



## **“Growing, laughing and living life- not struggling to survive it.”**

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I will never forget the day my youngest son was diagnosed with pneumonia at only 5 months old. Jaime had a daycare cold that just never seemed to go away. Week after week I expected his deep phlegmy cough to improve and yet it never did. With every antibiotic provided by the doctor, it just seemed to get worse. On our fifth trip to the pediatrician I requested a chest x-ray to rule out pneumonia. Although the doctor insisted that the chances this was the case were extremely low for his age she was willing to appease this advocating Mom with a referral to radiology. Sure enough, there it was staring back at me on his x-ray; lungs inflamed, damaged and gunky with pneumonia spread throughout. My heart broke. Why did this innocent child deserve this? How did it progress so rapidly? Why had none of the antibiotics prevented this from happening? So many questions raced through my “fix it” mind. Although I overthought all of the negatives surrounding his situation I couldn’t deny the relief I felt from finally having a diagnosis. A starting point. It was time to become an expert on infant pneumonia and get my baby better. For ninety-four nights in a row I slept on the floor beside his crib waking up the instant I heard any change in his breathing. Fearful any moment he could take his last breath and be gone forever. Jaime was referred to a pediatric pulmonologist who started him on breathing treatments- a long-acting inhaled corticosteroid and a short-acting reliever with chest percussion throughout the day. We began to see improvement, for once, and I thought we were on the road to freedom. It was at one of our follow up appointments that the pulmonologist explained that the reason he was unable to get better and pneumonia developed in his lungs so early was the fact that his airways were constricted from asthma which wouldn’t allow them to clean out properly. It was then that I realized these new breathing treatments would not be a short term quick fix, rather an integrated part of Jaime’s day to day life. Jaime hated his breathing treatments. He would scream and thrash each time I held the spacer to his face. I tried making it fun with songs and games, but he continued to resist and my guilt grew. Even though I was noticing significant progress on his lung improvement with his treatments, I began avoiding them, skipping treatments, purposely forgetting, just to not hear his cry. To not feel like I was hurting him. Because of my neglect to keep his treatments consistent, his lung health began dissipating once again. It was then that I had a discussion with a staffer at American Lung Association about my struggles as a Mom of an infant with asthma. How I felt with each and every treatment. My fear of what I was doing to him psychologically. The staffer was kind, understanding and empathetic but reflected back to me the importance these breathing treatments had on keeping Jaime healthy and out of the hospital. The hospital. That resonated with me. All of those nights sleeping on his floor, listening to him breathe, consumed with fear he’d be admitted to the hospital or even worse- to lose him forever. What am I doing? So what if he screams and fights the spacer. The short few minutes of resistance is well worth the long term of having a healthy, happy baby boy who is home. Not in the hospital. In his Mommy’s arms growing, laughing and living life- not struggling to survive it. I am forever grateful for what I’ve learned through this journey and the incredible people who have supported me through the toughest of times. Best of all, I am now proud to consider myself an advocate for parents with children with asthma and grateful for those who dedicate their time educating the community on ways to manage this very challenging and scary respiratory condition.