



DIAGNOSIS IS NOT A DEFINITION

Jasmine Garland shares son Sebastian's sickle cell disease diagnosis story, modeling hope for her two warrior children, and becoming the advocate she once needed.

ABOUT JASMINE GARLAND

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My name is Jasmine Garland, and I live in Powder Springs, Georgia. I am the mother of two sickle cell warriors—my 18-year-old daughter, Jazlynn, who has HbSC, and my 8-year-old son, Sebastian, who has HbSS. I work as a real estate agent and became self-employed because a traditional work schedule was not compatible with the level of care my children need. **We have faced many challenges, but we have persevered in spite of sickle cell disease, and I am very proud of that.**

LEARNING ABOUT MY SON'S SICKLE CELL DIAGNOSIS

Sebastian was born prematurely and was in the NICU when his newborn screening was completed. **Before anyone spoke with me, a provider accidentally left his electrophoresis results in the room.** Because I had already gone through this with my daughter, I understood what I was seeing: hemoglobin F and S, but no hemoglobin A. I asked the visiting pediatrician not to sugarcoat it and to tell me plainly whether they believed he had sickle cell disease. He said yes. Sebastian was only four days old, and I was alone when I found out.

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Children's
Healthcare of Atlanta



RECEIVING THE OFFICIAL DIAGNOSIS

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The hematology team explained that they would repeat the testing and confirm the diagnosis, which took about four weeks. By then, I already knew what the result would be. When the official confirmation came, the sickle cell care team handled us with compassion. They explained that Sebastian had HbSS and discussed how his experience might differ from Jazlynn’s HbSC. I appreciated the care they showed, but I also refused to begin his life in fear. **I told them, ‘Sickle cell is not a death sentence. We are not going to start his life at four days old believing that this is the end for him.’** I was shaking, but I rejected the doom-and-gloom energy. We were going to be proactive and move forward.

WHAT I WISH I HAD KNOWN

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Even as an experienced sickle cell mother, there were important things I did not know. **I wish I had understood acute chest syndrome more clearly and received earlier, more specific education about priapism.** As a new boy mom, I did not know what was normal and what could be a sickle cell complication. I had associated priapism with puberty, not very young children. Parents of boys with sickle cell disease need clear, age-appropriate information early and often—what to look for, when to act, and how to respond without shame or embarrassment.



FAMILY, HEALTHCARE, AND COMMUNITY SUPPORT

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Our mothers—Sebastian’s grandmothers—were a tremendous source of support. They prayed, encouraged us, and constantly reminded us that he was going to be okay. Children’s Healthcare of Atlanta (CHOA) also gave us useful information, including a sickle cell passport with guidance about fever, ice, emergencies, daycare, babysitters, and important phone numbers. **Outside of our family, Sebastian’s village has included CHOA, the MTS Sickle Cell Foundation, and the Sickle Cell Foundation of Georgia’s sickle cell camp.** He attended his first MTS event when he was only a few months old. That community has helped both of us feel less alone.

FROM CAREGIVER TO ADVOCATE

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For years, CHOA nurses encouraged me to share my story with other families. I kept thinking, ‘Who wants to hear from me? I am just another mom trying to make it.’ They told me that other parents and caregivers could benefit from my experience and energy. Eventually, I found ways to get involved without interfering with my caregiving responsibilities. Sometimes advocacy is simply telling another family, ‘There is an event—just come.’ **I know what it feels like to operate as an island, and it is counterproductive for everyone.** Caregivers often try not to be a burden, but carrying everything alone leads to burnout. Nobody wins when caregivers become islands.

COMMON MISCONCEPTIONS

One misconception I wish had been explained more clearly is the 25% chance of inheriting sickle cell disease. It is not one out of every four children in a family; **it is a one-in-four chance with each pregnancy.** Because I have two children with sickle cell disease, people often ask, ‘What are the chances?’ The answer is that the chance resets with every pregnancy. Educational materials are clearer today than they were 18 years ago, but we still need to keep improving how we explain inheritance to families.

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WHAT I WOULD TELL A NEWLY DIAGNOSED PARENT



Do not despair. A child born today has access to more knowledge, treatments, and possibilities than ever before, and there is more still to come. Also, be mindful of how you respond in front of your child. **They are watching you to learn how they should feel about themselves and their diagnosis.** That does not mean you cannot cry or have emotions, but do not model hopelessness. If you need to cry in the garage or the shower, do that—but in front of your child, model strength, hope, and possibility. **Do not take away their belief in their future before they have had the chance to build it.**

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HOW MY UNDERSTANDING HAS CHANGED

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Over time, I have learned to move from panic to understanding. **When Sebastian is in pain, we talk about what is happening inside his body—how the red cells may be sticking together, and what we can do to help, such as warmth, hydration, breathing, and rest.** Earlier in my journey, pain meant immediate chaos: medication, rushing, panic, and fear. Now we pause, breathe, and create calm. It does not cure the pain, but it helps him understand his body and participate in his own care. The difference in how we manage pain is night and day.

