

'I AM A NEW PERSON'

Cutting-edge multiple sclerosis treatment at Northwestern restores local college student's vision, balance and energy

By Nara Schoenberg
Chicago Tribune

Ivy Marcucci can stand on one leg, with the other raised to the side and bent tightly in a yoga "tree" pose.

She can hike for hours without worrying that she will lose her balance and topple down a mountain.

She can ski down steep slopes, and even do a few small jumps.

None of this would have been possible, the college student from Riverside said, without the cutting-edge multiple sclerosis treatment she received at Northwestern Memorial Hospital in summer 2019. Before a hematopoietic stem cell transplant (HSCT) for MS, Marcucci, 22,

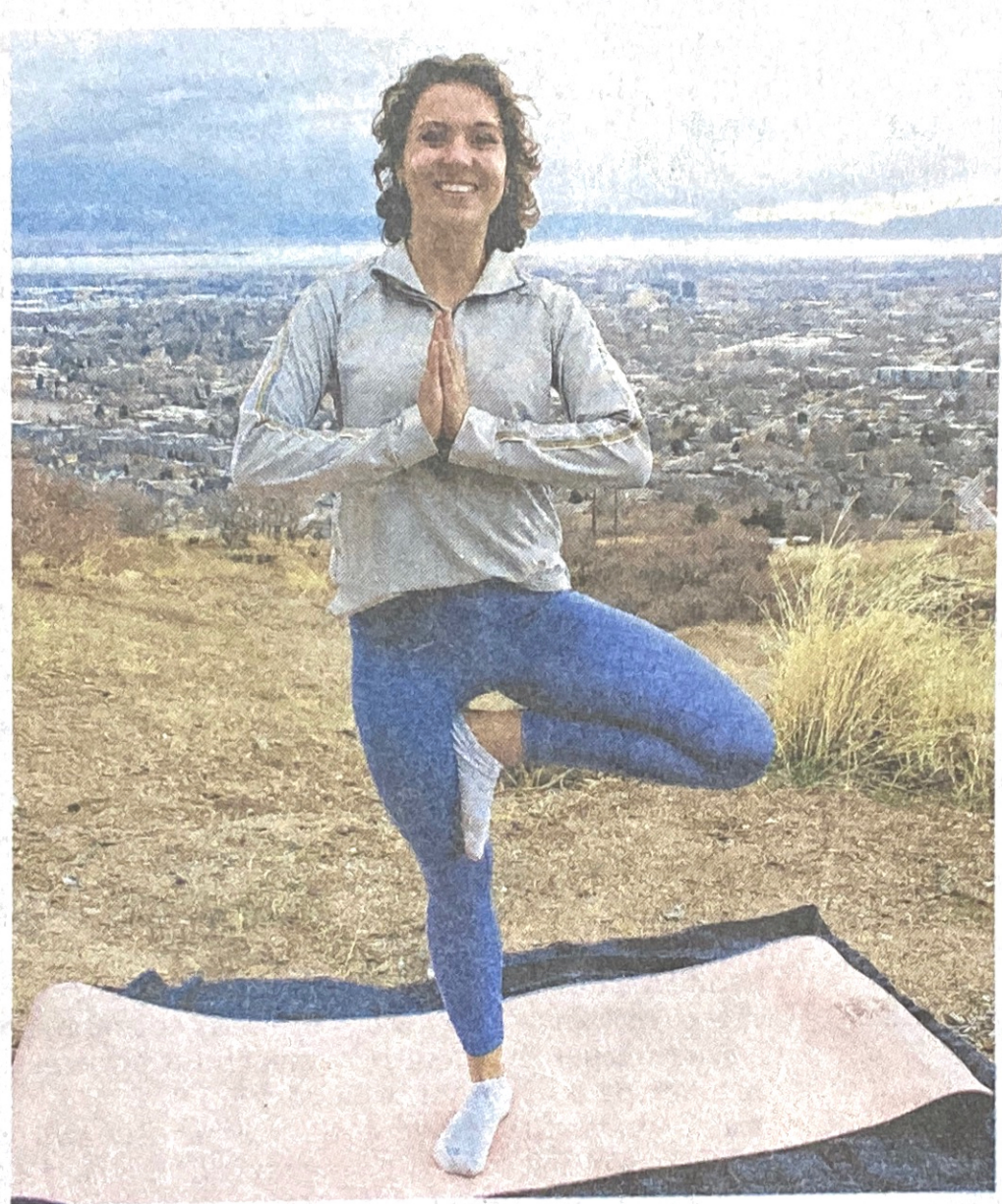
had double vision so bad she needed an eye patch, as well as balance problems and exhaustion, all due to her malfunctioning immune system's attacks on nerve coatings in her brain and spinal cord.

