



KM

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Photo by AM, KM's husband

KM and her son on vacation in Hawaii in 2019.

My symptoms started in my early 20s. I would go often to my family doctor with different vague complaints — leg pains, easy bruising, headaches occurring while outside in the sun. I learned to live with these issues and was reassured that my doctor didn't think there was anything wrong with me. I think my doctor's office had labelled me a hypochondriac; part of me started to believe that I was. But I have a strong family history of autoimmune disease — my mother has lupus and my father has rheumatoid arthritis.

My leg pain started to get much worse in my 30s — excruciating pain I could feel in my bones — and I told my doctor I wanted to see

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a rheumatologist because I was specifically worried about lupus. The rheumatologist I saw was not concerned — in fact, he told me definitively that I did not have lupus or rheumatoid arthritis and did not need any diagnostic tests. He said lupus was rarely passed on within families despite what I had read. I was so relieved. But it turned out to be false reassurance.

Pregnant with my first child, I started having chest pain and shortness of breath. I couldn't walk up a flight of stairs. A rash on my legs erupted — I now know it was erythema nodosum. I googled lupus and pregnancy, fearful of the potential harm to my baby if I had undiagnosed and untreated disease. I joined online groups and

spoke to moms with lupus. I identified a panel of tests I believed I should have and asked my obstetrician to order them for me. She didn't even hesitate. Sure enough, my antibodies were strongly positive and inflammatory markers sky high. Inflammation around my heart and lungs was what was causing my symptoms. I needed to start prednisone immediately. It was so stressful.

I got a diagnosis of lupus simply because my obstetrician took my requests seriously, but I often wonder if I could have gotten this diagnosis before my pregnancy. Even now that I have a diagnosis of lupus, I find doctors still don't take my symptoms seriously sometimes. For example, I developed a severe headache and light sensitivity and received a diagnosis of a lupus migraine in the emergency department. I left and went to another emergency department where I was admitted to hospital with meningitis. On the same day.

I put doctors into two categories: ones that have empathy and take an interest, and ones that just completely dismiss me. I used to stick it out. But, after what I've been through, if a doctor dismisses me I go elsewhere.

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