

Germelle's Story: Sickle Cell Disease

These are called beads of courage. It is a visual reminder of procedures that our son Germelle went through and milestones that he hit. It was hard, because I was really sick.

Yellow beads represent hospital stays. The red beads indicate how many times he needed blood transfusions. This white, clear bead stands for chemo. It affected the whole household. Just a journey, a long journey, and he achieved it. It's a happy feeling, and I know he's happy.

I'm just amazed at how far he's come. His sickle cell disease was labeled as severe. It causes severe pain. It was constant pain, stabbing, pinching. It was like getting hit with a bat all the time.

So the first three years of his life was very rough. We were doing everything to help him and to keep him out the hospital, and he would still have pain crisis after crisis. It was very hard for us as a family, one of us being at the hospital, one of us being at home with our kids. He missed out on a lot.

He couldn't do normal kid things. I took our other kids to the pumpkin farm. We would go to a waterpark and he couldn't go. And then he also missed a lot of school because common colds to us would be serious for him.

I ended up researching some things because his health was declining. And I looked into a bone marrow transplant and I brought it up with his hematologist. And from there on, she connected us with the bone marrow transplant team.

And from there, we started with looking at match for him to be the donor. I ended up being the donor for my son. And the process to that is Neupogen shots, and it makes your body produce extra marrow. I injected a shot to my stomach, and I just remember feeling pain. There's no relief to it.

It was just irritating. His hair was falling out and then I start to see like the chemo, his skin start burning up. He didn't wanna FaceTime, he didn't want the nurse seeing him, he didn't want any visitors. He didn't know what depression was, but I see signs.

Watching him go through a lot of sick days, I just, I felt regretful, but I had a lot of support from the nurses. My parents would go visit him. Everybody would wanna come to the hospital. Everybody wants to come stay with him. They would call him nonstop. My oldest daughter, whenever he's sick, she would always come to the hospital. She would stay overnight. She would do whatever to comfort him.

When I saw that Germelle lost his hair, I decided to cut my hair, and I knew that that would make him feel better, and it did. I remember feeling overwhelmed, because he came home on like 16 pills, and the further he got out from transplant, he was being weaned off medication.

I remember his doctor making the decision to take him off the medication, and I just remember feeling like, "Dang, we came a long way." I know I made the right choice for my son. I remember telling him he was able to go back to school, and it was exciting, like something so simple.

Seeing the kids that he haven't seen in two years. He was happy, we were happy for him. It just was nice to see him just interact with small kids again. He's doing everything that he couldn't do before.

He screams, he runs around the house loud. Just more energy, just more excited about life. My advice would be to do your own research, educate yourself, and to be a strong advocate for your kid.

Stay strong and be brave. You just gotta go through it.