



It all started with a spider bite at the end of my 5th grade year. My hand became all swollen and it hurt when you touched it. The next morning I couldn't get out of bed. Every joint in my body hurt when I moved. My parents were going away that day; I promised them that I would be just fine. They said okay and left. The following day a rash appeared on my face, it went over my nose and across both of my cheeks. My older brother said that I probably had poison ivy. Finally in four days my parents came home. I woke up early in the morning with the most horrible stomach pains; it felt like I was being stabbed by a bunch of knives.



My Mom took me to our family doctor who thought that it was a good idea to run some blood work. I had a low grade fever, was losing my hair, had ulcers in my mouth and on my face, my eyes were blood shot and my voice was weak, worse of all, I was more tired than I had ever been. It was not like when you stay up late at night and get up early; it was tired like I never felt before. My




doctor gave my Mom the script for the blood work and he wanted me to see a dermatologist for my skin.



I went to school as usual in the morning and about 9:30 I got a call down to the office. My teacher explained to me that I had to go to the doctor. My mom and I went to the doctor and the doctor seemed very concerned. I had no idea why it was just a spider bite and poison ivy, right? He told my mom that it looked like I had "Textbook Lupus" and that I would have to go see a rheumatologist and get blood work. I was more confused then ever. Why would I have to get more blood work I would rather die then have more blood work! plus I didn't even need any I was perfectly healthy!


Things kind of moved quickly at that point. Mom took me to the Dermatologist who thought that I most definitely had an autoimmune disease of some sort. Next

we went to the rheumatologist he was in New York City.  He told me that he didn't that I had lupus but that he didn't know because he didn't get the blood work results yet. A few days passed and no call. Finally we got the call from the doctor. He said that he couldn't discuss anything over the phone but that we had to come and see him. So we did just that. We traveled down to New York City to go see him. He sat us down, we listened to him for a long time and I didn't understand anything that he said except that I wouldn't be able to have children. After that long talk I still wasn't sure if I even had Lupus. He asked me if I had any questions and I asked him if I had Lupus. He said that I did. It didn't hit me, not yet.

My mom and dad weren't thrilled with the way that the doctor did things they took me for second opinion. As it turned out a family friend Una-Marie who was just 2 years older than me was diagnosed with Lupus too! Her mom told us that they loved her doctor so my mom and dad took me to him. His name is Doctor Lehman. We sat in his waiting room anxious to find out if the other doctor was right. All of a sudden we see a man coming down the hallway with a pin striped shirt and cowboy boots on.



He asked me if I was Aiden and I said yes. We went down to his office and he examined me. He told me that to him it looked like I had lupus but he needed to be sure. So he told my parents that I would need to have more blood work because

he needed more specific things.  More blood work, I just don't know that I can do this again! We left his office with out an answer but knew one was to come.



It was fifth grade graduation day! I was so excited I got to wear a nice dress and wow; I was actually going to middle school! The Graduation ceremony went great it was long but still it was the last day of elementary school so it was all

worth it. After the ceremony we all went upstairs for an inside picnic. It was a blast we had tons of food and were playing lots of games. All of a sudden the fun was put to a halt. My mom and dad came up to me and told me that we had to leave my last day of fifth grade early! To make matters even worse we were leaving because I had

to get blood work.  We left and took the drive to the blood lab. I was crying



I did not want to do this again. It was the same nice lady who drew my blood before so I sat down and let her do it.

Another long week passed by and I had to go to Dr. Lehman's. He looked at the blood work and told me once again that I definitely had Lupus. He put me on a bunch of medications and told me that I had to take them everyday.

Over the summer I was pretty sick. I never felt great. I continued to see Dr. Lehman every two weeks during the summer. I took my pills and did everything right. By the time school started my cheeks were huge and I was brutally aware of it. I had gone from an 82-pound kid to 150 pounds and I had kids coming up to me and asking why my face was so poufy and I would simply tell them it was because I had



Lupus. Still, it didn't hit me that I was *that* sick. It didn't hit me that this was something that would affect me for the rest of my life. Whether I liked it or not!

About two weeks passed by and I still never felt great. It was the next doctor's appointment that I found out that I was going to go on celcept. This was a pill form of chemo. After about a week of taking this pill I was taken off. I was throwing up and felt even worse on the pill. Then the real news came. I was going to be put on chemotherapy. I didn't mind the thought of doing this, it wasn't such a big deal...right?

