

Jenni, diagnosed at age 26

My name is Jenni. I am 31. I was officially diagnosed oh, about four or five years ago. I forget now. My doctors think that I probably have had it as a teenager and just not noticed the mild signs. (I was very active in sports back then, and just assumed that the aches and pains was due to the sports.)

I have two boys ages 8, and 4. My daughter is 6 1/2 (going on 20). I started having noticeable problems when I was pregnant. With each pregnancy, more and more problems started occurring. First it was mild Raynauds along with arthritis. With each pregnancy, the Raynauds got progressively worse. With my last baby I kept going into preterm labor-starting at 5 months along. I was so scared. I ended up having Alejandro 2 1/2 months early. Luckily, he only had minor problems that were corrected by the time he left the hospital 10 days later.

By that time, The doctors finally told me I wasn't crazy. There was something wrong. I had LUPUS. Now it had a name. That makes sense. I had atleast 9 of the many symptoms at that time. I read everything I could get my hands on to educate myself and my family. I have been to four different Rheumatologist now. Don't ever think that you are stuck with a certain doctor... For the first couple of years, the first two doctors just stuck me on the usual meds and wouldn't try anything else or change the dosages. So, I went looking for a doctor that would LISTEN TO ME!!! I now have a good rheumatologist who listens. She is willing to try something new. I have been on almost every medication imaginable. They even tried me on Viagra for the Raynauds! She put me on chemo for a while- after getting used to the meds I actually felt good!! Until she had to take me off. Then the problems came back. 6 months later she put me back on chemo and I was so happy. My symptoms were very mild and I was actually out and doing things again. Unfortunately, you can only be on it for so long.

Every year my symptoms have worsened. Oh my goodness. Lately my best friend is vicodin. Yeah. Nothing like trying to raise a young family and you can't even get down a flight of stairs to cook dinner. My kids are very helpful when they recognized that I am in pain (most of the time). My husband tries, but I know that he really has no clue how bad it really has gotten.

Things have been especially bad lately. It's winter here in Michigan, that means day time highs of 19 degrees. Remember, I also have raynauds. I get frostbite really really easy. I can't go out for long periods of time. That means I am unable to work. My arthritis gets really bad too. I have been having intestinal problems and horrible menstrual problems too. I can't sleep- the pain keeps me up and I can't get comfortable. (vicodin does not seem to help at night) I have been up the last four nights crying all night long. I can't play in the snow with my kids. That's roughest. I used to love being out. Now It seems like my lupus is like an invisible chain, keeping me from doing what I love doing.

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Well, I am going to try to get some sleep....try... Thank you for listening and giving me a voice. It really helps to know that there is someone out there with problems similiar to mine. I am not alone. My family may not understand, but you do. Thank you and keep fighting!!

My family keeps telling me that they know people with lupus.... (get ready) they are well over 50 or something. Their symptoms are mild. They don't understand that the younger you are when you get it the worse it gets. Not the other way around.

AARRGGHH !! I am not pretending. Why on earth would I make this up? I am so tired of people telling me that I need to think more positive, I need to exercise more, it's in my head, you get to get up and moving, I'm making it up, I'm being lazy, and other crap like that. I have been looking on the web and found a site www.cafepress.com. I love that place !!! They understand me completely. Especially the warning t-shirts. That really lifted my spirit when I found those shirts.