Let’s Talk About Sickle Cell Disease

September 19, 2014 By Cyntra Scott

I have procrastinated far too long contemplating the “perfect way” to begin this important blog that I’ve named Sicle Cell Savvy. Within the past three months three beautiful individuals I had the pleasure to know have passed away from complications due to sickle cell disease (SCD). Sydney, age 33, and Paradise, age 19, died similarly, unexpectedly at their homes. Then Margaret, who was a little older than age 60, went into the hospital for a sickle cell crisis, experienced complications and five days later passed away. That’s why I’m launching this blog now because there’s no time to waste.
This blog is my effort to educate and inform you about sickle cell disease. My blog will also serve as a forum to discuss the many issues that surround living with SCD and caring for those living with the illness.

In the 1970’s, individuals with SCD rarely reached the age of 30. But today, because of medical advances, the life expectancy for those who have the illness has increased greatly.

SCD affects 1 out of every 500 African Americans. But SCD doesn’t only impact African Americans, the illness also affects other population groups throughout the world.
One out of 12 African Americans are born with the sickle cell trait. I shall explain the genetic side thoroughly in another blog. But if you conduct a Google search about sickle cell trait, or SCD, you’ll find a wealth of information. Two great websites are the SCDAA website and the Boston University’s Center of Excellence in Sickle Cell Disease website.
I have sickle cell thalassemia (one of the types of SCD). I am a 41-year-old woman who is a substitute teacher and freelance writer living with sickle cell and I have learned many ways to manage the illness when I get sick and when I’m well.

Certainly, living with any chronic illness is a challenge that’s most often taxing and stressful for the individual. But having SCD presents the same challenges that also includes many unique obstacles and issues requiring great amounts of strength. Sydney, Paradise and Margaret exhibited this strength throughout their lives. For example, planning for the future, even a week away, can be tricky because you can’talways determine when you will find yourself in a sickle cell pain crisis.

I’m pretty sure many people have heard about the infamous “sickle-cell crisis.” Essentially, SCD occurs during periods (days to weeks) of painful episodes. These episodes are characterized by excruciating, make-you-break down-and-cry-like-a-baby, all-out, cannot-imagine-any-worse-kind-of pain. The pain can be felt in any part of the body where blood flows, which is everywhere.

Often pain from SCD is around the joints, shoulders to hip and elbows to ankles. The pain is caused by the “sickle-shaped” cells clumping together and causing blockages within the blood vessels, which prevents normal blood flow. The pain of this sickle cell crisis is extremely hard to endure once much less over and over again.

In addition, sickle cell disease generates a host of potential complications, such as organ damage, leg ulcers, difficulty breathing, a condition called acute chest syndrome, pulmonary embolisms, necrosis, or cellular death, of the bones and risk of strokes.
When I was diagnosed with SCD, I was almost two years old. The pediatricians told my parents that I would most likely be crippled by age 4 and dead by age 8. Clearly, they were wrong.

Now, decades later, I have benefited from the chemotherapy drug hydroxyurea, which the FDA approved for use in sickle cell patients after clinical trials proved successful. Until my early twenties I had frequent pain crises at least twice each month. But after I began taking hydroxyurea, I only got sick once every two months. This made a huge difference in my quality of life and I was able to plan more and do more.

With this blog I invite everyone to correspond, give feedback, express thoughts and feelings, ask questions and get answers. I will do my best to bring rays of positivity and encouragement through profiles of some extraordinary individuals who are living with SCD.
My goal is to expand the awareness of this crippling disease and inform, inform, inform!
If you have sickle cell, care for children with sickle cell or love someone who has SCD, “Living Well with Sickle Cell” can prove a valuable resource for you.

Thank you Sydney for your laughter and serenity.

Thank you Paradise for your vibrant spirit, fortitude and precious smile.

Thank you Margaret for your empowerment, energetic spirit and positive and kind nature.

I add these memories to my toolbox to manage my sickle cell condition.

Here’s this month’s blog question: Have you lost a family member or friend to sickle cell disease? Please share your memories.

Enrich, Empower, Encourage, Enhance
Be Well. Be Wonderful.

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