

Successful RND Treatment Ends Family Struggle

It was every parent's nightmare. A vibrant, athletic child, stricken with a mysterious condition that was as baffling as it was debilitating. But for Wendy Morgan of Greenville, Pa., it wasn't just a bad dream. It was reality. And it was happening to her 10-year old daughter, Rebecca Hood.

In the spring of 2004, Rebecca was a good student at Commodore Perry Elementary School with plenty of friends and several outside interests, including gymnastics and dance classes. When Rebecca began complaining of an ache in her back, Wendy attributed it to her daughter's active lifestyle, thinking it was possibly a pulled muscle or a stubborn bruise. But as the weeks wore on, Rebecca's pain increased. One evening in August, as she bent over to remove something from the oven for her mother, Rebecca doubled over in agony and burst, into tears.

In spite of following her pediatrician's recommendation for rest and relaxation, Rebecca continued to struggle with pain. "She couldn't sleep at night, she couldn't sit for long periods of time, she couldn't relax. She couldn't even take the school bus because the ride was so bumpy that it was excruciating for her," Wendy remembers.

Frustrated, worried and desperate for answers, Wendy immediately began taking Rebecca to see specialists throughout the region. Orthopaedic surgeons, neurologists and rheumatologists examined the girl and conducted a litany of tests.

Says Wendy, "I was told she had a tumor on her spinal column, spinal cord splitting, MS, muscular deterioration, growing pains. Every doctor had a different opinion, and none of them had answers. Rebecca was taking pain medication three times a day, and she would still wake up screaming in the middle of the night."

By December, the once happy-go-lucky child was despondent and so disabled by pain that she needed to use a walker in order to get around. Finally, Wendy was referred to Paul Rosen, MD, clinical director of the Division of Rheumatology, at Children's Hospital of Pittsburgh. Dr. Rosen – who is also a consulting physician at The Children's Institute – definitely diagnosed Rebecca with reflex neurovascular dystrophy (RND). When a second physician confirmed Dr. Rosen's belief, Wendy finally allowed herself to believe that hope – and help – was in sight.

"To say I was relieved is an understatement," Wendy explains. "The thought that she would be fine? It was unbelievable."

As Wendy and her daughter discovered, RND is difficult to diagnose. Once the diagnosis was made, a plan for Rebecca's treatment was developed. She was admitted to The Children's Institute's RND program, where she received inpatient therapy for two weeks.

“It was incredible. We could see a change after only a day. Se was able to walk more naturally and faster. By the time she was released, we were in awe. It was like having our daughter back,” admits Wendy.

According to Dr. Rosen, while some RND patients may experience an improvement in their mobility and functioning fairly early in the therapeutic process, the pain can take a longer period of time to improve.

Now, nearly a year since Rebecca began experiencing symptoms, she continues with her daily therapeutic regimen of exercises, designed to keep her fit and well. Though she hasn't yet returned to gymnastics, she has become an active participant of “Girls on the Run,” A program that encourages preteen girls to develop self-respect and healthy lifestyles through running. Rebecca completed her first 5K race this spring. And, like most kids her age, she is looking forward to a summer vacation full of fun with her friends.

Says Wendy, “Our case manager, Becky, and all of the nurses and therapists and doctors at The Children’s Institute were wonderful. Even now that Rebecca has the tools she needs to help herself, I know I can call anytime with questions or issues and I can information. You aren’t just dismissed, and after feeling so alone with this for so long, that means a lot.”