

cool rider

**5-year-old Carter handles
his rare disease like a pro**

Everyone at the Grant and Norma Davis ChildLife Center who helped Carter Berkley's intravenous treatment get started seemed like an old friend, chatting about the new toy he was assembling, asking about school, catching up.

And it was the same for 5-year-old Carter, sporting a fresh Mohawk his dad gave him the night before. He is cooperative and comfortable with the procedures after numerous treatments over the past four years.

"He loves the nurses here at Via Christi," says Carter's mom, Mandy. "He says, 'When can I go see my nurses?' He'll even get out his bag early sometimes and start getting ready."



Carter has opsoclonus myoclonus syndrome (OMS), which can manifest as a combination of involuntary, nonrhythmic eye movements and shocklike muscle contractions. He is doing well on the treatments, but they can take as long as 10 hours so he and other family members spend hours and hours at Via Christi Hospital on St. Francis in the center's brightly decorated, well-equipped playroom filled with arts and crafts materials, games, toys and other activities provided by Children's Miracle Network Hospitals at Via Christi Health.

"We can go downstairs and walk around if he feels like it, but we like the IV cart that looks like a car," says Mandy. "He never runs out of things to do here."

Carter is "one child in 10 million," the only OMS patient in Kansas the family has heard of, Mandy says. OMS comes on suddenly, often with flu-like symptoms. Opsoclonus and myoclonus together often are related to a tumor but none has been diagnosed in Carter.

"He was so young, we were just beginning to know what our little guy was like: outgoing, outspoken, very lively and always in a hurry. He was walking around furniture at 6 months and walking completely independently at 9 months. Then within a week, he couldn't walk, crawl or sit up. He had rage attacks that were far beyond a temper tantrum and no words to verbalize it. Words he'd had before he was sick he was unable to use.

"His eyes were twitching and turning back in his head. It was easy to see something was seriously wrong."

Because of its rarity, OMS can be hard to diagnose.

"In six weeks, we had a tentative diagnosis and we felt very fortunate for that. His immune system recognizes the protein around his brain cells as a virus and attacks his brain," says Mandy.

Children's Miracle Network Hospitals helps the family by covering gasoline expenses for their twice-yearly trips to consult

given three more rounds of chemo.

Children's Miracle Network Hospitals also helps pay the cost of some of his medications. While the family is fortunate to have insurance, Mandy says, Carter's medications are so experimental that none is FDA-approved, which makes the family's share more expensive.

"Even if you have insurance, you can't plan for everything," says



"Who would have expected to have to travel out of state to see a specialist?" says Carter's mom, Mandy. "It's great to have their help." Children's Miracle Network Hospitals helps the family by covering gasoline expenses.

Michael Pranzatelli, MD, professor of neurology and pediatrics at Southern Illinois University School of Medicine and director of the National Pediatric Myoclonus Center in Springfield, Ill.

Year-old Carter received two rounds of chemotherapy after his diagnosis, plus one about six months later. Two years ago, he had a full relapse after being taken off some of his medications and was

Mandy. "Who could plan for how much medications would cost? Who would have expected to have to travel out of state to see a specialist? It's great to have their help with both of those."

When he grows drowsy, Carter snuggles down to nap next to Shepley, a stuffed sheep he's had since he was 1 month old. Mandy describes the toy as his "very best friend."



Child Life Specialist Catherine Coakley, right, shares a painting activity with Carter in Via Christi's Grant and Norma Davis ChildLife Center. She and Child Life Specialist Angie Long help make the hospital less frightening for children through normal play and activities, medical play that helps explain procedures and even distracting them during procedures. They teach coping techniques and, as in Carter's case, even visit a young patient's school to explain the situation to classmates.

Shepley is so worn from their journey together he is no longer woolly and wears a protective sweater because his fabric cannot be mended. Just before he drifts off, Carter orders a meal of chicken breast, steamed broccoli, steamed carrots, rice and tea, with grapes for dessert.

"It's the same meal he's been getting for the past four years and he orders it the same every time," Mandy says.

Happily, Carter is back to being an outgoing, outspoken, lively boy. His

kindergarten classmates at Meadowlark Elementary School in Andover understand his need to wear a Mickey Mouse-decorated surgical mask to avoid infection and have all received instructions on how not to spread illness, such as covering coughs and using hand sanitizer.

"Sometimes they'll even say, 'Put your mask back on, Carter. You don't want to get sick,'" says Mandy. "Everyone has been so kind and generous to us, each in their own way."

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