

My daughter had just turned 19, finished her first semester of college, when she was diagnosed with systemic scleroderma. Her fingers had become stiff at age twelve, but two rheumatologists diagnosed it as juvenile rheumatoid arthritis. She really had no more symptoms until she was 18. Raynauds was first. Then her skin became very firm and shiny on her abdomen and chest, then her arms and thighs. After she was diagnosed, other symptoms began to develop. Large joint stiffness, she could not squat, it was hard to get off the floor. She had to have 30 blood tests at one time, chest x-rays, ekg's echocardiograms, pulmonary function tests, MRI's, CT scans, skin and muscle biopsies. She was supposed to be learning to be an adult, living in a dorm, hanging out with friends, studying for final exams, but instead she began a fight for her life. When the Dr told me what lay ahead as treatment options for this disease, I was in denial. She wasn't that bad. How could she need large doses of an immunosuppressant I couldn't even pronounce, and steroids, and maybe a chemo infusion once a month, and maybe a stem cell transplant, and you have to harvest eggs because the drugs could make her infertile. What are you talking about? How am I supposed to tell my 19 year old all of this? How is she going to understand?

She moves back home and tries to keep her life as normal as she can. We enroll her in community college. She was a four sport high school athlete and she makes the softball team. Makes new friends, attends classes, and plays softball, even though she can hardly squat far enough to field the ball, and she gets a finger ulcer when she tries to pitch. But I am so proud of her. I never missed a game, because I never knew which one would be her last.

More symptoms, beautiful long hair is thinning, skin is itching incessantly. I buy lotions, oatmeal body washes, Benadryl, prescription drugs for itching, and nothing helps her. You feel helpless. The itching is so bad she can't sleep. She is so strong and so brave and she feels bad for me, because I am trying everything I know how to make her feel better, and it's not working. Tears, lots of tears.

I see her beautiful face start to change ever so slightly. Her nose is getting smaller. I wonder if she notices. I wonder if she will become disfigured. I don't say anything because I don't want her to have to think about that too.

Shortness of breath, that's when reality hit. It was starting to affect her lungs. Chest CT showed a small amount of fibrosis in her lungs and pulmonary lung function tests showed a decline. Now I am scared. I call the Dr and say ok, the drugs are not slowing this down, what do we have to do to get the ball rolling to have a stem cell transplant?

Lots of appointments, and a five hour round trip every time we go for one. Sometimes we stay overnight because we can't get all the appointments and tests done in one day. She never complains, even when we have to get up at four in the morning to make an eight o'clock appointment.

She is 19 and loves children. She wants to be an elementary school teacher. She wants children of her own. As a mother I want her to have that chance, so we elect to harvest her eggs. The chemo she will have before they give her stem cells back, has a good possibility of making her infertile, so this is the best chance she has of keeping this one dream alive. I have to give her shots, a lot of shots, some sting and burn. She doesn't want me to know it hurts, but mothers always know. I try to hold back the tears until I am alone. I want to be strong for her, I don't want her to see my pain.

She has to get a port in her chest. Another battle scar. It feels like we are fighting a war. But she is a fighter and together we will press on. After 3 more days of shots, it takes five hours hooked up to a machine that takes her blood out, collects the stem cells, and then puts it back in.

Oh and she is still in school through all of this. She will take final exams and a week later she will be admitted to the hospital for her transplant. Dec. 23 she is admitted. Christmas, New Year's and her 20th Birthday will be spent in the hospital. But those things don't really matter right now, because who cares if we miss one Christmas, if it gives us the chance of many more to come. And we pray, and hundreds of people are praying for Kelly. From New England to California to Mission churches in Africa, there are people praying that this will work for Kelly. And we put our faith and trust in God, He has a plan for Kelly.

They give her drugs that completely wipe out her immune system. If she is exposed to a virus or bacteria at this point, it could kill her. More prayers. Not much sleep. But you have to stay healthy yourself or you can't go near here. Then what, she has to go through this alone. Please Lord don't let me get sick.

Then she gets her stem cells back and you wait. Her counts come back up, faster than most, and she feels good. She may get to go home early. Then random fevers, but she is ok. But she can't leave until she is fever free. She finally gets to go home. Her immune system is like that of a newborn, so she can't go back to school, but she can enroll in online classes. 12 credits, she is a full time student. She is bound and determined that she is going to go to Florida for Spring Break and play softball with her team. I don't want to burst her bubble, I feel there is no way she will be ready for that. But it gives her hope, something to shoot for, something to occupy her thoughts, instead of being stuck at home in the middle of Winter.

Her blood tests continue to improve, and you start to feel like maybe she is going to be ok. But you don't want to get your hopes up because you know she still has a long way to go. You make her wear a mask if she wants to go to the store. You freak out a little every time you hear someone cough. You wipe down bathroom and kitchen counters every day with disinfectant wipes before she wakes up, because you don't want her to think you have lost your mind. Everything is going well. You keep waiting for the bottom to fall out, but it doesn't.

The Dr tells her she can go to Florida and play softball. And on the last day of games, coach puts her in, and it's after dark, and the lights come on, and she takes off her hat, and she doesn't have a hair on her head. I learned how to post on Facebook that night because I wanted everyone to see my brave, strong daughter. I have never been as proud of her as I was that night. She has one tattoo which she got when she turned 18. It is the symbol for infinity, with the word strength in one of the lines. I was very upset, but little did she know at that time just how symbolic that would be for the rest of her life.

Kelly moved out of the house for the summer and is working two jobs. So far she continues to improve. She is part of a research study, so we still make that 5 hour round trip occasionally. She just had her 6 month follow-up, and so far so good. Her prognosis is good. She continues to take some meds to ward off viruses and bacterial infections and relapses. She will be starting classes again in the fall. I still worry about her, but less and less as time passes. I know her battle is not over, but for now she is winning. We thank God for the blessings He has shown on Kelly, and we pray He continues to heal her.

Lori, Kelly's Mom

