



My story begins on Valentine's Day 1982. Robert Tyler Massey came into this world at a healthy 7 pounds, 7 ounces. Fast forwarding to September, my son was admitted to the ICU needing life support. The doctors said he probably would not make it 24 hours. They were wrong. He was a fighter, he was on the ventilator for a week and continued to get stronger each day. He was hospitalized for 9 weeks. A diagnosis of Cystic Fibrosis (CF) was given.

With this diagnosis a new chapter of our journey began. We knew nothing about CF. No one on either side of the family tree had been documented with CF. There were several infant deaths listed, but years ago CF did not have a name, just listed as pneumonia or weakened lungs. A person learns quickly what it takes to keep a CFer healthy.

May 1988, we were blessed with another baby boy, Lucas (Luke) Edward. Back in 1988, a baby is not tested for CF until the age of about 3 or 4 months, unless there were obvious indications. I took Luke to see Dr. Barbero at the Springfield CF Clinic when he was 2 weeks old. I told Dr. Barbero that I didn't know if it was pneumonia or baby blues but there were signs to me that was too familiar. Luke was diagnosed with CF at 3 weeks old. I was shocked that Robert was excited about the diagnosis until he told me that "now someone was just like me!".

Cystic Fibrosis Association of Missouri (CFAM) began with the need for support and fund raising for a cure. Support from people that knew what the other person was experiencing. A shoulder to cry on, or how similar experiences could be approached. To be there when the heartbreak of losing someone happened.

Robert lost his battle with CF in February 1995. Luke celebrated his 20th birthday this year. He told me that this year was a milestone for him. I thought to myself, milestone? usually you hear about the 21st birthday being a milestone, legal age to drink. Then he continued to say that this was the year that was supposed to be his lifespan age.

Thank you for coming to Lois' Luncheon for CF. Thank you for allowing me to share my story. I truly believe everyone makes a difference, the cure for CF is just down the road.

Sincerely, truly
Mary McCutcheon