



MORGAN'S STORY

By Jennifer Benjamin, MBA, GCM, CDP

Like most six year olds, Morgan Leary was an active, energetic, happy little girl living with her parents and twin sister in their Center Moriches, NY home. She was involved in many sports including soccer, tennis, swimming and dance. She loved the outdoors, hiking and appreciated nature and trees. "She was always doling out I love you's to her family members", said Emily Leary, Morgan's mom. "She gave out what we called 'Morgan huggles', (which was the combination of a hug and a cuddle), while we watched TV together on the couch". She has always acted like the big sister even though she's older than her twin by one minute and has a responsible, determined personality. She worked hard in school and even her teachers took notice when they selected her to be the recipient of the "Exemplary Leadership and Perseverance Reward", which is a district wide ceremony for Kindergarteners. But, in the summer of 2014, Morgan's world drastically changed when after a tennis competition, her eyes were not moving normally. Her parents rushed her to the emergency room where she was given a CAT scan that pointed to a lesion on her brain.

Morgan was immediately transferred to NYU Hospital where doctors performed a biopsy of the tumor on her brain. After the biopsy, the tumor began to bleed and an emergency removal of the tumor was done immediately. After surgery, Morgan's brain started to swell which required a craniotomy, the removal of parts of the skull to allow the brain to expand. Morgan remained in NYU for the next seven months receiving physical therapy and occupational therapy. Once she regained strength, she endured three rounds of chemo therapy treatment and a stem cell transplant.

The battle for Morgan's life continued after that when she was transferred from NYU to a Children's Hospital in Philadelphia where she received thirty treatments of radiation over the course of another four months. From a tennis match to nearly a year in

hospitals, through streams of tears Emily stated, "My dad kept saying I just want her to have her happy little life back".

Morgan finally returned home in July 2015. Unable to walk, speak, or eat solid food, she required around the clock care. "She is re-learning to walk and speak with physical therapy, speech therapy and occupational therapy", explained Emily. Morgan went from not being able to sit up to standing on her own and walking with assistance with the physical and occupational therapy she was receiving. She can say some words now and communicate with her parents and sister.

A New Life

While Morgan was undergoing the various surgeries and treatments she needed to survive, her parents had to stop working to be there for her. "My husband is now back to work but we both did not work at all last year. I stayed at home with Emma (Morgan's twin sister) and my husband stayed at the hospital with Morgan," Emily explained. "Everything from hiring nursing services to assist at night with monitoring Morgan, to coordinating the in-home speech, occupational and physical therapy has been a battle. Fighting with the insurance companies was one of the biggest surprises. I have to battle with them to continue the nursing services at night and to continue the occupational, physical and speech therapy."

Morgan requires 24/7 supervision at home. Getting a good night's sleep is rare for Morgan and her parents because she has to be monitored to ensure that she doesn't have issues with breathing or her ventilator. Emily cannot travel alone with Morgan and depends on her parents (Morgan's grandparents) to help with getting to and from her outpatient therapy services three days a week. The family has also adopted a strict regimen of bacteria and infection control in the home from showering immediately upon arriving