Faith guides family of Taneytown boy diagnosed with rare condition

Not long after 5-year-old Elijah "Eli" Yanike came down with a common cold, he began crying about pain in his head and neck that wouldn't go away.

His brother, Joseph, 7, and his sister, Gwyneth, 8, had already recovered from the same cold, but Eli was alarmingly feverish and lethargic.

After multiple emergency room visits, his condition worsened. Unable to move his right arm and keep his head up without difficulty, Eli was taken by his parents, Anders and Lauren Yanike, to Sinai Hospital in Baltimore Oct. 11.

Eli was diagnosed with Acute Flaccid Myelitis (AFM), a polio-like condition that affects the nervous system and can cause varying degrees of paralysis. Thus began an ordeal of doctor's appointments, tests, a week's stay at Sinai and intense physical therapy at Kennedy Krieger Institute in Baltimore.

The kindergartner at Mother Seton School in Emmitsburg finally came home in early November, with more therapy and treatment on the horizon.

"Our faith is what gets us through this," said Lauren, whose family worships at St. Joseph in Taneytown. "We believe it's the reason Eli is making jaw-dropping progress nearly daily."

Rare condition

The Centers for Disease Control and Prevention estimates that fewer than one in a million people in the U.S. will get AFM every year. Most of the cases it has learned about have been children. Kennedy Krieger has treated more than 30 children with the condition.

"AFM is generally the result of what people believe is a viral infection," said Janet Dean, a pediatric nurse practitioner at the International Center for Spinal Cord Injury at Kennedy Krieger and an expert on AFM.

Dean said parents should be aware of any episode of sudden weakness in one or more limbs or one side of the face, or of difficulty swallowing or breathing. If there is any sign of trouble breathing, a child should immediately be taken to the emergency room.

Dean, one of the medical professionals providing care for Eli, said recovery is a marathon, not a sprint.

While at Kennedy Krieger, most of Eli's days were filled with five hours of physical and occupational therapy. He went home Nov. 5 and began intensive outpatient therapy Nov. 9. Three days a week, he undergoes three hours of physical and occupational therapy and one hour of pool/agua therapy.

Dr. Cristina L. Sadowsky, a physician and clinical director of the International Center for Spinal Cord Injury at Kennedy Krieger, described it as a "multidisciplinary, team approach."

"All of us - the multidisciplinary team - are helping him and directing him to continue living his life and incorporating activity-based therapy in his life to restore his day-to-day and neurological function," Sadowsky said.

Eli's right arm remains mostly paralyzed and his neck is still weak. He continues to have balance issues, poor reflexes and carries a higher risk of injury if he gets bumped or falls. While he has made incredible strides, the Yanikes are unsure when he will return full-time to Mother Seton School.

He continues to see a neurologist, pediatrician, spine specialist and other professionals as needed. If his arm paralysis does not recover, nerve transfer surgery in four to six months is an option.

Both Sadowsky and Dean believe a positive attitude aids in a positive outcome.

"If parents are hopeful and have high expectations for their children, then their children are going to have the same expectations for themselves," Dean said.

"In my heart, I believe that the more hope you have ... you're in a better position to accept stress," Sadowsky said. "We do believe that hope is an integral part of

recovery."

'Closer to him'

Faith has been an integral part of coping with the family's stress, which included Anders staying at home with the two older children while Lauren stayed with Eli at Sinai and Kennedy Krieger Institute. Mother and son prayed together every night, thanking God for their support system and praying for continued healing.

Lauren said her family harbors no anger at God, believing that the experience has brought them closer to Christ.

"We recognize that Eli's condition could have been much worse," Lauren said, "so we count our blessings that Eli is still with us and that his strong will and determination keeps him going strong."

Family and friends are updated via a Facebook group. They include Lauren's sister, Jordan Tippett, pastoral associate at St. John in Westminster, who organized a "meal train" and is planning a T-shirt fundraiser.

"Every tear, struggle, fear and pain, watching Eli battle this every step - we turn to Him," Lauren said. "We place it at the foot of the cross; we ask our friends and family and perfect strangers to pray for us."

The Yanikes are convinced that their large "prayer army" - which includes monasteries, convents and Masses offered in Eli's name - are helping him grow stronger every day.

"I never realized the underlying support system we had," Anders said. "When something happens, people come out of the woodwork."

Lauren noted that the experience has been "extremely humbling for our family."

"We have always strived to be able to get through life without relying on others," she said. "Now, we are forced to rely on others, including perfect strangers, and the experience has brought us to our knees in gratitude."