



Ivy Marcucci, 20, of Riverside, recently received a hematopoietic stem cell transplant at Northwestern Memorial Hospital to help treat her multiple sclerosis. It is the same procedure that actress Selma Blair, who also has multiple sclerosis, recently announced she had received. (Brian Cassella / Chicago Tribune)

In the past, she had been able to explain away the occasional strange symptom — numbness on one side of her body, or an electric shock sensation in her spine. Maybe she had a pinched nerve, maybe her backpack was too heavy.

But now Ivy Marcucci couldn't ignore what was happening to her eyes.

The 20-year-old college student from Riverside said her vision blurred and doubled last December as she tried to watch the movie “Mary Poppins Returns” with her parents and younger sister. Her father, an emergency room doctor, saw her squinting and observed that her eyes weren't moving in tandem; it almost looked as if she had a lazy eye.

He took her to the emergency room, where she quickly received a diagnosis: Ivy had multiple sclerosis, a disease of the central nervous system with widely varying

but often disabling outcomes. Within 25 years of being diagnosed, half of patients can't work, require assistance to walk or can't walk, according to a 2015 article in the journal JAMA.

"It felt like the air had been sucked out of the room," Ivy said of her diagnosis. She recalls thinking, "Am I going to be in a wheelchair tomorrow?"

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Her head freshly shaved, her dark eyes sparkling, her red dress bright and stylish, Ivy has come a long way since then. Last week she was discharged from Northwestern Memorial Hospital after completing a hematopoietic stem cell transplant, the same procedure that actress Selma Blair, who also has multiple sclerosis, recently announced she had received. The treatment, which is not widely available, got a big boost in January when a study in the journal JAMA reported it outperformed conventional therapies, with 79 percent of patients experiencing no symptoms after five years.

Ivy is grateful, hopeful and determined to get the word out, particularly after having been denied coverage for the procedure from her insurer, Blue Cross and Blue Shield of Illinois.

"I want to talk about it because this works, people need this, and it should be accessible for more people," she said.

Her parents, Jared, 46, and Matia, 44, were able to raise \$125,000 for the procedure by refinancing their house.

"We were so fortunate to get funds," Ivy said, "but not everyone can do that."

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Ivy Marcucci, 20, with her sister Mazzy, left, and parents Jared and Matia Marcucci on Aug. 5, 2019, at their Riverside home. (Brian Cassella / Chicago Tribune)

Blue Cross and Blue Shield of Illinois issue a written statement saying, “Blue Cross and Blue Shield of Illinois does not disclose our members’ personal or benefit information as a matter of privacy. We are committed to providing our members access to quality, cost-effective health care within the benefits outlined in their plan and in keeping with our medical policies.”

In January, a JAMA study of 110 patients with relapsing-remitting multiple sclerosis, the most common kind of MS, found that 98% of patients who received hematopoietic

stem cell transplants showed no evidence of disease activity at year 1, compared with 21% of patients who took standard medications for MS. After five years, 79% of the transplant patients showed no evidence of disease activity, compared with 3% of patients on standard medications.

“It was so much better than the drug therapy,” study co-author Dr. Richard Burt said of stem cell transplant approach, which he’s been working on for 30 years. “It kind of blew it out of the park.”

Burt, the chief of the division of immunotherapy at Northwestern University, said the transplant procedure usually is covered by insurance.

Stem cell transplants for multiple sclerosis have serious potential side effects, including death, with a recent study showing a transplant-related mortality rate of **2 in 1,000**. But MS medications can also come with sobering warnings, including increased risks of death, cancers and brain infections.

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In the earlier stages of MS, immune cells attack the nervous system, causing damage that can lead to disability. Burt uses a noncancer regimen of immune-specific chemotherapy and antibodies to eliminate many of the malfunctioning immune cells, then he reintroduces stem cells from the patient's own body. The idea is to reboot or reset the immune system, so it will function normally.

While formal cost analysis needs to be done, hematopoietic stem cell transplantation is potentially less expensive than existing medication-based therapies, Burt said. Transplantation has a one-time cost of about \$125,000, while medications cost about \$70,000 a year but can range up to \$200,000.

