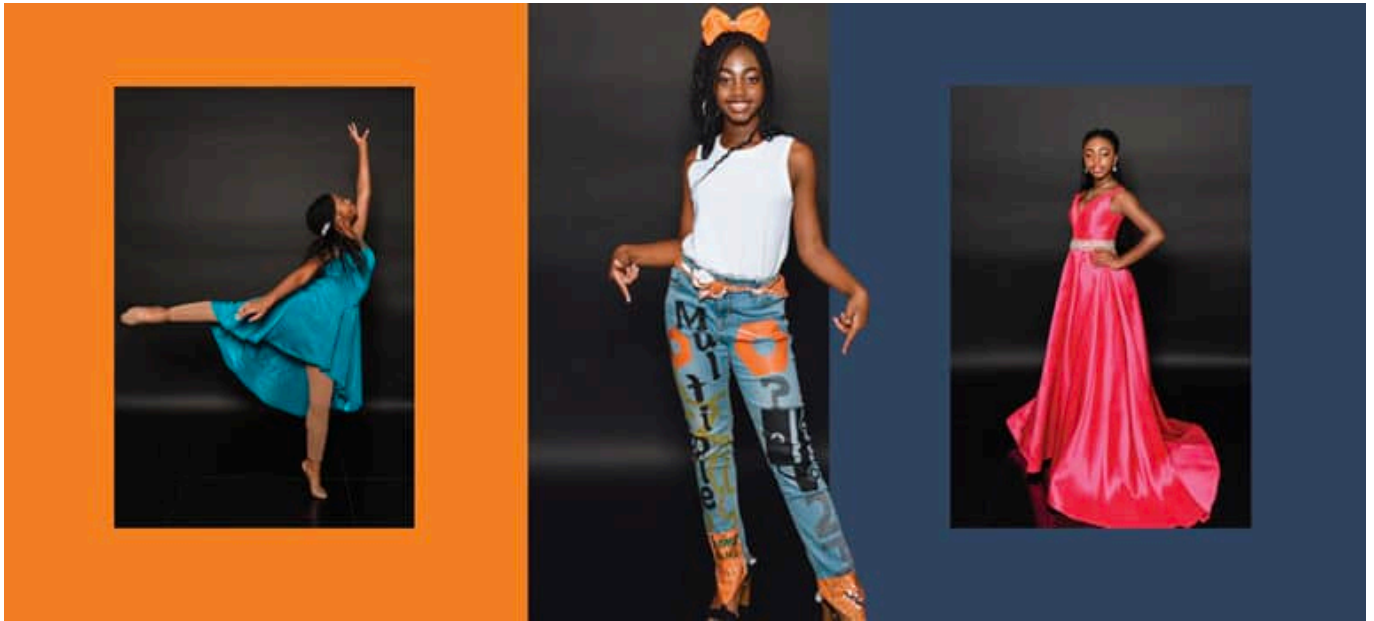


Taking the stage



Preteen advocates for people with MS through pageantry.

by Shara Rutberg

Sarah Addison remembers feeling terrified when she found her mother, DeLeon Addison, paralyzed in bed while visiting her maternal grandparents at their home in Huntley, Illinois. It was 2020 and Sarah was 9 years old. She remembers crying when the EMTs refused to let her ride in the ambulance with her mom when they rushed her to the emergency room. And Sarah remembers not knowing what multiple sclerosis was when her family received the diagnosis three weeks later.

For months and months, Sarah did not talk about her mom's MS with anyone outside her family. Not with school friends. Not even with friends from dance class.

Recently, however, Sarah bounced across an international stage beaming, explaining to an audience that, "like 2.8 million other people in the world, my mom has multiple sclerosis ... and I want to help support families that are dealing with this disease because I know from personal experience that it's hard, not only on the patient but also on the people that care about them."

Sarah's journey to becoming an MS ambassador is "inspirational," says Ginny Wiehardt, manager of content for the National Multiple Sclerosis Society. Wiehardt's mother also had MS. "I only recently grew out of that stage of not wanting to talk about it," she says. "I'm so impressed with this preteen who made that journey at such a young age."

