Katherine was a beautiful, 15 year old healthy, active dancer in the Spring of 2015. In March of 2015 she was signed up to do a solo for her dance academy recital a few months later in June. In late March Katherine told her mom she was struggling to get on pointe in dance class and she didn't know what was going on. Her mom told her, 'well you just need to work a little harder, stretch out and you'll be fine.' Well it wasn't to be and her solo never happened.

Katherine began seeing specialist after specialist trying to figure out what was happening. In the meantime her left leg was becoming weaker and a foot drop began. She continued to seek medical help and was now going to specialists. She had a muscle biopsy, an EMG, a plethora of tests, multiple MRI's that all came back normal or inconclusive, but still the progression was continuing and she was becoming weaker. This went on for almost a year until a new neurologist at Children's Hospital Los Angeles suggested another EMG. In April of 2016 an EMG was performed and the results were immediately of great concern and at that time a full chromosome genetic test was ordered. Her geneticist insisted we probably would find nothing, with no family history of anything. So off we went getting more blood drawn than any child should have to endure and wait for results from what was called 'the Cadillac of genetic tests' to be completed. We waited 2 months until we received a call from her geneticist on June 20th, 2016. The call would change our lives forever and spiral us into a year of lasts and a disease so cruel you wouldn't wish on your worst enemy.

Katherine's progression continued. She didn't go back to high school for her sophomore year as the doctor told us she had a very rare rapid progression form of pediatric ALS, specially on the FUS gene. She was now in a mobile scooter full time with very little leg mobility. In October of 2016 we celebrated her Sweet 16 with a huge party. Likely knowing this would be one of her last birthdays, we went all out with an In N Out truck, a sundae truck, a dj with karaoke and a photo booth. It was the best night. In December we were told it was time to begin thinking about a feeding tube as her breathing was becoming worse and it was scheduled for the first part of January. We enjoyed what was our last holiday season and prepared for 2017 and the unknown challenges ALS would certainly be bringing. By February 2017 she was losing arm strength and was using her Trilogy breathing machine during the day, not just at night. Eating on her own became more challenging and Chick- Fil-A Oreo cookie shakes were a frequent request for meals in addition to her feeding tube feedings. She was using her wheelchair now and not her mobile scooter as her core strength was rapidly weakening. By late spring into summer we knew our time with her was fleeting as her breathing became much worse. She was on the Trilogy full time and we had a caregiver 3-4 days a week at night so we could get some sleep. She was no longer able to eat solid foods at all and had had a couple of choking incidents as she desperately tried to enjoy a bite of her favorite foods. Summer came and went. She was at home a lot, not able to get out too much. She was tiring easily and sleeping a lot. Fall came and it became evident we were in the last days with our girl. Katherine was freed from ALS on October 9th, 2017 one week before her Golden 17th birthday.
Katherine never complained once. Always had a smile on her face. We miss her terribly, but find hope in the promise that we will see her again one day.