When Ivy was diagnosed with MS, her doctors found evidence of more than a dozen MS lesions, or areas of damage, in her brain and upper spinal cord. Her doctor put her on steroids in an effort to stop a flare-up of the illness, but her double vision continued, a sign that the steroids weren't working well enough.

Ivy's father, Jared, did some research and found Burt's study in JAMA.

"This is really awesome," he told Ivy. But Ivy's MS was quite active, and it appeared, in hindsight, that she had been having symptoms on and off since age 17. Her parents wanted to prevent more damage to her nervous system and get her a transplant while she was still well enough to be eligible, so the clock was ticking.

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Contacted by email, Burt at first didn't think Ivy was the right candidate for a transplant, Jared said. But then Burt — who declined to discuss Ivy's case with the Tribune, citing privacy concerns — looked at images of the damage to her brain and spinal cord, which was more severe than her symptoms suggested, Jared said. This was in February; Ivy was still having vision problems; she had to wear an eye patch

for her double vision, and she was experiencing another symptom, "cognitive fog," which for her meant forgetting words and names and repeating the same story multiple times.

A Northwestern neurologist examined her and reviewed her MRIs, writing in a report that the burden of the disease on her brain was "moderate-to-severe" and that her need for more aggressive treatment was "fairly urgent."

"It was one of those things where you look at the MRI, and you say, 'Why isn't she in a wheelchair?' " Matia said.

Burt approved her for a transplant, Jared said, but their insurance company balked. The Marcuccis submitted appeal after appeal, and each time they were met with the argument that a transplant was an experimental therapy or wasn't medically necessary, according to records they showed the Tribune.

It was particularly frustrating, they said, to discover that Blue Cross actually does cover the transplants for Illinois residents who belong to a plan for federal employees. The Marcuccis delayed the transplant while they tried to work out the funding, eventually refinancing their house. Financially it was very hard, Jared said.

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"Nobody has \$125,000 sitting around," said Matia, who runs a medical billing business. "He's a doctor. We make good money. We're not poor, but \$125,000 is \$125,000." And for other families, she added, the cost could be prohibitive: "Why do you have to be rich to get good treatment? It just seems unfair."

Ivy found it stressful to see her parents sacrifice financially, and she too was frustrated with Blue Cross.

"You look at their little motto: something about standing by their patients in health," she said of Blue Cross. "Well, what about this? What about me? You're not

standing by me.”

