



Mackenzie Joyner's Story

When our daughter, Mackenzie, was 4 she was diagnosed with pneumonia, again. She seemed to be doing better, so we almost skipped the follow up appointment with the pediatrician. Glad we didn't. The doctor said "Yes, her pneumonia is better. However, the chest X-ray showed something unusual. Her heart is on her right side. I don't think it is anything to worry about, but I want you to go to a pediatric cardiologist." WHAT?

We live very close to two major University hospitals. We contacted both UNC & Duke to schedule an appointment. Duke could see her first so we opted for the quickest appointment we could get. When the day came, Mackenzie (who we call "Kenzie") lay still on a hospital bed for an hour while an echocardiogram confirmed her heart is truly on her right side. It took a long time because the technician said everything she usually saw was backwards. Luckily, she is a mirror image of most folks and her blood flow is good. The cardiologist then sent us downstairs for Kenzie to get an ultrasound. They then found that all her abdominal organs were reversed too. She now wears a medic alert bracelet so that in case of emergency, they will know where to find her appendix, etc. but on a daily basis her organ reversal doesn't cause her any problems.

The young cardiologist asked if we had any more questions before we left. Thankfully, my dad is a retired physician who had prepped us, so we definitely had more questions. Our daughter has had a runny nose since we can remember, more infections than we can count, multiple pneumonias and bronchitis. We asked if these were related to the other items they just discovered. The cardiologist said he would be right back. I am convinced to this day he went to search the web. When he came back, he said, "I think you should see a pediatric pulmonologist -- your daughter may have Primary Ciliary Dyskinesia (PCD). PCD is a genetic condition similar to Cystic Fibrosis. With PCD, Cilia do not function correctly to clear fluid from lungs and sinuses." Two months later our daughter had her sinuses scraped. It was incredibly painful because they cannot use any painkillers or put patients to sleep. She yelled "No Mommy No" as I helped hold her still. In all, it took 4 adults to hold a small 4 year old down. Diagnosis confirmed. Kenzie has PCD.

What has followed has changed our lives. Kenzie does morning and evening medical treatments, every day. They last from 15 – 90 minutes each. Her pulmonologist and ENT are now at UNC and she is part of a 5-year medical study that will allow doctors to monitor the progression. This disease, or "condition," as we call it, is very rare, affecting only 1 in 30,000. We hope that through early diagnosis and aggressive treatments, Kenzie can avoid the double lung transplants others with PCD have endured.

When we go to UNC now, we see so many children that are worse off than she is. All of us have to live with the cards we are dealt. Our girl is now 6 years old and has her 7th set of ear tubes. She coughs like a 3 pack a day smoker. She is also a typical six-year-old -- beautiful and spirited, loves the Jonas Brothers and drawing fantastic pictures. She is a great swimmer, who can run and play with her friends. Most of those friends don't know much, if anything, about her condition until they say the pledge of allegiance. Kenzie puts her left hand over her heart on her right side. If they ask why she does that, she'll share her story. We hope to share her story with more and more people to raise awareness of PCD .