

Jordan Diggs- PEDIATRIC FMD

She's a giggly girl. She says she's funny too, knows a lot of jokes. But when you ask her to tell one, she just giggles instead. The giggle and a big, toothy smile cover up that Jordan Diggs, 9, has been sick most of her life.



She has fibromuscular dysplasia. The Web site E-medicine.com defines the condition as an “arterial disease of unknown etiology typically affecting the medium and large arteries of young to middle-aged women.”

The condition is rare, according to Jordan's parents. It affects arteries in different parts of the body. In Jordan's case, she has arteries that look like a string of beads in her kidneys and in both her small and large intestines.

If the condition moves to the carotid artery, it can cause different kinds of strokes. How serious is it? E-Medicine.com says in the United States, the condition is found more frequently by autopsy than by other means. The bubbling of her blood vessels decreases blood flow throughout the body and causes high blood pressure, which is how the condition was discovered five years ago, when Jordan was 4.

Her blood pressure hit 299/148 at that time. She was sent to Piedmont Medical Center, but the Rock Hill hospital sent her home and told her to come back if she didn't feel better the next day. Jordan's mother Emily said the family took Jordan to Dr. Sam Stone after coming back, and he sent Jordan to Carolinas Medical Center. Her main problems now are focused on her intestinal arteries. She gets nauseous and doesn't want to eat or drink, so she suffers from dehydration frequently.

She doesn't like to say how she feels when she's sick. She remembers the gas and feeling “funny” when she was anesthetized way back when. Emily Diggs remembers the emergency staff at CMC having to give her daughter an intravenous drugs to get her blood pressure down. Doctors were afraid the girl had had an aneurysm until they took a look at her kidney veins.

Jordan has had angioplasty a couple of times on her renal arteries, the ones in her kidneys. She is young, and those arteries haven't fully grown yet. The ones she has had worked on are just big enough to allow the smallest “balloon” insertion to be put in to open up the arteries. She's had balloon angioplasty done to one artery in her left kidney and to two arteries in her right. She's got to wait until she's grown up more to do other angioplasties on her intestinal arteries. She can go to school with her friends, but she often has problems when she doesn't eat and drink enough. So she has been in and out of the hospital all her short life. The condition can be life threatening. She goes for routine exams every four to six months. It's been almost a year since she was hospitalized for dehydration. She admits, with a giggle, that she didn't have any problem eating or drinking last week.

The Make-A-Wish Foundation, an organization that grants the wishes of children with life threatening medical conditions, accepted an application from Jordan's family, signed off on by her specialist in Charlotte, to grant Jordan's wish. She wanted to go to Disney World, her mother said.

She got to do that, and more. The foundation paid for a week in Orlando, where the entire family, Jordan, her father Bill, Emily and Jordan's 11-year-old brother Tyler, they took in all the attractions - Universal Studios tour, Seaworld, GatorLand. Jordan got to meet her favorite princess, Cinderella.

It was a special week. She didn't know if she was the only kid in her school who got to go to Disney World for Spring Break, but Tyler knew he was the only one in his class to go. Jordan hugs her kitten Chloé as she talks about her trip. Her father "got scared" on the Dino-Putt golf course. "Who knew the dinosaur would spit water?" Bill says. That was the "most funniest" part of the trip, Jordan said.

They went to the Animal Kingdom and Expedition Everest more than once at Disney, all the while staying in a villa. Everything was paid for by the foundation. Bill took "about a thousand" pictures over the week. They got away from some of the harsh realities of Jordan's conditions. Bill was just laid off from a warehouse company, but had an interview Thursday. Emily has insurance at her job. Jordan does qualify for Medicaid, so the medical expenses for all the doctor visits and emergencies and prescriptions are paid for, after they met a \$500 deductible and a \$1,500 out-of-pocket equipment. She's 9, and she's taking two blood pressure pills. Two pills for her stomach. Two pills for epilepsy, and a pill for attention deficit hyperactivity disorder. She's a little girl on a lot of pills, waiting to grow up big enough to get the surgery to open her arteries up. The Make-A-Wish Foundation gave them a week away from it. Its motto says it tries to "enrich the human experience with hope, strength and joy." After meeting SpongeBob, Micky and Minnie, Goofy and Pluto, Barney, Spider-Man, etc., Jordan's smile showed her joy.