HOW SICKLE CELL CHANGED ME

Sickle cell has made me more patient, observant, and flexible. I can often see subtle signs that Sebastian needs to slow down before a full crisis develops. It also completely changed my definition of success. I once measured success by grades, career, salary, and material things. **Now success is being pain-free, eating healthy meals together, spending time as a family, sending my daughter to college feeling confident, and watching my son pursue guitar, camp, sports, and life without fear.** I do not know what next week will bring, so when everyone feels well, we live. We go to the museum on a Wednesday. We take the trip. We enjoy today.

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THE HARDEST PART

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The hardest moments are the helpless ones—when Sebastian is in pain and I cannot fix it. What makes it even harder is that he still worries about me. He will be hurting and ask, ‘Mom, are you okay?’ He wants me to call his grandmother and tell her not to worry. Seeing such a kind, pure-hearted child go through so much, while still smiling and caring for everyone else, is painful. **The hardest part is reaching the point where we have done everything we can and then having to wait for the pain to pass.**

WHAT BRINGS ME THE MOST PRIDE

I am most proud of my children’s lack of bitterness. **They have every reason to be angry, yet they continue to return to joy.** Even after hard moments, they bounce back, keep dreaming, and keep living. The world—and sickle cell disease—may try to wear them down, but joy continues to be their default. That resilience brings me tremendous pride.

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WHY I KEEP SHARING

I remember how confused and alone I felt after Jazlynn's diagnosis, and that feeling still stings. Moving to Georgia and connecting with CHOA and the sickle cell community was the first time I felt that I might not have to do this alone. **I keep sharing because there are still caregivers sitting in the dark, searching the internet, attending appointments alone, and wondering who they can trust.** If my voice can help another family find community sooner, then it is worth it. The caregivers, clinicians, researchers, and advocates doing this work all deserve to be seen and connected.

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IN ONE WORD: RESILIENCY

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Resiliency is the word that describes this journey. **Sickle cell will keep knocking you down, and you have to decide that getting back up is the only option.** It is not simply about whether you can; it is about deciding that you will. I have tried to model that for my children in caregiving, business, and life. Sickle cell was not going to stop us from reaching for our dreams. I want them to learn to care for their bodies, believe in themselves, and keep moving forward.

WHAT BEING A SICKLE CELL PARENT MEANS TO ME

Being a sickle cell parent means modeling both perseverance and self-care. I want my children to see me striving, but I also want them to see that I have boundaries and take care of myself. I cannot teach them to protect their health if I am constantly burning myself out. One day they will look back at how I handled this journey. I want them to remember that I gave my best, kept going, and also knew when to put on my own oxygen mask.

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MY CHILD'S DIAGNOSIS TAUGHT ME...

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Diagnosis is not a definition. A diagnosis does not define who a person is. My children both live with sickle cell disease, but they are completely different people with different personalities, interests, triggers, strengths, and dreams. We cannot define any warrior by a medical label. Each person is unique.

WHAT GIVES ME HOPE TODAY

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Seeing adults with sickle cell disease living into their seventies and eighties gives me hope because it challenges the limited life expectancy I heard about growing up. **Research, new therapies, gene therapy, and seeing warriors become parents, professionals, and even pilots give me hope.** Sebastian is now being considered for gene therapy—something we once thought was years away. The advances already here, and the possibilities still coming, give me hope for his future.

CLOSING REFLECTION

I am grateful for the opportunity to share our story and contribute to this work. **My prayer is that it travels far and wide and creates real impact.** If walking around with a megaphone would get the job done, I would do it. Sometimes we cannot make everything perfect; we simply do what we can. I am thankful to be able to do my part.

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HOPE LIVES HERE



Jasmine's story reminds us that while sickle cell disease brings challenges, no family has to face it alone. There are trusted resources, caring professionals, and a strong community ready to walk alongside you.

LOOKING FOR INFORMATION OR SUPPORT?

You're Not Alone.



Children's
Healthcare of Atlanta

Children's Healthcare of Atlanta
Sickle Cell Clinic

404-785-1200

choa.org/scd



AUGUSTA
UNIVERSITY

Augusta University Pediatric
Sickle Cell Clinic

706-721-0174

augusta.edu/mcg/pediatrics/hemoc-oncol



MTS Sickle Cell Foundation

Community support • Transportation
assistance • Family resources

mythreesicklers.org



Sickle Cell Foundation of Georgia

Education • Support
Community programs

sicklecellga.org



sickle cell
information center

Sickle Cell Information Center

Clear, accessible information about
sickle cell disease for all.

scinfo.org