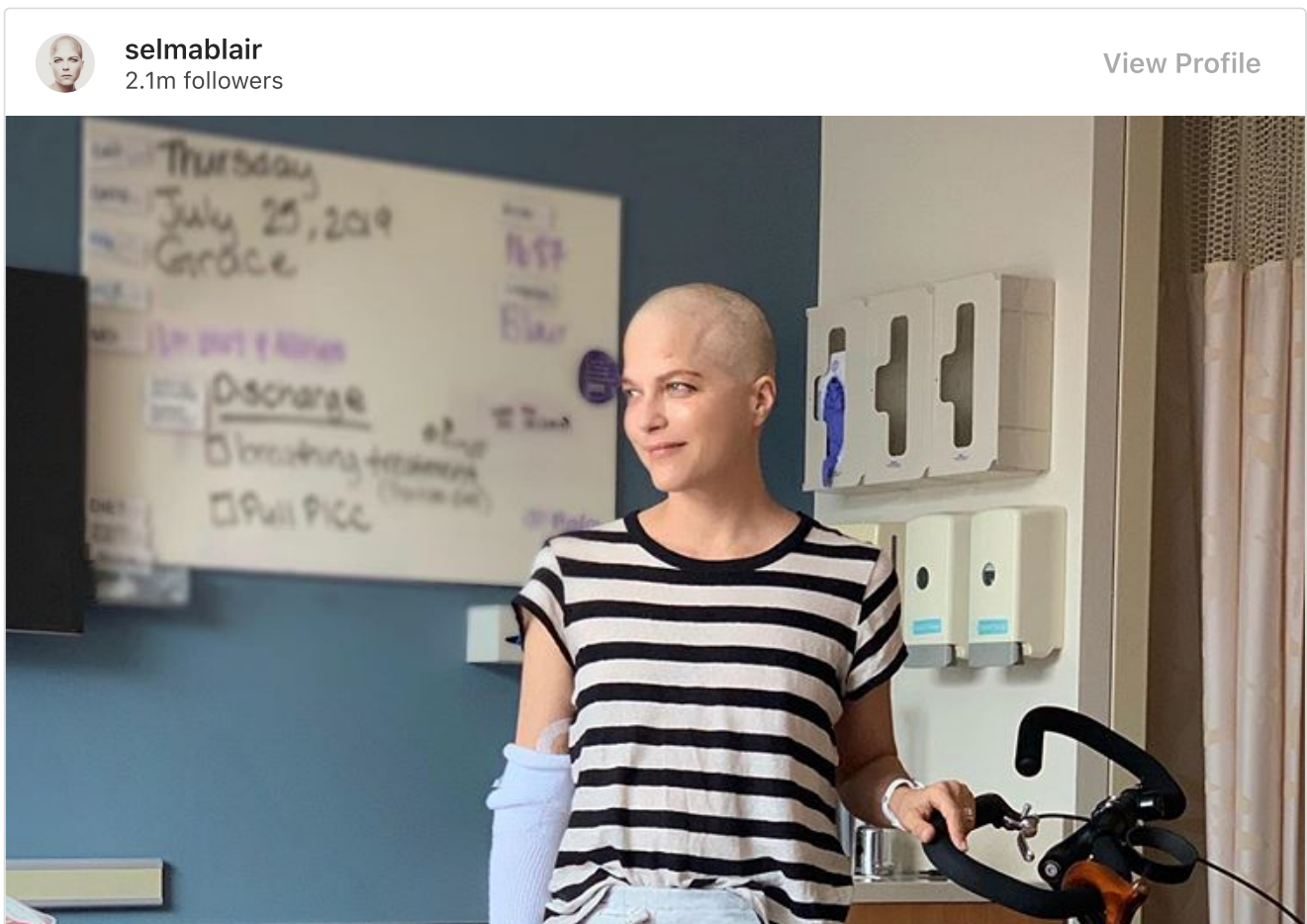
Last month she had her 17-year-old sister, Mazzy, shave her head in preparation for a 15-day hospital stay that would include four days of punishing chemotherapy.

Her father volunteered to shave his head in solidarity, but Ivy turned him down: “Stop trying to take my spotlight!” she said with a laugh. “I want to own this.”

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In the hospital, chemotherapy made her vomit repeatedly. She was on steroids so it was very hard to sleep, and she suffered through a high fever, which is not unusual after a stem cell transplant.

There were high points, too, she said. She was still in the hospital when Blair posted on Instagram that she was completing the same procedure, with a photo of a hospital room that looked strikingly like Ivy’s.





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Today is a banner day. I am being discharged from the care of an incredible team of nurses and techs and a visionary Dr. who believes in my healing as much as I do. This has been a process. And will continue to be one. I am immunocompromised for next three months at least. So no kisses please. I wanted to make sure any complications that might arise here were my private space. And we got through brilliantly. I thank you all for your love and support and that extra dose of great with a [@people](#) cover. I see things so much more clearly now. And I am excited to share this journey when I am ready. For now, I have recovery. And a great [@the_alinker_world](#) so I gotta split. Bye!!!!!! This is the best gift I could give to Arthur. [#newimmunesystem](#) [#whodis?](#) 🎂

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And now she's home in Riverside, still tired and recovering from chemotherapy, but feeling a little better every day. Always a go-getter — in high school she was captain of the soccer team, prom queen and president of the honor society — she's learning to pace herself more, she said. A junior at Brigham Young University, she's taking a break from college until January, doing yoga and trying to support others who are going through stem cell transplants for MS.

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When she's better, she's hoping to volunteer for the Multiple Sclerosis Society and get certified to teach yoga, with the goal of leading a class for people with chronic illnesses.

"It's been cool, just being on Instagram," she said. "People see Selma Blair, and they're like, 'OK, I can relate to her,' but then me being just a plain, regular person, people can reach out, and I can answer their DMs and be like, 'Here's my experience.' I can write about it. I can talk about it and just be more accessible."

nschoenberg@chicagotribune.com

Nara Schoenberg

