Shortly after our family's first ever fun-filled Spring Break trip to California in March 2016, our daughter Hayley began experiencing symptoms of ALS. She was only a few weeks away from celebrating her sweet 16th birthday when these troubling symptoms started appearing. Her speech sounded a bit "off"to us and she began to experience some neck weakness as well. She had also lost around 10lbs without actively trying to lose weight and was experiencing some odd stomach cramping at times. In hindsight, I'm positive the stomach cramping was the start of her respiratory muscles beginning to be damaged by ALS.

These troubling symptoms led us to her pediatrician's office in June where the physician ordered blood work, tested her thyroid level (hyperthyroidism runs in our family...which would have been a logical explanation for the weight loss). All of the test results came back normal. Being a 16 yr old teenage girl, the pediatrician was concerned about an eating disorder. Hayley was referred for an intake appointment at a local eating disorder clinic in Sept. of 2016. At that appointment, it was determined that she did not fit the criteria of someone experiencing an eating disorder. The nurse practitioner there was concerned about her neck weakness and suggested we should seek out a neurologist. By this time, Hayley could not lift her head off of her pillow when lying on her back.

We were able to get Hayley an appointment with a pediatric neurologist in late September and he ordered tons of blood work along with an MRI of her head and cervical spine. All of the bloodwork and MRI results came back normal. He saw some tongue fasciculations which really concerned him and he referred us right away to a pediatric neuromuscular neurologist whom we saw in early October as well. This was a very long appointment and tons more bloodwork was obtained along with an order for another (more complex) brain MRI. If everything were to come back normal, he suggested an EMG would be the next logical test. This test requires small needles to be inserted through the skin into the muscle and is used to help diagnose neuromuscular abnormalities.

Once again, all of her bloodwork and MRI results came back normal and an EMG was scheduled for mid-October. Besides her neck weakness she began to have shoulder and upper arm weakness too. The EMG results showed abnormalities and was very concerning. She then endured a lumbar puncture to test her spinal fluid and a muscle biopsy was also scheduled for the beginning of November 2016 to determine if this was a neurogenic (nervous system) or a muscle disease (myopathy). We received the biopsy results in late November that confirmed it was a neurogenic disease.

By this point in time (around Thanksgiving) Hayley was having a great deal of trouble with eating and drinking as her mouth and throat muscles continued to weaken and her speech was becoming harder to understand. Her breathing also started to become labored especially while sleeping. She woke up with frequent headaches. We were able to get her admitted for overnight sleep study in mid-January 2017. This study confirmed she was having alarming episodes of low oxygen saturation throughout the night and, immediately after this appointment, she was prescribed a Bipap machine to use during sleep.

After 5 months of testing, we still did not have any concrete answers other than Hayley was suffering from some type of undiagnosed motor neuron disease. By this time her speech was mostly unintelligible. She had endured countless blood draws and had been tested for thyroid disease, Myasthenia Gravis, Pompe's disease, Tay Sachs disease, and Spinal Muscular Atrophy. A genetic test called WES (whole exome sequencing) was ordered in hopes of finding an answer. WES is a comprehensive genetic test that can identify genetic mutations in a person's DNA that can cause disease. More bloodwork was drawn for this test.

We continued to be alarmed by how much weight she was still losing and how much work it was for her just to eat and drink anything. We pushed for surgery to place a permanent feeding tube in her stomach in early February of 2017. After this surgery occured, it was the last time she was able to eat or drink anything by mouth.

Results of Hayley's genetic testing was received in late April 2017 and we were then given the devastating news that Hayley had a mutation in the FUS (fused in sarcoma) gene. FUS mutations are responsible for an extremely aggressive and very early-onset form of ALS. We were told it was a 100% fatal disease and there were no curative treatments available. Hayley was handed a death sentence at age 16.

By mid-May of 2017, besides needing breathing support at night, she progressed to needing daytime non-invasive ventilation too. This required her to wear a mask with hose attached to a ventilator to help her breathe almost 24/7. A Trilogy ventilator, cough assist machine, suction machine and a nebulizer machine became part of her daily life to keep her lungs clear and hold off respiratory distress. Instead of spending the fall of her junior year in high school with friends, Hayley began in-home hospice in October 2017. She was on hospice for 5 months and gained her freedom from ALS on March 15, 2018 just a few months shy of her 18th birthday.

Throughout the course of this brutal disease, Hayley only cried once. She is without a doubt, the bravest, toughest and most amazing person I'll ever know in my lifetime. Not once did she ask why this horrific disease happened to her. Instead, she focused on making sure all of us around her got through each and every day all while never losing her positivity and perseverance. There really are no words that I can write to do her memory justice. She blessed us with joy every day of her life. She taught us that no matter how bad a day can be there is always a reason to be positive, find a smile and give a thumbs up. We miss her terribly and not a day goes by that we don't think of her. We'll keep her memory alive by giving each day a thumbs up and working towards a cure, in her honor, until the day we are reunited again.