

Sophia Soars: A 700-Mile Journey to Treat a Daughter's Cerebral Palsy



Sophia's Story

As she strolled through the centuries-old streets of Florence, Italy, taking in the sights several summers ago, the other tourists couldn't have known that for the now 14-year-old, Sophia Slinkard, each step along the cobblestones was a success story and the culmination of a journey that began many years prior.

"Sophia was diagnosed with cerebral palsy (CP) several months after her first birthday," her mother, Susan recounts. "At first we were told that she may have some kind of developmental delay, but when she wasn't crawling at 14 months, we knew it was something more serious. Receiving the diagnosis was painful, but it did provide us with some closure. It gave us answers and next steps. We could finally put a plan together to get her the care she needed."

Sophia began receiving care near the Slinkard's home in Fayetteville, Arkansas and was eventually able to walk with the assistance of a walker. Because the intervention came so early, Sophia responded well to therapy.

"It became her normal," Susan says. "But as a parent, you struggle. While Sophia could get around, it was hard for her, and it was only getting worse as she grew. We always wondered if we could be doing more and what the future might hold for her."

It was with "more" in mind that when a local provider spoke to them about touring the James R. Gage Center for Gait and Motion Analysis at Gillette Children's, the Slinkard family began looking into care sites outside of Arkansas.

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An Out-of-State Solution

"We researched the best treatment centers for cerebral palsy in the country," Susan says. "Our neurodevelopmental pediatrician was familiar with Gillette and strongly advised we go there because of their comprehensive, multidisciplinary approach."

Sophia had her first appointment at Gillette in April of 2013. As Susan will tell you, this approach was on full display from the beginning.

"I think we saw at least six different doctors and therapists," Susan recalls. "In that single visit, they explained more about Sophia than we had ever known. It was both strange and comforting to have that many people focused on your child."

Among the physicians in Sophia's first consult was Marcie Ward, MD, a pediatric rehabilitation medicine specialist.

"At Gillette we prefer to evaluate patients as a team, and that directs the way we proceed with our patient's care," Ward says. "Here, we treat children who have cerebral palsy every day; we know their needs well. The parents and family are an integral part of the decision process, so rather than split up a number of individual appointments, we get everyone in the same room and on the same page."

After Sophia's initial visit, her team put together a comprehensive treatment plan that included Botulinum Toxin and Phenol injections, serial casting, and several other treatment options that the family had not been offered in the past. Sophia's doctors were hopeful that these procedures would mitigate Sophia's spasticity and allow her greater ease when walking.



"They Don't Perform Rhizotomies in Arkansas"

The Slinkards would return to St. Paul for treatment every three months over the next year. At that time, Ward and Sophia's care team determined that they weren't seeing the progress they had hoped to see. Having exhausted alternative measures, the Slinkard family scheduled Sophia for a selective dorsal rhizotomy (SDR), a neurosurgery that permanently reduces spasticity by cutting the nerve rootlets in the spinal cord that are sending abnormal signals to the muscles.

"We had read about rhizotomy surgery, but there wasn't a hospital that could perform the procedure in Arkansas," Susan says. "We were looking for the best long-term solution for Sophia, and the knowledge that everything—the surgery and the rehab that would follow—would be done at Gillette made us confident in moving forward."

Unlocking Potential

Following SDR surgery, patients like Sophia undergo weeks of inpatient rehabilitation as their muscles learn to move without their former level of tightness. "During this time, we quickly see the untapped potential that the procedure can unlock," Ward says.

"From the time Sophia was about 2 years old, she could never walk flat on her feet even with bracing," Susan says. "The first time she walked flat-footed on parallel bars, I broke down and immediately started crying. Seeing her be able to do that, you can't even imagine how that felt." The family returned to Arkansas following Sophia's rehabilitation at Gillette. Sophia continued therapy near her home and continued to make incredible progress.

Single-Event Multilevel Surgery

"One year post-SDR, we returned to Gillette for a Single-Event Multilevel Surgery (SEMLS) orthopedic surgery with Dr. Tom Novacheck. Coupled with the SDR and ongoing therapy, the changes as a result of these two major surgeries have been immense. Sophia is now able to walk with heel strike and without her toes turning in. Her strength has increased significantly, and she can even hop on one foot! Her balance has improved so much, as well as her overall coordination. In fact, her walking improved so much, she was able to move from her Ankle-Foot Orthosis (AFO) to much smaller orthotics that simply fit down inside her shoes. This was a huge leap for our girl!"

The Slinkards recently returned to Gillette for her annual follow-up appointment with Ward and Novacheck.

"Sophia and her family have been the picture of dedication to her well-being, fitness, and strength to maximize her function and walking ability," Novacheck says. "As a result of that dedication and the treatment that she has had, her future is much brighter! It makes so much difference."



Sophia and her family will still return to Gillette for care on an annual basis. They're happy to be able to spend more time at home and travel for fun rather than health care. They also say that it's bittersweet; that Gillette will always be a special place for them.

"We're thankful every day that we found Gillette when we did. Everything Sophia is doing now—the traveling, tap dancing, riding a recumbent bike—none of that would've been possible without the world-class care our daughter received there over the years," Susan says.

"As she's gained greater mobility, it's been amazing to see just how much the world is opening up to our daughter. It's so easy to take something that seems as simple as walking for granted. Being able to move around gives a person agency and independence, and that's the gift Gillette has given Sophia. Every step that she takes is a testament to Dr. Ward, Dr. Novacheck, and the countless other individuals who made it possible."