

The Monthly Flow

THE OFFICIAL NEWSLETTER OF SICKLE CELL FOUNDATION, INC.



What's New

A WORD FROM THE EDITOR

.....

MEET A WARRIOR

.....

COMMUNITY VOLUNTEERING



Meet A Warrior
 Advice -
 from



Josef Johnson

Who you are and where are you from?

"I am from Tallahassee, Florida born and raised."

What do you currently do in the community?

"I am a Mortgage Loan Officer, I help individuals and families purchase real estate. From finding and viewing homes or refinancing theirs. I also have a background in finance. It truly is a great experience I enjoy every day. To be a part of the smiles on their faces once they get to a closing table is an awesome feeling that's what I love and am passionate about. Anything mortgage real estate, that's what I love to do."

At what age were you diagnosed with Sickle Cell Disease?

"I was diagnosed at birth, I knew all my life I had Sickle Cell Disease. I have a sister that has Sickle Cell Disease as well."

How is living with Sickle Cell for you now?

"When I was a kid growing up, having Sickle Cell was really tough. I was experiencing a pain crisis back to back. It sort of affected me pretty badly. I couldn't participate in a lot of the activities I saw my friends experience, even traveling was limited. I was always limited on what I could do. My parents sort of sheltered me a little bit because of the Sickle Cell. I sort of lived in a bubble, but I never let that stop me from reaching the goals I had growing up and where I am today. As I got older the Sickle Cell symptoms got better for me. I started taking care of myself, drinking a lot of water, trying to work out a little when I can, being stress-free as possible which is hard at times with what I do every day. I just try to take care of my body, say my affirmations, and my prayers. I thank God I haven't been hospitalized. Honestly, I don't know how long. So, yeah it's awesome I can't complain."

What has the Sickle Cell Foundation, Inc. done for you?

"So, right as I was wrapping up high school, the Foundation helped me dual enroll at Tallahassee Community College at the time. The Sickle Cell Foundation is very active in the community and I love that. A lot of people don't know about Sickle Cell or what it is so I appreciate the Foundation being in Tallahassee and trying to spread awareness for the disease because it does affect a lot of us."

What tips would you give those living with sickle cell?

"Just keep your head up, I know it can feel discouraging at times. I know it's tough, the crisis are unbearable at times but honestly keep your head up, stay prayed up. The main things I would suggest are to take care of your body, drink as much water as possible, and try to do a little bit of working out. Whether it's walking in the neighborhood, nothing too drastic, do some grounding, you know I do that sometimes. Just go outside and put your bare feet in the grass and just take advantage of that because that does help us as well. And continue to chase your dreams, don't let it discourage you, and hopefully what I say will help others out there."





Volunteers have served a vital purpose and have done so in roles ranging from office administrative duties to community health fair events. But volunteering with the Sickle Cell Foundation, Inc. doesn't just help us fulfill our mission. Volunteering is a great way to network with others in the community.

We can always use extra hands!

The importance of volunteers cannot be over-emphasized, for it is the collective effort of our volunteers, staff, and donors that enables us to offer essential services to the Sickle Cell community. There are so many meaningful ways to get involved with The Sickle Cell Foundation, Inc., and volunteering your time is one of those ways. Volunteer service is truly an important contribution to our mission here at the Sickle Cell Foundation, Inc.

Volunteers are screened and interviewed; will receive training and evaluations; and assist through various areas, as needed.

If you would like to join our volunteer team or have questions, please email *Carissa Hunter* our *Community Outreach Director* at: carissa@sicklecellfoundation.org or call 850-222-2355



SCD TOOLBOX

Preschool Pain Management Program

Preschool Pain Management Program Letter of Invitation

Thank you for your interest our program! This program helps caregivers learn behavioral pain management strategies with information, examples, and tips provided through online videos and supporting materials. The program is designed to be completed in approximately six to twelve weeks based on how quickly you are able to finish watching the videos. The program is based on strategies that have been used successfully by a broad range of parents all over the world and informed by the perspectives of 50+ parents of young children with sickle cell disease who shared their needs and preferences with us.

In addition to the pain management program, we are continuing to make this program better. If you decide to participate, you will be asked to complete surveys for our program evaluation. We will send a thank-you gift for each evaluation survey. There is an eligibility survey to get started. If you are eligible to participate, you will then be asked questions about your family, your child, their pain history, and how you respond to your child's pain. After watching videos in the program, you will also be asked to complete online surveys about the quality of the videos a brief phone interview about your thoughts on the behavioral pain management skills. In addition to improving the program, this information is important for us to promote wider use of effective strategies- most parents have told us this information is not provided through their child's sickle cell care.

