

Perseverance.

Bruce Leibowitz

The word that comes to mind when I think about our son Spencer is perseverance. When Spencer was born in February 2001, two prouder parents you could not find. Although he was born about 5-6 weeks early, we were ecstatic. But then our extreme joy went to life-threatening worry. Spencer was immediately whisked away and placed in an incubator. It would be several hours before we could see him. The doctors did not have a diagnosis at this time but knew this baby was in distress. He had low birth weight; pectus (concave chest), clubbed feet, little to no voice, very little movement and difficulty breathing. On day 7, Spencer stopped breathing and it was determined by Jeanes Hospital doctors and us that Spencer needed more intensive care than they could provide. Children's Hospital of Philadelphia would send an ambulance outfitted with a doctor and nurse. Numerous tests and meeting with doctors would follow.

After the blood tests and muscle biopsy results came back, the diagnosis was given...Myotubular Myopathy (MTM - a form of Muscular Dystrophy in which children usually didn't live past a few years at best). The worst part was when we sat down with a neurologist and was told to take him home and provide quality of life for him as he would only live about 6 months (that was 16 years ago and counting). My wife cried for 2 days. After we were put in contact with a family who had a child with MTM who was in fifth grade, our viewpoint changed. Once the doctors saw how we were not going to give up on Spencer their outlook changed as well. He was not going to be a statistic; he was going to beat the odds.

Spencer would be in and out of the hospital every four months for the next year and a half (mostly for collapsed lungs) until July 2002 when he coded at CHOP and the decision was made to give him a tracheostomy. His entire demeanor changed. He was more alert, verbally louder, and able to move a little better. This is when the real work began for him.

As the years passed, Spencer's schedule would be jam-packed with physical, occupational and speech therapies. Then there were the follow up appointments

with all of his doctors; which included a neurologist, pulmonologist, otolaryngologist, gastroenterologist, geneticist, etc. All through the visits and overnight stays, Spencer's resiliency showed through.

When Spencer turned ten he began to study for his Bar Mitzvah. In addition to his regular school work, Spencer would be tutored once per week and attend Hebrew school every Sunday. All of this hard work paid off as Spencer read from the Torah on March 29, 2014 (this was the proudest moment of our lives). Ten days later Spencer would endure spinal fusion surgery which would keep him in the hospital for five weeks with an additional three weeks of therapy; all at A.I. DuPont.

Fortunately for our family, things have calmed down regarding any surgeries and hospital stays. But through it all, the perseverance of our entire family has made Spencer a stronger and well-rounded individual.

