



my Lupus journey

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My story – I’m sure like many of yours is one of confusion, frustration, and admittedly fear, early on. I was diagnosed 16 years ago after a lifetime of being an extremely active person. I was an avid runner ... running at least six miles every day. I started having hip pain and after about a year of orthopedic docs and rheumatologists, I was finally diagnosed. As it is for all of us – and something that can make this disease so frustrating – we don’t have singular symptoms, so it’s hard to diagnose...and hard to treat.

So, like many of you I’m sure, I jumped in to find out as much as I could only to be terrified ... and in my case, honestly, angry. But I’m one to look at things pretty optimistically, so instead of feeling helpless and letting it dictate my life, I decided to focus on what I could do, instead of what it was doing to me. Don’t get me wrong, this disease sucks – and I’m not at all minimizing its impact. But I just felt like I wanted the upper hand in any way I could. I am a single mom of two amazing boys: Zach, 21 and Isaac, 19. For most of their lives I have had to manage my disease, their busy lives, and my work schedule and the LAST thing that was going to come in the way was THIS DISEASE! So I focused on essentially three things:

- First, getting the proper medical advice – and let’s be very honest, for any of us who have had this for any length of time, we have made great progress on the medical front. No, we don’t have a cure...but we do have better medicines to help control our symptoms.
- Second, I needed to listen to my body: when I needed rest, I NEEDED TO REST. When I felt something out of sync, I talked to my doctor. I wasn’t paranoid about every little thing, but I learned to listen to what my body was telling me, and between experience and my doctor’s advice, I now know what is a big issue, and what I can handle on my own. My doctor knows the same, if I call and say “I’m sick”... I really am sick...and probably should have called a few days prior.
- And finally, third, I got very serious about my diet. I am very disciplined about what goes into my body....and that was difficult. I’m not a health nut, and I LOVE food: Ice cream, pizza, pasta, pancakes, and challah. But I couldn’t do those anymore. Now I focus on gluten-free and dairy-free. I can still have my favorites by changing the recipe slightly or picking a different brand. I feel tremendously better in making these adaptations.

As I said, I am not a Pollyanna, nor do I want to minimize anyone’s symptoms. But at least in my case, I felt actively managing my lupus gave me hope. I feel better much more of the time. And I know I’m at least doing my part...and that in and of itself is rewarding.

I still have good days and bad ones. But I’m winning.

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