

Lupus: Conquer the Fear
By Rocky Lewis

George Costanza from Seinfeld had a lot of fears and neurosis, but I always laughed at his hypochondriac tendencies. "Lupus?! Is it Lupus?" He'd ask almost every time something physical befell him. Thanks to Seinfeld, my Lupus diagnosis got some humor built right in around my house, but it wasn't always funny. My story is like so many – starting out with exhaustion, pain, and the most common pre-diagnosis question: What's wrong with me?

I had already established an answer to that question when Lupus took over my life. My answer was: "Nothing, it's all in your head." That's because 10 years earlier, when the suffering began, I was diagnosed with Fibromyalgia and told to reduce my stress and take an anti-depressant. That experience with the medical community was so unsatisfying, I stopped going to doctors when I had pain and (what I now know to be) flare ups. I ignored Lupus until it refused to be ignored.

Six months after the birth of my son, my ankles swelled to the point where I could barely walk. I went to bed every night after I put the baby to bed – and slept 12 hours, just like he did. And yet I was dying for sleep all day. My jaw was killing me, and I got these ulcers in my mouth and down the back of my throat for 2 weeks that made me think I had strep. The only good news (I thought) was that even though I could barely walk, I had managed to lose 5 lbs.

George Costanza and I had opposite fears – he was worried he'd get a diagnosis, and I was worried I wouldn't. I knew this pain seemed much worse than ever before, but I was terrified to go the doctor and be told I was crazy and nothing was wrong. For some reason suffering the chronic pain alone seemed better than learning there was no hope of it subsiding. After 4 months of wearing only flip flops because my feet and ankles could not fit in shoes, my RN mother finally convinced me to go see someone.

My new family doctor (who had no knowledge of the Fibromyalgia diagnosis) sent me immediately to a Rheumatologist that saved my life with a diagnosis – Lupus. I'll tell you, I was overjoyed to have real problem. Until it sunk in that I had a real problem. No longer was it Diet Coke, lack of sleep, refined sugar, or too much stress at work. I had Lupus.

I had been a runner and had been forced to stop. I could not carry my son up and down stairs. I could not ride a bike. And I suddenly had a large collection of pills to keep. The fear came back. This time it was George's fear. What does this mean for my life? Does this define me?

I was a new mother with a business to run and the statistics were not encouraging. 50 percent of people with SLE have major organ involvement; 10 to 15% will die prematurely; 2 out of 3 patients stopped working because of Lupus.

Ultimately, I found hope by deciding to acknowledge the fear and then let it go. Could Lupus define me? Yes. Will I let it? No.

It was time to make changes and take charge of my lifestyle and prioritize health. I knew if I didn't take charge, no one would. Doctors mean well, but my Rheumatologist sees 30-40 people A DAY. We each get about 10 minutes. I knew it was my job to tell him what I needed and wanted and not be afraid to take charge. I told him up front that I wanted to avoid the cycle of pain and relief that often comes from steroids and pain pills. He told me, "We'll see." We're 4 years into the diagnosis and so far, so good.

I also took charge of my health at home. I knew extra weight was not beneficial. I knew alcohol and lack of sleep gave me pain. So the vodka, diet cokes, and Mac & cheese came out of the fridge. I went to bed with the kid and still do. I like 10 hours of sleep, and I don't care what anyone in my house or life thinks about that.

That strength, of knowing what I need and standing up for it, was essential for changing all aspects of my life. I knew flares were often times of stress for me. So I started saying, "No." I said it at work, and I said it at home. I prioritized what I valued in life, so I could know and justify where I spent my short lived energy. Was it more important to walk my son to the park or vacuum the stairs? I bet you know the answer to that!

And finally, I learned I had to care for my soul. I knew isolation and self-pity were not helping me. I learned that fear and sadness should not be ignored, but addressed. So I reached out to family and asked for help when I needed it. I gave myself a break and forgave my body and mind for needing medication and help. I stopped chastising myself for not being strong enough and perfect enough.

And most important of all, I found my gratitude for all the gifts in my life, including this gift of health. That's right. I'm healthy, and when people ask if I have my health, I say "yes," without hesitation or clarification. I am young, strong, and cared for by top doctors. I can afford medication. And I contracted Lupus at a time when there is relief. It's no longer a death sentence, and the next 40 years of my life will only bring more innovation and support. I am lucky. Very lucky, in fact, because I have conquered the fear.