

Nearly 5 years ago

Nearly 5 years ago, approximately 4 months after I gave birth to my only daughter, I was 21 years old and diagnosed with Lupus SLE. I've heard of the illness but never really understood anything about it until I was faced with the disease. My mother was the one who has been my savior in all of this, along with the team of doctors who have cared and supported me through this very confusing and heart breaking discovery of my illness. My family & friends have been an incredible support as well, especially since I have a small child to take care of. Not long after I was diagnosed with Lupus SLE, my oldest sister was also diagnosed. I have another sister in between us who has yet to have children at this time. I hope and pray that she will be spared from this illness that rocked my family's world. Just imagine, what are the odds of three sisters from the same parents all having the same illness? My sister and I experience the same symptoms, are prescribed similar medications, and we both are treated to the almost fullest extent of the disease. Biopsy's, blood transfusions, and even chemotherapy to help prevent the kidney failure we both face! More problems meant more doctors and believe me we have never experienced anything like this ever! It was all so new to us and most of the time my sister and I got sick at the same time which made everything at home with our families and personal lives much more complicated, since we both have children to take care of. My sister is married with children, but I'll let her tell you her story. I on the other hand, am a single mother with the day to day struggles of raising my daughter in a world that is on the verge of war and disaster, a world that is about to take her father away from her in only a few short years.

In the midst of the attack on America, September 11, 2001, my body was also being attack by a disease that was so foreign to me. I had no idea what would become of me and the obstacles I would have to go through to control this incurable disease. I hear the word incurable and my heart just leaps from my body. Is this illness gonna take me away from my newborn baby? I had already lost so much time with her just being in the hospital going through treatments and being poked and prodded. I was so weak, not to mention mentally stressed out. It was hard to even lift my baby into my arms at times. When I think back to that first year being diagnosed, a lot of the memories with my daughter are filled with hospitals, doctors, 1 hour visits and the rest is pretty much a big blank. It's kind of upsetting because those are supposed to be the most precious times a person has to bond with their children, and the first five years of my daughters life has been full of awful memories of her mother being in and out of the hospital not really knowing why this was happening.

The first couple of years of trying to fight this illness I definitely went through the motions I'm sure all other Lupus patients have gone through. I tried the whole out of sight out of mind thing, I even stopped taking some of the medications that were detrimental to my recovery. It worked for a little bit, or at least I thought it did because I was feeling so good and hadn't had a flare up in almost two years! Then the fun ended and I was right back where I didn't want to be, the hospital, and found that it only made things worse for me by avoiding the situation at hand. At that point I had to restart all the treatments I had already been through but much more intensely. All the medications that were supposed to be helping me were no longer in my system because of the length of time I had stopped taking them. That meant higher doses of steroids, which absolutely drove me crazy, literally, and more rounds of chemotherapy. Because of the kidney failure my nephrologist told me I was one of his sickest patients and that I should have never

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Written by Administrator

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taken myself off the medications that were preventing total failure. I got extremely upset with my doctors, but I guess I was madder at myself, which brings me to today. I promised myself that I would try harder & not give up hope that one day I will be able to say I'm a survivor not a statistic of this disease that is taking over so many lives. I would definitely love to help others in similar situations and if my life story helps just one person, than I know that everything I went through and still going through served a greater purpose. Stay strong and never give up the fight, a cure will be found one day!