How did Sarah go from silent to sharing? It took an exceptional mom, sequins and sashes — and a very special pair of jeans.



Sarah Addison (right) and her mom, DeLeon Addison. DeLeon lives with MS.

A foray into pageantry

Sarah has been twirling and leaping across stages in dance competitions since she was 7 years old. A few years ago, a dance team friend persuaded her mom to let Sarah compete in a pageant. DeLeon, who has a doctorate in nursing practice and teaches nursing at Tarrant County College, competed in a few pageants as a teenager and was familiar with the world of evening gowns and talent competitions. Sarah loves it, “especially meeting so many amazing girls from different places. It’s just amazing!” she says of her “pageant sisterhood.” The Addisons travel to one pageant a year.

In 2022, Sarah set her sights on the Royal International Miss Pageant, held in Clermont, Florida. Preteens from around the world enter to compete for scholarships and other prizes in a contest that focuses on, according to its publicity materials, “empowering young women while giving them opportunity to grow and develop a positive self-image.” Sarah qualified to enter as Miss Puerto Rico PreTeen in the pageant, thanks to her Puerto Rican great grandfather. Contestants vie for the Royal International Miss crown and can also compete for a Royal Miss Role Model crown. The pageant work begins long before they land in Florida.

Each contestant must choose a platform, or cause, to advocate for during the competition. As part of the role model competition, competitors must field questions from a panel of judges about their cause. Additionally, for Sarah’s division, each girl had the option to customize a pair of jeans conveying their cause to wear onstage when they introduce themselves to the

judges and give an elevator speech about their platform. They also compete in the categories of interview, fun fashion, evening gown, talent (for Sarah, dance) and runway contests.

Adding a personal touch

Sarah chose MS as her platform. But when it came time to rehearsing questions before the pageant about the disease and why it was important to her with her pageant coach, the usually loquacious 11-year-old fell silent. "It was just too personal," she says.

DeLeon and Sarah decided to put interview practice aside. Instead, they focused on the jeans. "Maybe working on them would help her process my diagnosis," DeLeon says. She and Sarah have always been very close, from mother-daughter manicures to a dedicated 30 minutes of together time before bed every night, but MS brought them even closer.

Together, they combed through Sarah's closet to find an old pair of jeans. Then, they dug into the Society's website. As Sarah began to learn more about her mom's disease, what struck her most was that she and her mother were not alone; in fact, 2.8 million people live with the disease. "I realized me and my mom and my family were not the only people going through this," she says.

She grabbed a marker and inked a huge "2.8" on one leg of the jeans.

Over three weeks, Sarah also learned how MS affects the body and translated it onto denim.

"MS is broken nerves that can't send signals correctly and that kind of looks like nuts and bolts to me, so I ironed those on," Sarah says. "I added lines to make nerve endings."

She also added a brain and cut bright orange bandanas from Walk MS events she and her family had participated in and added them to the jean's cuffs and back pocket. "I put a giant question mark because we didn't know what was going on those first weeks," Sarah says.

She ironed on a big black ambulance driving down the left front leg of the jeans. And, of course, in green capital letters outlined in white, the word "MOM."

When the Addison's arrived at the competition in Clermont, the jeans were ready — and so was Sarah. When it came time for her interview, she faced the six judges with a smile. When they asked her why she chose her platform, she took a deep breath and told them: "My mom has MS.... and MS doesn't just affect the patient, it affects their families, too." It was the first time she spoke about it outside her family. Sarah placed top 15 in the Royal International Miss Pageant.

Sarah started talking about MS during the pageant, but her work to help people learn more about the disease hasn't stopped. As part of her pageant service project, she's organizing several DIY walks over the next few months and a Pageant Sister workshop to help girls prepare to be contestants, all to raise money for MS.

Unlike her evening gown, the MS jeans are not reserved for competitions, says Sarah, who dreams of becoming an ER nurse. She wears them to the mall, to school, “I wear them all the time.” And when kids ask her about them, the 11-year-old, now quite fluent in “lesions” and “physical motor skills,” tells them all about it. And about her mom.

Shara Rutberg is a writer in Evergreen, Colorado.