



Jennifer and Kyle's Story

"Sir-Itch-a-Lot"



In the fall of 2011, I got a call from the gastroenterologist's office. The receptionist said I needed to make an appointment to come in and see the doctor. Kyle had been very ill, and many tests had been performed. At the appointment, I sat there alone and listened to a very kind doctor as he explained this "very serious" disease with which my son had just been diagnosed.

"PSC is a chronic, progressive and devastating autoimmune disease of the bile ducts that often leads to liver failure and the need for a liver transplant. There is no cure."

I had no idea what was going to happen next. I had no idea what the future held, or what Kyle's life would be like. He was very sick, and my family and I were searching for answers. We were soon introduced to several amazing doctors, as well as a host of other specialists throughout

many states. The next few months would bring many more tests, a TON of medication, and many appointments. I learned more about the GI tract and the liver than I ever anticipated knowing, and Kyle endured and fought his way through more struggles than any kid should ever have to experience.

Kyle is now six years into this journey, and we are all still riding the highs and lows of this insidious disease. There are countless complications and many difficult days, but there is also indescribable joy and perfect peace. So much good can come out of something so tragic, and our family's goal is to always find the good in every situation. Anyone who meets Kyle immediately recognizes that he has PSC, but PSC doesn't have him. He is full of life even though his liver, affectionately known as Sir Itch-A-Lot, causes him daily suffering. He is my hero and I want to be like him when I grow up. I want to see the good in everything like he does, and I want to be a light just like him in the otherwise scary world of PSC.

Our family is walking this PSC journey together, and we will continue to fight with and for Kyle as long as it takes! He needs a cure. PSC need a cure. But, in the meantime, I'm sure Kyle will smile at everyone he meets.