A few weeks later I started chemo with my friend Una-Marie. I wasn't scared. We walked into the hospital and realized it was Lupus awareness month. Really? How do I have Lupus and not even know that this is the special month for Lupus. We got up to our rooms and settled and they wanted to start my IV right away.



They put a numbing cream on my hand so I didn't feel the needle going in. Una and I didn't waste any time we got into our PJs and exchanged our Lupus gifts. This was something that doctor Lehman came up with, for each day in the hospital

you get gifts. I gave Una a teddy bear with a live strong bracelet.



At that moment it struck us! Why don't we contact the Lupus Foundation of America to get a bracelet for Lupus? We both sat down and e-mailed the LFA. Immediately we got a response. The response said that they were thinking that too and asked us if we could be the teen spokespersons for the purple bracelet campaign (also known as "Someone You Know Has Lupus").

That evening in the hospital they tried to start my IV. The numbing cream shrunk my vein and it didn't numb my skin anyway. They tried and tried to get an IV but could not. Eventually they got a neo-natal doctor to come and start the IV.

I continued my cycle of chemo and then one day we went down to the city



and met with Keri Strug the Olympic gold medalist and Una and I got a photo shoot with her and our new purple awareness bracelets. It was such a cool experience. We continued our chemo with no real interruption. Soon my 6th grade year was over.

Over the summer I was in Myrtle Beach and I was continuously zoning out. I felt weird and out of it. After a while of testing it was determined that I had absence seizures.

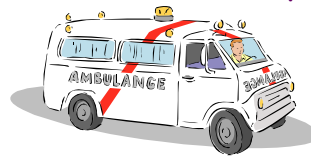
It was a Friday evening, January 16<sup>th</sup>; I was just getting out of the hospital after spending the week in for my chemo. I left the hospital not feeling right, a bit different than my past treatments. It was January 18<sup>th</sup>, two days before my 13<sup>th</sup> birthday. I woke up itching my face. The next day I developed a very ugly rash on my face. My mom sent pictures to Dr. Lehman and he said that I had to go to the hospital in New York City right away. We got to the hospital at about 11 o'clock. At



11:59 I got my IV in. It was now my 13<sup>th</sup> birthday. This was the point I realized that Lupus was going to affect me for the rest of my life whether I liked it or not. I spent a terrible 10 days in the hospital not being able to move my mouth the rash was so bad. It was diagnosed as shingles. Everything that could go wrong that week did. Finally I got to go home. I still continued my chemo cycle.

Nothing much happened until the fall of my 9<sup>th</sup> grade year, my "new normal" as I call it included trips to Dr. Lehman once or twice a month, blood work once or twice a month and then just learning to cope with my symptoms and my treatments.

It was a fall day and my brother was watching my younger brother and I while my parents were away. I came home from school and my chest was hurting. I didn't say anything. The next day was a normal day until my chest started to hurt again. I laid down and took a nap. I woke up crying the pain was so bad. In about 3 hours my parents came home and decided that I had to go to the hospital. I went to



the hospital and then was rushed into New York. I spent another week and a half in the hospital. This time with no real answer.

Life with Lupus is anything but predictable. My parents have learned to expect the unexpected with me. I no longer can be in the sun and in fact, I have to wear



sunscreen every day because of my photosensitivity. The sun and even the lighting in our homes and schools can do damage to my kidneys, damage that might not be able to be undone! I no longer play competitive sports, two years ago I was diagnosed with Freiberg's Disease, basically the second metatarsal bone in




my left foot has crumbled. I break bone quite easily as well. I have had to step down from having a full load of honors classes as well as frequent bouts of being home taught. My memory is not always great and it seems that my head aches and stomach problems are a constant thing in my life. Taking medication is an everyday thing. Not quite a typically 15-year olds life!

I have learned to make the best of it, what else can I do? One of the things that really occupies my mind is how can I make a difference so that the next child/person who is diagnosed with Lupus does not have to go through some of the same things that I have had to. For instance many people have heard of Lupus but they do not know how serious it can be or that you can die from it. There are many people that I have met in the past 5 years who had Lupus who no longer are with us



including a 15-year-old girl. People mean well, but I cannot even count how many say to my Mom and myself, Chemo for Lupus? My Mom has had to have special meeting with the administrators of my school to tell them to think of her daughter as if she had cancer because everyone knows how horrible cancer is. My

dream is to help put Lupus and its victims on the map!  I would love for those affected by Lupus to have the support without all the explanation. We need funding for better less harmful medications and treatments and one day hopefully a cure.

please help me be part of the means in finding a cure for my disease LUPUS.



Love,

Aiden