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GREENLAND — Catherine and David Meinen just knew — really knew — that something was "definitely not right."



Their 3-year-old daughter, Zoe, seemed increasingly lethargic. Her right arm, which used to flail and wave frenetically through the air as her father chased her around their 9 Bayridge Road home's fireplace, was near motionless, as if some mysterious, invisible force was tethering it to her side.

The once-energetic girl who was all smiles was nowhere to be found. Tests and pediatrician evaluations came back inconclusive for months — that is, until the Meinen family went in for a follow-up visit less than a week after the birth of their second child, Cameron, in August 2011.

Catherine Meinen said the doctor, whom they had never met, "didn't even say hello." Instead, she took one look at Zoe's motionless right side and uttered words that are forever etched in the Meinens' memory: Zoe should undergo brain scans at a major surgery center immediately because she most likely had a brain tumor.

Ninety minutes in a Boston hospital's waiting room and one life-changing scan later, Zoe was diagnosed with a baseball-sized atypical teratoid rhabdoid tumor (AT/RT), a rare childhood cancer that carries an equally rare chance of long-term survival.

"We never thought it was a brain tumor," said Catherine, whose brother was diagnosed in April 2011 with a different, and deadly, type of brain tumor that had a noticeably contrasting affect on his body. "We thought it would be a complex array of degenerative symptoms brought on by some syndrome with a long name, and that it would cause a decrease in Zoe's abilities ... until she'd plateau and be that way for the rest of her life."

Fewer than 30 U.S. children are diagnosed with AT/RT each year, and Zoe's initial survival rate was 30 percent — at best.

Zoe's tumor was successfully removed from the center of her brain during a 12-hour surgery that involved 28 rounds of proton beam radiation in a procedure interrupted when a rare Massachusetts earthquake caused all of the emergency room machines to automatically reset. However, the cancer could resurface without warning after months or years of inactivity.

"There's no cutoff or cancer-free date like other cancers," Catherine said. "You can die after being cancer free for five years. Whenever the disease crosses the threshold, it takes you down in eight weeks."

Catherine was hesitant at first to begin Zoe on the 17 rounds of chemotherapy called for in the lesser of the only two courses of treatment for AT/RT, both of which she described as "terrifying." She didn't want her daughter's only memories to be of pain.

"I didn't want her to go through treatment, especially if you, on average, live seven months with this disease and you die in treatment," she said. "So, you die being tortured. It's a horrifying experience."

David Meinen wanted to see if his daughter could make it through, though, and he and his wife agreed that they would stop the treatments if at any point Zoe somehow indicated or communicated that she could no longer handle it.

That moment never came, and Zoe, now 5, has recovered and begun to regain some of her mobility, memory and ability to speak clearly.

There have been many bumps along the way, most notably in the form of frequent and "violent" seizures that up until recently inexplicably plagued Zoe roughly 20 times every day, according to Catherine.

Those seizures, lasting between 7 and 8 minutes each, started about two months after Zoe's cancer surgery. They have eroded more of Zoe's motor function and cognitive ability, largely because they went undiagnosed between September 2011 and June 2012 because medical tests during that time frame were inconclusive. This was due in part to the fact doctors were performing tests that can't actually identify and diagnose seizures, according to Catherine.

Zoe has been seizure free for the past five weeks, though. The cause of that unprecedented reprieve is unknown, though the Meinens credit it to a variety of factors, including Zoe's closely monitored high-fat diet, which she has been on since March 2013. The diet involves "starving the brain of carbohydrates" and "feeding the brain" with 700 calories a day, 80 percent of which is fat, while the remaining 20 percent is protein, according to David.

Zoe has also been enrolled in a variety of specialized therapies not covered by insurance, including in-home music therapy sessions multiple times each week. The Meinens heavily credit the music therapy for lifting Zoe's "spirit" and aiding in her recovery, as Exeter-based music therapist Ryan Judd has been able to get Zoe to stand on her own — "something no other nurse or physical therapist has been able to get her to do," Catherine said.

Zoe could only move one finger and she couldn't speak when Judd began his sessions, but she now freely sings along with Judd's interactive songs and uses both hands — with limitations — to beat drums and shake maracas in time with the songs.

Judd credits the involving, encouraging and creative nature of music and his multi-instrument sessions as a big factor in boosting Zoe's self-esteem and confidence, as he said it inspires her to do things she otherwise may not consider herself capable.

The Meinens' goal is to build Zoe's confidence and further her treatment to the point that she can be autonomous and as medication free as possible.

“You don’t take anything for granted, for sure,” said David Meinen, whose income in his information technology job at TUV America in Peabody, Mass., is the family’s only source of income. “Just every day you celebrate whatever it is that we’re doing, even if it’s a bad day for her it’s still just… Yeah, glad that she’s still with us.”

The various therapies, around-the-clock nurses and transportation for Zoe are costly for the Meinens, especially since they just celebrated the birth of their third child, Hannah. Catherine, a former teacher at Portsmouth Christian Academy, can no longer work due to Zoe's needs and the 2-week-old baby, so community members have banded together to help the family.