

After 13 miscarriages, our son, John, was born in April 1989 with Myotubular Myopathy. John coded at birth and was on a ventilator for several weeks. He had a fundoplication and trach at 7 weeks and at 11 weeks we brought him home from Texas Children's Hospital in Houston. We were told that he would probably only live a couple of weeks and never see his first birthday. Not exactly the entrance to parenthood that we'd dreamed of, to say the least.

This past April, John turned 24 years old and last May he graduated college. We always encouraged the doctors to do all that they could for John and to treat him as if they did not know about Myotubular Myopathy. We have faced many trials, illnesses and surgeries, but to the amazement of everyone watching, John always came through.

John decided when he entered high school to use his ventilator 24/7 because of the long honors classes. Before that he used his ventilator only when asleep. He has been ventilator dependent since high school and it seems to work well for him.

Some families try to protect their child by keeping him in bed and not interacting with other people. John went to a Methodist preschool at age 2. The nurse and I checked noses each morning and if we saw a sick kid we just scooped John up and went to get a toy at the toy store. John's life was too precious to spend in bed!

John is very intelligent, has a strong will and a very dry sense of humor. His life has been well worth fighting for and we love him dearly. We let God take the lead in John's life and God and John have done just fine. There is no room for doubt and despair with a fragile child. Do all you can then let go and let God.

-Pam Scoggin