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|  | **Introduction to Lupus: My Story**  I am going to tell you my personal history with the disease. It all started about four years ago when I was in eighth grade. I decided to go to a high school football game on a cool October night, when I still lived in Georgia. I bundled up and even wore thick socks and hiking boots but it still wasn�t enough. When I got home from the game that night, my toes were completely numb and white and only a hot shower revived the circulation to my feet. This was the first time this had ever happened to me and I thought it was a little odd, but I just dismissed the incident, assuring myself that it had just been a really cold night. I had kind of forgotten about this mystery until about a year later when I won Freshman Homecoming Queen. I never thought that this title would change my life, but it did. When I walked onto the football field that night in my sleeveless homecoming gown, my toes were in pain. I clenched my teeth as I completed the march but when I finished, I burst into tears as my mom looked at my painful feet. This time they were not white, but bright blue! We concluded that it was frostbite so the paramedics came and had to warm up my feet. From then on, I was very careful in the cold as my family and I had decided that I was just very sensitive to cold temperatures. I moved to California about six months later, in April, and did not have any problems with the sunny and warm climate of California. However, I did develop another minor problem known as Anorexia. Over the next six months, I dropped fifteen pounds, which does not seem like much, but considering that I am five feet tall and was only 100 pounds before I lost weight, it was a lot. I got down to 85 pounds and was taken to the doctor. I had weigh in sessions and when I realized that I had a problem, I gradually started eating healthier, but it took a long time to gain the weight back. As winter rolled around, so did the pain and numbness in my fingers and toes. My mom took me to our family physician who said that it was a mild case of a very rare disorder called Raynaud�s Phenomenon, but that there was nothing we could do about it. He just suggested keeping my hand and feet warm and try to avoid cold temperatures. I followed his advice but it became increasingly hard and nearly impossible in February when my family and I took a ski trip to Squaw Valley. My parents got me silk underwear, and tons of layers, and even special boots with foot warmers in them, so we were sure that I would be warm enough on the slopes. I got all bundled up and after five minutes in the snow, I could no longer feel my feet, so I spent the rest of the afternoon warming myself in the lodge while my parent enjoyed an afternoon of skiing. On the way back to the car, my feet got cold again and I nearly had to go to the hopital because my toes were so blue. It was at this moment that we realized that this was something serious and that I must totally avoid cold temperatures and especially the snow. Two monthes later, in April, my family planned a nice warm vacation to Maui for spring break. I was especially looking forward to this becase the sun would be hot and I loved to lay in the sun for hours. This time, my fingers and toes did not turn blue, but after two days of laying in the sun, I broke out all over in an itchy rash. My mom and I are both severly allergic to peanut products, so we assumed that the sun tan oil I had been using had some kind of peanut in it. I was devestated because I could not lay out the rest of the vacation. The rest of my sophomore year flew by and I had a great summer. Then, in November, I had to go on Birth Control pills due to irregular menstrual periods. Two monthes later in January, I ran into big problems. I was so tired all the time that in cheerleading practice, I felt like I did not even have the energy to walk to my correct position. Caffeine colas temporarily fixed this problem, which I soon learned was another big mistake. Also, not only had my fingers and toes gotten worse, but the bottoms of my toes started getting calluses on them that looked like athletes foot or some kind of fungus. Again, we went to our family physician who looked at my feet and also assumed the problem to be a fungus, so she refereed me to a podiatrist. The podiatrist took one look at the calluses and asked if I had any joint pain. I said no, and with a very concerned look on his face, he said that I needed to go see a rheumatoligist immediately. In the meantime, he said that he was going to give me a shot of cortisone to help my feet. Within twenty-four hours of receiving the shot, the calluses fell off, so I assumed I was cured. When my mom told me that I still had to go the the rheumatloigist, I was confused but agreed to go. I had no idea what a rheumatologist was so on the way to Dr. Emory�s office at UC San Francisco, I had never been that nervous in my life. Dr. Emory did a physical examination, which was normal except for the blue color of my fingers and toes, and then followed that with blood work and a lot of questions. She said that she could not make any final diagnosis until the blood work was back, but that a had a very severe case of Raynaud�s Phenomenon and that she was doing the blood work to make sure I did not have any other auto-immune diseases such as Lupus. Now I was really scared because first of all, I did not know what a rheumatologist even does, and now she is telling me that I might have a potentially fatal disease that I had never even heard of. Dr Emory told me to go off of birth control immediately, as it is known to aggravate symptoms of Lupus and she put me on Procardia, a heart medication that expands blood vessels and increases blood flow to my fingers and toes. A week later, she called with my blood results. Everything was normal except for my ANA, which was extremely high. She then explained that this is typically very high in Lupus patients and other people with auto-immune diseases, but that I did not have Lupus because I had no other symptoms. Some of the advice she gave me was to be careful in the sun, avoid caffeine as it worsens Raynaud�s, and sleep when I am tired. Spring Break was again approaching, and this year we were going to Grand Cayman Islands. I could hardly wait to get back in the sun, and this time, without peanut sun tan oil! The first day we arrived, I immediately changed into my bathing suit and laid down outside for a day of sun bathing. To my surprise, about an hour later, I again broke out all over in itchy red bumps. I could not figure this out, as I had double checked my sun tan lotion for peanuts, and was sure that there was none. I then remembered Dr. Emory�s warning that sun sensitivity is often involved with high ANA. I was devestated as I realized that I would never be able to lay out in the sun again. When I got home, I decided that I was going to try and find out everything about this disease and do everything I could to control it from impairing my life. I read everything I could get my hand on about Lupus and now that I knew what it was, I tried to figure out how it related to me. I tried to think of everything that seemed to bring on symptoms or make me fell bad and the list I came up with included heavy sun exposure without protection, caffeine, decaff coffee, and surprisingly diet coke. I began to remember that every time I had drunken a diet coke in the sun, I instantly broke out in a rash and got a cringing headache. Oh no, this could not be happening. I lived off of diet coke and Equal. I put Equal in my coffee, cereal, on fruit, in oatmeal, in cookies, and just about anything else I could think of, usually consuming around twenty packs a day. After some more research, I found out that aspartine (Nutra-Sweet) was possibly somehow linked to Lupus. I then immediately gave it up and have not had any aspartine in about a year. I noticed that this drastically helped my symptoms and reduced my rash and headaches. For about eight monthes now, I have been leading a fairly normal life, minus laying out in the sun and drinking diet soda. I am still on Procardia, which has really helped my Raynaud�s syndrome and still go see Dr. Emory once every six monthes where she repeats physical examinations and blood tests. I am so grateful that we caught my problems early and were able to treat them before they got more severe. Recently, my Grandma (my mom�s mom) was diagnosed with cancer of the lymphnodes, and had to have her spleen removed. She is getting better now, but what she had is also a malfunction of the immune system, which makes me even more suspicious that some genetics are involved in this disease. When I started my senior year, I was so excited when my AP Biology teacher, Mr. Theil, told us about the Science Fair project we would have to do. I immediately knew I was going to do Lupus. I decided to investigate into some factors that could contribute to the disease because doctors still do not know what causes it. I created a survey that included some of my own findings about complications with Lupus including aspartine, coffee, eating disorders and family history. My results proved my hypothesis that aspartine was commonly used among almost 90% of the patients I surveyed. Not only has this project given me a chance to learn more about Lupus myself, but also it has allowed me to possibly help others who are struggling with this mysterious disease.  ([Next)](http://docs.google.com/intro4.html) | |
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