

Lucile Packard Children's Hospital. March 26, 2003 TIMESTAMP

Her water broke. Not five minutes ago, she was asked to leave the hospital. It seems that the ample distance between contractions were giving the doctors a false perception of the time left until delivery. Here's the good news, the doctors knew what was coming based on the green streaks in her amniotic fluid now on the hospital floor, but the bad news, there was meconium surrounding the baby. Let's fast forward to delivery. The fears of the medical staff had come true, and triggered by a nurse's cue, "Meconium!", the hospital room was suddenly bustling with new people and activity, trying to clear out the airway of the newborn. New to parenthood, this all seemed odd, but what did they know? Some 20 minutes later, their healthy baby was placed into the arms of her mother and father.

Of course, I don't remember any of this. The incident my parents experienced was passed over rather smoothly, as meconium aspiration is not completely unheard of in a typical birth (7% of births). Little did my parents know that this is often the first manifestation of something bigger. With the combination of its rarity (about 0.06% chance), the novice nature of my parents relationship with infants (I was an unexpected first), and my relatively healthy, happy disposition, the possibility of Cystic Fibrosis was only considered after the accumulation of the many symptoms that compelled my doctor to perform the required blood test. Results: positive. It wasn't until I was almost 6 years old (4 years older than average) that I was diagnosed with my condition: Cystic Fibrosis, a genetic defect that causes cellular dysfunction in one's internal organs, namely the lungs and pancreas.

This was unbelievably hard on my parents. A shock that almost felt like I was being taken away. Feelings of worry and uncertainty coupled with a barrage of statistics and treatments were being thrown at them. At the time, predicted survival rates for CF children were rising, but still significantly lower than national averages for individuals without the defect. *How long would we have her?* Aside from the news about me, this had implications for the rest of their family too. This newly acquired knowledge that they carried a fatal hereditary mutation in each of their genes meant the likelihood that any child they might bear would have a 25% probability of having CF. This tripled their anxiety, as at this point I already had 2 younger sisters, one 3 years old and the other 3 months. *Would they test positive too?* To their relief, I was the lone receiver of not one, but two copies of the most common CF genetic variant, Delta F508. In an even more "one-in-a-million chance", out of my entire family's genetic past, to the best of our knowledge, I am the only one in my lineage to have this condition. So that's me...unique...improbable. This time was all too overwhelming. *What have we done?* To counteract that spiral of worry however, were three, small little smiles and contagious giggles from three beautiful girls. Ironically enough, while it was impossibly difficult for my parents to cope with this fate, the harsh reality I had in store for me was unrecognizable in my hyperactive, social, smiley self.

Unique as a way to say abnormal. Abnormal in the sense that while I was taking pills and breathing through nebulizers, other kids were playing with toys and making messes with their mother's makeup. And yes, while I did my fair share of those things, the idea of daily pills and breathing therapies were a staple in my daily routine. It has been this way as long as I can remember, and though I knew my friends weren't taking part in these activities at home, I never saw it as weird, I saw it as me. Because of this outlook (whether due to ignorance or confidence I'm not sure), I don't remember feeling self conscious or wallowing in self pity, wondering why me, or that life is unfair, rather I was a typical curious, happy-go-lucky, energetic "ball of sunshine", as everyone called me. I was essentially a typical kid, at least in my own mind. I was never scared to share my ailment. In fact, I often let my friends try on my airway clearance vest so they could experience the intense vibration to which I had become accustomed or loquaciously boasted of my array of brightly colored pills and "potions" to those willing to listen. I saw it all as a part of my unique person and I have always felt fond of it in that way. One cannot have this condition without their entire life revolving around it.

Now that I am a little older, I do have a much more realistic view of my rank on the "normal" scale, and in case you hadn't caught on I will tell you it is not average. Oddly, I am extremely thankful for

that. I am thankful for the way that my condition has impacted my character. Living with a chronic illness has changed my entire outlook on life and I couldn't imagine how different I would have been without it. I have grown into a wildly sympathetic and compassionate person. I take my pain and struggles and use them to create perspective on the hardships that others go through. I am mentally strong. I am determined and I know how to preserve. I don't have the option to forget about my treatments simply because I don't feel like it. I have learned and persisted in finding willpower to continue to take care of myself even in the darkest times. This change is not just because I'm older, more experienced, or better educated...but because I have endured an inescapable, medically imperative, daily routine imposed upon me, (first by my parents and then, as a teen, by myself) in order to stay alive. Despite this headspace I have grown in, the older I get, the more crushingly heavy the burden becomes.

Treatments started with digestive enzymes with every meal, nebulized medications and airway clearance therapy once a day. This was the list of treatments that were given to me as a preschooler. In 3rd grade I reached a point where my routine as a toddler was not going to keep me at the level of health that I need to be. I was getting sicker. Not enough to worry (not that that stopped my parents from being fearful), but enough to start the process of "bumping up" my treatment plans. I have a strikingly vivid memory of this. Sitting down doing my once a day treatment and talking to my mother. Being the social creature I was, I was voicing my plan to visit a friend later in the day. She looked at me, trying to orient her tone as casually as possible, and informed me that my plans would need to include time to complete a second course of vest therapy that day. It was at that moment I realized; my life was not going to be as free and easy as those of my friends. Still, being the ignorant optimist I was, I consoled myself with the hope that I'd soon return to a once a day regimen. Nearly ten years later and I'm still optimistic.

In Junior High, I started taking more responsibility for my treatments, but despite my family's steadfast encouragement and my determination to manage my health, it was no match for the inevitable, recurring lung infections that required periodic hospital stays. Having CF means that typical, normally inconsequential illnesses (like cold, flu, and allergies) are more likely to result in hospitalization than for the average person who would treat with some rest and hot soup. Continuous, preventative measures are required to keep me healthy. I have endured frequent poking, prodding (such as bronchial lavages and sinus surgery), and complications (bacterial and fungal airway infections, diabetes, and hypothyroidism) resulting from the confluence of CF, medication side effects, and typically non-life-threatening ailments.

These days, everyday, my routine consists of 43 pills, insulin management, vest therapies, nebulized meds, preventative care for my sinuses, daily needles and machines calibrations, and all the rest of the things a normal, healthy teenager is supposed to do, like attend school, study, be active, be creative (I enjoy painting and playing music), engage in extracurricular activities (I volunteer at the hospital on weekends, attend youth group, and church), keep my room clean, finish chores, be a good role model for my sisters, maintain social ties with friends and family, and so on. But, still, as exhausted as I often am, I constantly crave more from myself. Everyday I strive to be a better person for myself and for those around me, to be kind and helpful. I want more for others in need. I want to learn to help them in the same way that people have helped me on my journey and I want to help them as my profession. I'm convinced that the reason for this obstacle in my life was to drive me towards the medical field. I'll do it... if given the chance to learn... and if not, I'll still find a way to make it happen just as I have accomplished goals with myself, my health, and my school so far.