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Creating Memories: Parenting a Child With Multiple Medical Issues

Cynthia and Keith Mosley's Story
By Sarah Morgan

Who are Cynthia and Keith? Cynthia answers the question immediately and simply: "We're Noah's mom and dad." Noah is their 16-year-old son, whose multiple medical issues include cerebral palsy and a seizure disorder, likely caused by a genetic condition called pontocerebellar hypoplasia (PCH) Type 6.

While nonverbal and in a wheelchair, Noah is definitely a teenage boy: "If it's inappropriate and he shouldn't laugh at it, he does." But the challenges that have affected his life – and the lives of his family members – have been daunting. At times he would have pneumonia a dozen times in a single year. He's needed a rod in his spine to correct scoliosis and had a broken femur from osteoporosis.

Cynthia, Keith and Noah live with Noah's older stepsister Tristin and her six-year-old daughter Kinlee. Their home has plenty of tools to help care for Noah: his wheelchair and communication device; a specially equipped van, a hospital bed with a special mattress, and a ceiling lift to help movement from bed to chair to tub; a CPAP machine to help him breathe; a pump for his gastric tube; suction machines, nebulizers, cough-assist machines and chest vests.

Yet, the family travels as much as possible. "Last summer," Cynthia says, "We drove up to northern New York state, then over to Wisconsin, stopping at Niagara Falls." Self-proclaimed "DisNerds," they loved visiting the Disney parks but have curtailed air travel since being faced with a connecting flight in Texas after an airline brought Noah's wheelchair out in pieces. It was, Cynthia says with a degree of understatement, "not enjoyable." Today, "We go anywhere we can in his van."

"We try to do a lot with Noah – anything we can figure out. He loves

to do things and be a part of things. He's a happy guy." She points out,

"People say, 'You're such a strong person ... how do you do it?' It's not a choice. It's life. You do everything you can to create memories and share them with your loved ones. It's simply that."

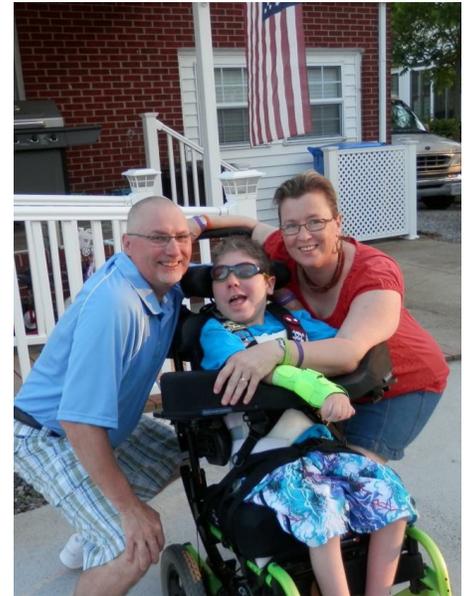


"It's not about how many times the alarm goes off in the middle of the night, or how often you have to talk to insurance, or school. None of that is what makes Noah incredible. We're ordinary people trying to live our lives like everyone else. But a lot of times, it can be tricky, because those other things get in the way."

Cynthia finds that those tricky factors often get in the way of people interacting with Noah himself. "I try to help people see there's a person in there. Often, if you don't walk or talk, people think obviously you don't

have anything worth saying. But while he is nonverbal, he can communicate. He has body movements, he has his communication device, and he does have thoughts and feelings just like anyone else.

Put down your expectations, and what the norm is supposed to be, and look at this incredible person. ... I say that one a lot."



Family selfie after a race this past winter.



Noah, Keith, and Adam and Sarah Shafer pose at an I Run 4 Michael (IR4) event. Visit <http://bit.ly/2d5YFbe> to learn more.

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