Here is how you can participate:

Step 1: Complete a brief eligibility survey. The program is designed for parents or caregivers of children with sickle cell disease 2 to 5 years of age who have had a pain episode. Regular access to a cell phone, computer or tablet, and WiFi/internet access is also needed to participate. **Step 2:** Complete a phone or Zoom conversation with the project coordinator, Julia Johnston, about your child's pain history and watch an introduction video. This should take no longer than 30 minutes. **Step 3:** Complete an online survey about your family, your child, their pain, and how you respond to your child's pain. **Step 4:** Watch six videos over 6-12 weeks (at your own pace) about helping your child with sickle cell disease manage their pain. Each video is between 10-15 minutes long. **Step 5:** Following each video, text Julia at (803)-386-1884 to let her know you have finished watching the video and complete a 5-minute survey online to tell us what you thought about the video. **Step 6:** One week after watching each video, there is a phone questionnaire asking about the skills that you learned in the video. This questionnaire can be completed in fewer than 15 minutes. **Step 7:** After watching all of the videos in the program, you complete final program evaluation measures through an online survey.

Your participation in the program and completing our surveys is voluntary. You can choose to not answer questions or withdraw from the program at any time. Participation is confidential. The survey information does not include information that identifies you and will be kept in a secure location at the University of South Carolina. The results of the surveys may be published or presented to people interested in pain management, but your identity will not be revealed as a participant.

You can receive **up to \$85.00** for completing surveys. You will receive \$5 for completing the first phone interview and \$10 for completing the first online survey. You will receive \$5 for every post-video online survey and \$5 for every post-video survey for a total of \$75. You will receive \$10 for completing final program evaluation survey completed after you watched all of the videos.

We will answer any questions you have about the project! You may contact me, Julia Johnston, at (803)-386-1884 or by email (jdj9@email.sc.edu). You can also contact Jeffrey Schatz, the psychologist who helped develop the program and who is responsible for the integrity of the program and program evaluation work: phone: (803)-434-3513, or email: (schatzj@mailbox.sc.edu).

If you would like to participate, please contact Julia at (803)-386-1884 or by email (jdj9@email.sc.edu).

Warm regards,

Julia Johnston (803)-386-1884
jdj9@email.sc.edu

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A Word From The Editor

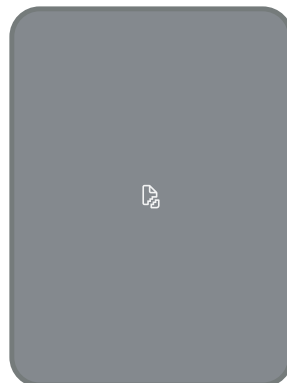
by Carissa Hunter, HHP.
Community Outreach Director & Social Media Strategist

"Building the Vision"

Dear Reader,

Being a part of the Sickle Cell Foundation has been an amazing opportunity. To share the space to collaborate my love for holistic healthcare and social media truly has been an honor. The Foundation has allowed me to combine my passion for not only holistic health and wellness but also my love for the art within my profession- this encompasses writing, photography, and content creation. Let me share a little bit of who I am. I am originally from Leesburg, Florida, but I was raised in North Florida. After finishing grade school I moved to South Carolina, then to Georgia. Over a span of 7 years, I spent time as a Medical Assistant in mainstream healthcare clinics from Primary Care, Orthopedics, Sports Medicine, Neurology, and surgery centers. I am a Sickle Cell trait carrier as well as a parent and primary caregiver to my 3-year daughter who lives a healthy life with Sickle Cell Anemia Type HbSS.

Shortly before my daughter was born in year 2017, I struggled with antepartum depression, CPTSD, and Hyperemesis Gravidarum throughout my pregnancy. I battled suicide, many hospitalizations, postpartum depression, infant and child loss, and birth trauma. I eventually decided to harvest that pain from my own experience into my art and passion within healthcare so that I can help others. It really brought me peace and hope for my own journey to self-empowerment and healing.



In 2017, I created what is now called "*Healing Journey Intuitively*" dedicated and named after my daughter *Journey*. It all started with my own mental health journey, so I wanted to weigh in on that awareness for others also. I went from handcrafting jewelry, formulating aromatic and herbal products from my online store to now offering clinical and individualized holistic health services. As I prepped for my daughter's birth that same year I decided to step away from mainstream healthcare and return back to school and focus on Complementary Alternative Medicine. I realized in my experience there was a lack of holistic health modalities offered in the health community. I truly wanted to join others and change the narrative hoping to one day see both conventional and alternative medicines work together.

Along with my role at the Sickle Cell Foundation, Inc., I am a Holistic Health Practitioner, Birth & Bereavement Doula specializing in clinical herbalism, aromatology, energy and bodywork, and sound healing. I am truly thankful I get to share my gifts with others, involve my own family, and do my best at guiding, educating, and speaking up on sensitive topics most just avoid or are afraid to discuss and acknowledge in reference to natural healing and living with Sickle Cell Disease, or LGBTQ+ community, as well as issues of public health and racial justice mistreatment in healthcare. I hope to honor, empower and inspire others to tap into that same power in themselves.



The Sickle Cell Foundation, Inc. was organized on February 21, 1980 at the office of the Tallahassee Urban League. Upon installation of the newly organized foundation, an official charter was issued and later received nonprofit organization 501(c)(3) exempt status. There are sixteen (16) chapters in the State of Florida. The Sickle Cell Foundation, Inc. is the only local agency serving District II providing services to the following counties: Leon, Jefferson, Wakulla, Madison, Taylor, Gadsden, and Jackson counties.



Walk- In or by appointment for
FREE Sickle Cell Trait Screening



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