

Kendra, diagnosed at age 18

My name is Kendra and I suffer from life-threatening SLE. I first started having symptoms at age 13. I would complain of joint pains, headaches, and stomach problems. I was treated for tendonitis, stress headaches, ulcers, scoliosis, and other things. By the time I was 17 it became apparent that I had something more going on than a string of unconnected illnesses.

I was not insured at that time so my doctor visits were sporadic at best. I had a great-grandmother that had Rheumatoid Arthritis (RA), so after doing some research, RA was my best guess. I was experiencing a lot of joint pain at that time, even to the point of being crippling at times. My "bad days" were more like bad 3 days. I was having fatigue and weakness but didn't realize what was causing it, and like most of my symptoms I just assumed it was normal for a long time.

At 18 I got insurance for myself and began seeing a doctor. He told me that it looked more like Lupus than RA, but that more work needed to be done to find out for sure. At that time I was going through many flares and remissions. At times I would be pretty well fine and other times I would have crippling joint pain and fatigue.

I lost my insurance and wasn't able to continue treatment. I treated myself during this time with massive quantities of Aleve and rest. I had many, many periods where I was unable to work, socialize, etc. for weeks or sometimes months at a time. This continued really until I was 24.

Around 24 I again got insurance for a short time and began seeing doctors again. At that time I was diagnosed with Premature Ovarian Failure secondary to the Lupus. Basically that means I went through menopause and will never be able to have children of my own. With the hormone changes I gained about 20 lbs at that time. My flares got longer and closer together until I was counting the good days because it was easier than counting the bad ones. I had to quit working and filed for disability.

Even though I had no insurance my illness was too severe to not go to doctors so I went as much as I could afford to pay for, and I got as much medicine as I could afford to pay for. OMG, I could tell you some stories about some heartless doctors and some of the shotty care I got because I didn't have insurance, but that is another story.

I finally got the Lupus diagnosis for sure in early 2004, making me officially un-insurable. At that time they discovered that there was severe damage to my kidneys, and I was admitted to the hospital for a kidney biopsy. The results came back as Class VI Lupus Nephritis and I was told that meant my kidneys were scarred the most they could be and there was nothing to treat it with, the damage had already been done over the years I wasn't seeing doctors. I was told that my kidneys would fail and I would need dialysis and a transplant.

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During that time I also started the parade of medicine. I have tried so many drugs I couldn't possibly remember them all. Some of them I have been allergic to causing all sorts of nasty things, I remember those drugs. I have had drug toxicity due to my kidneys inability to clear them from my body. Many just plain didn't work. The best part though has been the side effects of the ones that actually worked.

One of those meds was Prednisone, a steroid. After starting Prednisone, I promptly gained another 30lbs, my face turned into a balloon, my ankles became flotation devices and my skin lost collagen so I got stretch marks all over my body. Another fun medication I started on was a chemotherapy drug called Cell-Sept. This one cost \$400 a month and for that I got the pleasure of headaches, thinning hair and reduced resistance to infection. When I was having a particularly bad flare, I would get a bump in Prednisone and another 10lbs.

After moving back to Iowa where I am on a program for the un-insurable, I have seen some of the best doctors in the world at the University of Iowa. I am getting excellent care, unfortunately that doesn't mean I feel better, as a matter of fact I feel worse. They have doubled my dose of chemo, tripling the side effects. Because of my decreased resistance to disease, I got a case of Shingles for the record books I think. If you haven't had the pleasure, let me just tell you it is a little slice of hell! I have endured a lot of pain in my day but Shingles takes the cake by far! I also got a complication of Shingles known as PHN which is basically code for the pain hangs around for months or even years after the rash is gone.

Currently, December 2006, I am taking pills 5 times a day, over 50 pills per day in all, not counting any as needed meds. I go to doctor appointments on average 2-3 times a week. I have manageable pain (and by that I mean Vicodin is my friend), random joint inflammation and pain, pain from the Fibro, severe insomnia, depression, anxiety, pancreatitis from the Prednisone, Hyperthyroidism, Sleep Apnea, daily headaches caused by Idiopathic Intracranial Hypertension that is threatening my eyesight, and I am sure I am forgetting things. I don't recognize myself in the mirror anymore. I spend most of the days I am not at doctors' visits resting, and watching TV. I have had to stop trying to lose the 70lbs I have gained over the last 3 years, it is impossible on the Prednisone dose I am on right now.

Now that I have talked about all the bad things it is only fair to mention the amazing gifts I have gotten from having this disease. I know that sounds strange but, I am honestly thankful for the patience it has taught me. It has made me live in the moment and to make the most of everyday. Lupus has also given me an amazing amount of compassion and empathy for others! And, I am most grateful for the strength I have built, I know I can make it through anything!