But two years later, Marcucci is back at school at Brigham Young University, her sight clear, her balance restored.

"I am a new person," said Marcucci. "I had MS symptoms in high school, so I guess I didn't fully know what it was like to be a healthy young person. Now, oh my gosh, I feel so good."

In HSCT for MS, a procedure pioneered in the U.S. by Northwestern University's Dr.

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After a pioneering treatment for multiple sclerosis at Northwestern, Ivy Marcucci, 22, of suburban Riverside, has returned to college in Utah. She can now hold a one-legged yoga pose. **LEYNA VARNEY**

Treatment

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Richard Burt, chief of the division of immunotherapy, the immune system is suppressed with powerful medications before being allowed to reboot, with the hope that it will reset to normal function and stop attacking healthy tissue.

The treatment is called hematopoietic stem cell transplant because stem cells retrieved from the patient's own body are used to speed recovery, but the immune-suppressing medications are the key element, according to Burt.

Once a controversial alternative to medications that are less risky but also less effective, HSCT for MS got a big boost in 2019, when a team led by Burt published a study in the *Journal of the American Medical Association*. The study of 110 patients with relapsing-remitting multiple sclerosis, the most common kind of MS, found that 79% of patients who received HSCT showed no evidence of disease activity after five years, compared with just 3% of patients who took standard medications.

"It was so much better than the drug therapy," Burt told the Tribune in 2019. "It kind of blew it out of the park."

HSCT carries serious risks, including death, with about two in 1,000 patients dying from treatment-related causes in recent years, according to a 2017 study. But MS itself also poses a serious threat in some cases. A 2013 study in the journal *Neurology* found that 10 years after diagnosis, 9% of MS patients needed a wheelchair or had been left bedridden.

The actress Selma Blair also received HSCT for MS at Northwestern in summer 2019, and in October of 2020, the influential Multiple Sclerosis Society published a position statement saying that "studies on (HSCT) have repeatedly demonstrated high efficacy and a durable outcome in people with relapsing multiple sclerosis" and HSCT "may be a useful treatment option" for



Ivy Marcucci, who has multiple sclerosis and received a stem cell transplant at Northwestern, at her home Aug. 5, 2019, in Riverside. BRIAN CASSELLA/TRIBUNE

certain kinds of MS.

Marcucci's neurologist, Dr. Roumen Balabanov, said that his patient has experienced "remarkable improvement" and he would expect her brain scans and bloodwork — scheduled for this summer — to be consistent with that.

"Self-report of symptoms is very telling (with MS)," said Balabanov, an associate professor of neurology at Northwestern Medicine who has monitored Marcucci's progress by phone while she is in college in Utah.

"It's very unlikely someone who is feeling well, very active, able to ski and hike and do well in college, would have hidden disease progression."

Marcucci, who was part of the last wave of patients to get HSCT for MS at Northwestern before Burt took a break from treating patients to publish and promote his HSCT findings, considers herself extremely lucky.

The treatment, never widely available, was slowed by COVID-19, but a major study based at the Cleveland Clinic with 20 locations across the U.S. has started accepting patients.

In addition to enjoying her good health, Marcucci is talking about her HSCT experience on social media, along with Blair and other Burt patients.

"It's been amazing to be kind of like a pioneer of it," she said.

HSCT uses medications similar to those used in chemotherapy for cancer, and patients lose their hair. During the period when the immune system is most suppressed, they are very vulnerable to infection. They often feel weak and tired, and in some cases intensely nauseated.

A former high school soccer team captain, prom queen and honor society president, Marcucci put up a brave front when she was interviewed by the Tribune a

week after she was released from the hospital, but looking back, she confided that she vomited shortly before the interview.

"I felt like I was on my deathbed," she said.

MS patients' symptoms vary greatly, with some of the more common signs including weakness, fatigue, chronic pain and difficulties with movement and speech.

