RENA: Explaining lupus to my daughter...I try to stay as open as possible. Anything that happens, I let her know. I don’t try to hide it. I tried that once. I had to have a hip surgery, and I didn’t tell her, and when she got outta school and she found out that I had surgery, she was devastated. So, I learned the hard way to just be open and honest because kids understand way more than we give them credit for, so I try to explain everything in detail what she can understand as far as what’s going on.

I would tell people who are living with lupus, when they’re talking to their children about the illness to describe to them, you know, basically what it is they’re going through, that when you say you’re not feeling good, it’s not a typical, “I have a cold, I’m not feeling good,” or the typical, “I’m tired. I’m not feeling good.” It really means that you truly do not feel good, that when you can’t make it to a certain event, or you can’t go to a certain place, or take them to a certain party, it doesn’t mean that you don’t want to, it means that you are physically are unable to.