



my Lupus journey

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I am 44 years young and a mother of one amazing young man that I am so grateful I was able to have before my entire reproductive system became toxic and had to be removed.

I believe my lupus trip began in 1985, at my ripe old age of 9, when I found my calling in ballet!!! Unfortunately, my calling did not agree with this body. I had swollen wrists, elbows and knees regularly. Discouraged but determined, I followed my heart and danced for the next 14 years pushing through painful swollen joints after every performance. Doctors told me things like: It was growing pains; I wasn't eating right; or it was because I was "turning into a lady." Ugh - none of these were correct!

By 18, I had knee surgery and a hole in my stomach from years of excessive ibuprofen used to control the pain. I went to so many doctors in 3 different states, that my brother called me a hypochondriac. Discouraged again, I stopped going.

By my son's early teens, I was becoming markedly worse, straining our relationship. I had continuous joint pain and swelling EVERYwhere making me so irritable. I never wanted to do anything. With my lack of energy, as a single mother, I barely had anything left for him. I had brain fog to the point that I would walk out of the store and forget where I was or what I was doing; debilitating migraines with vision loss and vomiting that would take me out the rest of the day; depression; anxiety; and extreme chronic fatigue - not just being tired but being exhausted. I would have to choose between taking a shower or doing laundry or doing the dishes or making a sufficient dinner.

I sucked it up and started going back to the doctor. I told my PCP to dig deep. Think outside the box. Go back to his medical books. Figure out what the heck was wrong with me!!! My first rheumatologist said the problem was I was "thin and flexible." That one cracks me up to this day. Finally, in 2009, my 4th rheumatologist said, "You have lupus!" I had 9 of the 11 markers. I saw my diagnosis as a saving grace! Now we could figure out how to make it all better!!

I was told to research all I could, join a support group, check out my local lupus organization. I found all I needed and more in my Lupus Foundation ~ Indiana Chapter. They have been and still are Amazing!! They gave me so much information about lupus, hooked me up with a support group, helped with medication, got me involved with the Walk, where I served for the next 10 years as the Logistics Coordinator.

After a year of trying to slow down my progression, my doctor told me if I didn't make some lifestyle choices, I might not make it past 3-5 years. That will wake you up real fast!!! I ended up losing my dream career in veterinary medicine and then my house. Then I went through 6 years of lupus clinical trials. I did so well in the last trial I was in! It is currently en route to being on the market and is called Anifrolumab. I am praying that it will make it.

My progression finally slowed. I saw my son finish high school, then graduate from Purdue. Although I am in a constant flare, I am stable. I can enjoy life a little more. I am stronger and fighting every day to not let lupus win. I Am a Lupus Warrior!!!

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The Cruel Mystery
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