Like many HSCT patients, Marcucci continued to have some of her old symptoms in the first year after HSCT, including numbness in her hands. And even though she knew that was normal, she worried.

"In the back of my mind, it's a reminder of this very threatening disease, and what the future could have been, or what it still could be, because we don't know," she said.

Although HSCT is very effective overall, there's no way to know for sure whether it will work for a specific patient.

Her balance and energy improved gradually, but by summer 2020, she was feeling much better. A marketing major, she landed a sales internship at Adobe, where she spoke to 200 interns about her treatment and raised money for stem cell transplants.

Today, she said, she sometimes gets really tired, and she definitely needs eight to 10 hours of sleep. If she gets stressed out, sick or exhausted, she can get mild versions of her old symptoms, such as numbness or tingling in her fingers.

But while once she couldn't hold a basic one-legged yoga pose for five seconds, today she can last for over a minute. She can stay in a handstand for almost as long.

"Last summer I hiked all the time and had a great time, and I was not afraid of falling to the bottom of the mountain," she said, laughing, as she recalled writing off her earlier balance

problems as clumsiness. For years, she said, she just accepted that, despite all the time she spent practicing, simple yoga poses were beyond her.

She has learned to ski since her treatment, and this winter she tackled some of the harder trails at Utah's Park City Mountain.

Marcucci hears from a lot of other HSCT patients on social media and has been able to get tips and offer support.

Blair followed her on Instagram, which was a thrill, and Marcucci is excited about growing support for HSCT among medical experts, as well as MS research focusing on mRNA, the genetic material used in two breakthrough vaccines for COVID-19.

"I'm so hopeful," she said. "Every day is getting a little better for the MS community."

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Ill. polluters not reporting data to EPA

Medline, Sterigenics say it's not required and they give ethylene oxide info to state

By Michael Hirschman
Chicago Tribune

Several major medical device manufacturers say they do not report ethylene oxide emissions to the U.S. Environmental Protection Agency as required by law, according to a report by the state's Department of Health.

Medline Industries Inc. and Sterigenics Inc. are the two largest manufacturers of ethylene oxide in Illinois, according to the report. The report also says that Medline and Sterigenics have not reported ethylene oxide emissions to the state's Department of Health as required by law.

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Passengers wearing face masks on the Metra train, which is one of the many trains that are part of the Metra system. The train is one of the many trains that are part of the Metra system.

Riders slowly return

Here's what they're finding on Metra, CTA buses and trains

By Sarah Fritzsche
Chicago Tribune

Riders are trickling back to buses and trains as more people get vaccinated and go back to work. The number of riders on Metra, CTA buses and trains is slowly increasing.

With ridership on CTA and Metra still at a fraction of pre-pandemic levels, the agencies are planning for the possibility that ridership will never return to pre-pandemic levels.

CTA buses and trains are carrying more than 300,000 riders a day, about one-third of their pre-pandemic levels.

Metra is also seeing a similar increase in ridership. The number of riders on Metra is slowly increasing.

Netanyahu signals attacks to go on

Planes pound Gaza amid international calls for cease-fire

By Peter M. ...
Associated Press

GAZA CITY (AP) — Israeli warplanes pounded a strip of heavy armor in several locations of Gaza on Sunday, Israeli officials said. The attacks are part of a military operation in Gaza.

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Protesters call for end to occupation

Thousands gathered Sunday afternoon in the West Bank to demand the immediate end to the occupation of Palestinian territories.

Not everyone is ready to give up masks

As more Americans get vaccinated, many are still wearing masks to protect themselves from the virus.

'Take Flight' exhibit ready for liftoff

Reopened Boeing 737 is set to be the centerpiece of the new exhibit at the Museum of Science and Industry.

'I AM A NEW PERSON'

Cutting-edge multiple sclerosis treatment at Northwestern restores local college student's vision, balance and energy

By Tracy Schenberger
Chicago Tribune

By March 1, she could see and walk. By May 1, she was blind and unable to walk. She was diagnosed with multiple sclerosis.

She was diagnosed with multiple sclerosis. The treatment helped her regain her vision and energy.



After a debilitating relapse from multiple sclerosis at Northwestern, by March 21, of multiple sclerosis, she returned to college in which she was a member of the Phi Kappa Phi Honor Society.