

STUDENT ROUNDS

Finding Community

A CHRONIC ILLNESS SPURS MEDICAL STUDENT NICOLE SPENCER '25 TO PROVIDE SUPPORT FOR OTHERS.

As a first-year medical student, Nicole Spencer '25 never imagined becoming a patient herself. But shortly after she began her medical studies, Spencer began suffering episodes of dizziness and heart palpitations.

She was diagnosed with postural orthostatic tachycardia syndrome (POTS), a blood circulation disorder. Ultimately, her physician determined the POTS was caused by Ehlers-Danlos syndrome, (EDS) a rare connective tissue disorder that affects every part of the body.

"I've had symptoms of EDS since I was a child, but because it's a rare disease, no one ever put two and two together," says Spencer, who had to take a medical leave halfway through the year because she was too sick to continue.

It was a difficult time. Feeling isolated and worried she'd have to give up her dream of a career in medicine, Spencer turned to social media. In this virtual world, she found genuine support and connection. "I didn't know anyone who had these same illnesses, but I found a huge online community for people with chronic illnesses, and specifically for people with POTS and EDS," she says.

It shouldn't have been surprising. Back in high school, Spencer created an Instagram account to create support for her childhood best friend, who had been diagnosed with cancer. That account, Smiles for Ella, ultimately gained 50,000 followers. "When you're young and you're ill, you feel very lonely," she says. "Social media provides the opportunity to not be so lonely and to find people going through a similar thing. We started an Instagram page together talking about her experience going through cancer being so young and we met a lot of really good friends along the way."

Now Spencer found the same community and support for herself. "The cool thing was that I actually managed to find a bunch of people pursuing medicine who were dealing with these illnesses," she says. "Being able to see people who

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—Nicole Spencer '25

were ahead of me in this journey and to connect with them motivated me to keep going with medical school and to maybe try to inspire others coming behind me."

Struggling for purpose while on leave, Spencer set out to support others struggling with the unknowns of chronic illness. The result was Potsie Packs, care packages for teens and young adults containing practical items to help with their illnesses as well as other items to provide cheer. Spencer solicited companies for donations and began reaching out to people she connected with online to ask if they'd like to receive a gift.

"As soon as I started sending them out, people started posting about the packages, and it took off from there," says Spencer, who has sent out nearly 500 Potsie Packs in the last year.



Nicole Spencer, who suffers from Postural Orthostatic Tachycardia Syndrome, prepares to record a video for her Instagram account.



Spencer prepares a video for her Instagram and TikTok with the intent to help others with similar struggles.



Nicole photographs her emotional support dog, Tara, while preparing a package containing medical and motivational accessories with her roommate.

“Most of these sorts of efforts are targeted to children,” she says. “Older teens and young adults are kind of a forgotten demographic.”

Potsie Packs has its own Instagram page. People requesting a care package fill out a Google form with questions about their symptoms and Spencer tailors the packages to those needs. “One of the biggest problems with POTS, and with some other chronic illnesses, is dehydration, so I have several companies that donate hydration packets,” she says. People who use feeding tubes might receive pads and tape or a pillow that makes wearing a seat belt more comfortable. Other items include compression socks, bath bombs, face masks, laptop stickers and dog toys. She has received donations to cover shipping and is in the process of filing for nonprofit status to reduce those costs.

Now back at Upstate, Spencer is figuring out how to navigate medical school with a chronic illness as she goes. “It’s difficult,” she says. “One of my issues

is that I can’t stand for long periods so there’s a lot of things that have become a challenge that wouldn’t normally be. I’ve been very lucky to have people at Upstate who have helped me uniquely figure out ways that I can still do what everyone else is doing and get the most out of my education without worrying about me passing out.”

She’s started using a wheelchair for clinical experiences, something she imagines she’ll do full time once she begins clinical rotations. “It’s an ongoing journey and I’m still figuring it out, but I’m thrilled to have the support I do from Upstate,” says Spencer, who hopes for a career in pediatrics.

Although her time to devote to Potsie Packs is more limited, she is currently assisted in assembling the care packages by her roommate, third-year medical student Nuttha Siriwatanakul ’24, and hopes to eventually expand the effort to get other medical students involved.

Even though she’s back in school,

Spencer says her Internet community remains a big part of her chronic illness and medical school journey. “There are a lot of studies that show the negative impact of social media, but when you’re in a unique situation like I am, having a niche community is more of a uniting factor than a separating one,” she says. “I’ve shifted from looking for support and information for myself to using my medical student perspective to educate others through my own personal Instagram page.”

A recent post posed the question, “Can I still chase my dreams despite my diagnosis?”

Spencer’s answer: “Yes,” she says. “With help.”

“Just because you’ve got a disability doesn’t mean you can’t be a doctor,” she says. “More students and doctors should realize there are people with disabilities all around them.”