

ROCK HILL, SC On a typical weekday, Meghan "Meg" Bayer wakes up around 9 a.m. The 25-year-old faces a mountain of work as she works toward her Masters in Social Work degree at Winthrop University, where she's enrolled online. But she first must do other things.

Bayer checks her blood sugar on a phone app to keep her Type 1 diabetes in check. Then she pops in her cochlear implants, which allow her to hear after being born deaf. She puts her glasses on. And if her feeding tube has been running, she stops it to change the bag. If it hasn't been, she gets a feed set up.

By noon each day, she's at her computer, digging away at her schoolwork. And when she isn't working on her degree, she's handling the administration of her nonprofit.

Bayer has Stiff Person Syndrome, a neurological disorder that experts say affects only about one or two in a million people. Bayer is the founder of Meg's Miracles, a 501(c)3 nonprofit organization she founded to raise money for SPS research.

Bayer says her symptoms include severe muscle spasms that can cause dislocations and torn muscles, attacks that leave her looking "like a fish," she says. The condition can affect her breathing. She has been on a ventilator multiple times. Her stomach also is paralyzed, which is why she has the feeding tube.

She says she does the work for the few others who share her diagnosis.

"I don't want someone else to have to hear that this is a progressive, potentially terminal disease," she says. "I've been able to keep moving forward because I still have hope."

The cause is unknown

Bayer said she began to experience symptoms of SPS in 2012 shortly after her 16th birthday. After receiving a vaccine, which she would later learn contained an aluminum preservative her body could not break down, it was like a switch went off. Some say the reaction is a coincidence. Bayer figures she may never know.

"My body just fell apart," she says. "One system after another started failing. My parents basically had this point where their daughter was slipping away. The daughter they had 24 hours ago was now critically ill."

She struggled for years to find a diagnosis. While experiencing the same symptoms as now, Bayer says doctors didn't believe her.

"It's all anxiety, it's all in your head," she remembers being told three years into her search. "Stop

trying to get attention."

At one point, she fell into an unexplained coma, she says. The cause of her condition remained unknown.

In January 2017, Bayer took matters into her own hands.

"I was sitting in my dorm room, and I felt this overwhelming sense of impending doom come over me. And I was like, if I don't find someone to help me, nobody will. So I started out on trying to find that one-in-a-million doctor for a one-in-a-million condition," she said.

She found him at The Johns Hopkins Hospital in Baltimore: Dr. Scott Newsom.

Newsom gave Bayer the diagnosis she had searched for, and he's still her doctor today.

In 2018, Newsom would found the Johns Hopkins Stiff Person Syndrome Center, the only outpatient center for SPS in the world.

The center's goal is to offer "effective symptom management and hope for the future," according to its website. It serves over 100 people with SPS.

"Our center is trying to promote awareness for SPS, identify the full spectrum of this condition, and help identify immune markers that might be associated with SPS pathogenesis, severity, and subtype," Newsom says.

Today, Bayer is giving back to the same doctor who has helped her. One-hundred percent of proceeds raised by Meg's Miracles go to the Johns Hopkins SPS Center.

"We may not have the answers, you know, in three years, but five years, 10 years, 15 years down the road, we're curing these diseases, because we're doing the work now," Bayer says. "We have to fund raise for the work now, in order to get there."

A taekwondo champion

It's a big dream, but when you meet Bayer and hear her story, you learn one thing: don't underestimate her. This is a young woman, with an almost intimidating grit and determination, who doesn't give up.

She uses a wheelchair for mobility, which she says people often notice first. "His name is Nemo," she says. "That's how I break the ice with adults."

Like from the children's movie?

"Right," she laughs, quoting the film. "'Just keep swimming.'"

She'll tell you all about her passion for social work and advocating for others with disabilities, as her face lights up. When her mother suggested the profession, Bayer investigated.

"I was on fire once I knew what was all entailed in social work," she says. "I just have this overwhelming sense of peace that's like, 'yes, this is where you're supposed to be.'"

Bayer dreams of advocating for disabled people in Washington, D.C., on Capitol Hill, she says. It's not so hard to picture.

Sure, she's a bubbly, petite blond. But she's also a woman who could kick you in the face from her wheelchair - for real.

She's a nine-time world champion in Taekwondo and currently training for her fourth-degree black belt.

She competes against people who stand. And she wins.

She can compete only in events where she's judged on her posture. Regulations prevent her from fighting. But at home, she'll spar with anybody.

"My instructor, he's like, 'Ms. Bayer, let's get you over here with the tallest guy in the room, that weighs 250 pounds. And he's all the way up here, and I'm trying to figure out how to make it work.'"

But Bayer's up for the challenge.

"I'm always here," she says, and then reaches up towards the ceiling. "And the bar is up here. I'm still always climbing for that bar."

As it comes up on its first anniversary, Meg's Miracles has raised around \$8,000.

"The first big goal is obviously to hit that \$10,000. I don't know how long that's gonna take. But in my mind, it doesn't really matter, because it's about getting closer to the goal," Bayer said.

It's always about getting that much closer, Bayer says, even if she's just inching forward. Always reaching, always climbing.

You can donate to Meg's Miracles at megsmiracles.org/donate-now.

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CITATION (APA STYLE)

Nell Perkins, T. (2021, November 26). Winthrop student advocates for others with rare syndrome. *Herald, The (Rock Hill, SC)*, p. 1A. Available from NewsBank: Access World News – Historical and Current: <https://infoweb.newsbank.com/apps/news/document-view?p=WORLDNEWS&docref=news/186865381B948FE8>.

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