, visit the study website at [beat-ms.org](https://beat-ms.org).

Learn more about [aHSCT and find a treatment center](#).

Find out if [aHSCT is right for you](#).