Anastasia Monoyos

Since the day I was born, my Dad, Teddy, has had ALS. The usual life expectancy from diagnosis is 2-5 years. It will be 18 years this March that he has battled the disease and surpassed the odds. He is fully paralyzed, on a feeding tube, ventilator and blinks to communicate. As I grew up and realized my family was different, I asked my Mother questions and she explained the struggles and emotions they went through. How their original plans of her being a stay-at-home Mom and Dad expanding his business all changed.

In March 1997 they found out they were pregnant with me and two weeks later, Dad was diagnosed. The doctors said he probably would not see his unborn child go to Kindergarten. I was born that October. Mom had to keep working and Dad had to stop. She was the breadwinner and caregiver. When I was 3, Mom ended up in the hospital for a week from exhaustion. A year after, Dad went on the ventilator and Mom arranged for his care at home with nursing and supplies. He asked for a divorce – not because he didn’t love my Mom, but he was scared of something going wrong with him in front of me and he didn’t want my Mom to get sick again caring for him.

Listening to what they went through those early years made my heart ache for them. Yet my world never felt the problems. My memories are of always having family around and feeling very loved. Most importantly, I never felt like I had divorced parents because we always saw my Dad during the week and I slept there every Friday night until I started High School Cheerleading. He lives 20 minutes from us with his family.
Watching him fight to live has given me the drive to live the same way. My Dad has proved the doctors wrong. He has not only seen me go to Kindergarten, but graduate Middle School, and now hopefully see me graduate High School this June. He was stripped of all the things he loved to do, and of being the Father he envisioned he would be.

If I see pictures or videos of him before he got sick I cannot relate to that person. The man today paralyzed and non-verbal is my Dad. I strangely always knew to talk to him so he could answer with a blink for YES and raise his eyebrows up for NO. I don’t feel I’ve been deprived of having a “normal” Dad. I feel closer to him than other people do with their fathers. How many can say they wash their Dad’s hair or read to them? Just because someone lives with their father who is healthy does not mean they are close or feel loved. And that is what I have an abundance of from him. True, I have never heard him speak, and I have never received hugs. So yes, it’s been difficult, but the one thing I have always felt is his love for me.

I see him and call him often so he can hear me ramble about my day. My entire life since birth has been effected by his disability/disease. It took away moments in our lives that may have happened if he was not sick, but it gave us moments that I cherish that I probably would have taken for granted otherwise. ALS will not take away our bond or the love we have for each other.

Today I am the person I am because of him. Every year we participate in the ALS Walk with our team “Teddy Bears and I coordinate getting friends to join, collect donations and raise awareness. Would I be doing this if he was healthy I wonder?

My love for my parents is what makes me apply for this Scholarship. I hope that I am selected because I know financially they cannot help me how they wish. Mom has been my sole
supporter and waived child support and alimony when they divorced. Dad wears a bracelet that says “Never Give Up”. As I type this, he has lost vision in his left eye. His spirits are low - but when I told him I was applying for this Scholarship he gave me the biggest smile. A smile that said he’s proud of me for trying. A smile that said “never give up”. If I don’t get selected I will definitely be disappointed, but I will remember that smile I gave him forever.