Sickle Cell Partners of the Carolinas Presents

Sickle Cell Partners of the Carolinas

Awareness Support Cure

Sickle Cell Disease

"let's talk about it"

day conference

Saturday, September 21, 2019 • 9 am to 2 pm

Friendship Missionary Baptist Church Conference Center

Sickle Cell Partners of the Carolinas

Awareness Support Cure

Sickle Cell Partners of the Carolinas

Greetings "Sickle Cell Disease… Let's Talk About It" Attendees!

On behalf of Sickle Cell Partners of the Carolinas, I welcome all of you to our 5th annual conference, "Sickle Cell Disease… Let's Talk About It!" As chair and a founding member of this non-profit organization, I invite you to engage, explore, and feel empowered knowing that you are not alone living with sickle cell disease. You are also not alone in caring for someone who lives with sickle cell disease. Sickle Cell Partners of the Carolinas hopes our day conference – YOUR – day conference gives patients and families a platform for an open discussion on their health and well- being living with sickle cell disease.

The focus of "Sickle Cell Disease… Let's Talk About It" this year is emotional well-being and the resilience of patients and families who live with this hereditary illness. Sickle cell disease hurts in many ways physically and emotionally. Many of us know how painful it can be. Our goal this year is to help you manage and maneuver through those times that may be overwhelming. With any chronic illness, we all need help coping emotionally. Patients and families often experience depression or feel the stigma associated with sickle cell disease because oftentimes, it is a misunderstood illness. Don't let that get you down, remain strong.

Please know there are tools available to you. Start that conversation… do not be afraid to ask your caregiver, a social worker, a community organization, or your family for help when it gets difficult. We are here for you! You can thrive living with this illness and we want to make sure you have what you need to do that. Knowledge is power. It is our sincere hope that the keynote address delivered today and the various sessions throughout the day bring better understanding for patients and their families who live with sickle cell disease.

Sickle Cell Partners of the Carolinas is dedicated to its mission to provide a network of support for patients and families affected by Sickle Cell Anemia; to raise awareness and educate the community; and to advocate for a cure. We need you on our team! Everyone's journey living with sickle cell disease takes a different path. This is where our paths cross so let's work together. We welcome your ideas, comments and your input. We have "partners" in our name because we cannot do it alone.

Thank you for attending "Sickle Cell Disease… Let's Talk About It" and our sincere gratitude to our conference facilitators for providing information and insight during their sessions. As you spend your day with us, Sickle Cell Partners of the Carolinas invites you to engage sincerely, uplift powerfully, and advocate strongly on behalf of patients and families affected by this condition. "Sickle Cell Disease… Let's Talk About It!"

Warmest Regards,

Dagny McDonald, Chair

Sickle Cell Partners of the Carolinas

AWARENESS SUPPORT CURE

P.O. Box 480714 Charlotte, NC 28269 sicklecellpartners@gmail.com sicklecellpartnersofthecarolinas.org

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City of Charlotte, North Carolina
Proclamation

WHEREAS, Sickle Cell Disease is among the most common genetic disorders in the United States and affects thousands of patients across North Carolina, an estimated tens of thousands across the United States, and millions more worldwide; and

WHEREAS, Sickle Cell Disease is a complex inherited blood disorder characterized by chronic anemia; episodes of debilitating pain; infections; bone deterioration; disability; damage to vital organs; and in some instances, death; and

WHEREAS, Sickle Cell Disease is a chronic but treatable health condition although there is no single best treatment for people with Sickle Cell Disease, treatment options vary for each patient depending on symptoms which can be from mild to severe; and

WHEREAS, support for research and continual understanding on the treatment and management of Sickle Cell Disease, as well as overall awareness, are vital to improving the quality of life for persons with Sickle Cell Disease; and

WHEREAS, Sickle Cell Partners of the Carolinas is a support group formed to provide a network of support for patients and families affected by Sickle Cell Anemia, to raise awareness and educate the community, and to advocate for a cure; and

WHEREAS, the conference "Sickle Cell Disease…Let's Talk About It" will include discussions for patients and families to promote optimal living and care for patients affected by Sickle Cell Disease, and promote more awareness and understanding for the community-at-large; and

WHEREAS, Sickle Cell Partners of the Carolinas in collaboration with major medical centers, regional educators and counselors, local health departments, blood banks and community-based programs are committed to raising the level of awareness to help meet the needs of Sickle Cell patients; and

WHEREAS, the faces of those affected by Sickle Cell Anemia across the world are many and vast and where an opportunity will be provided today to come together and have conversations to discuss the needs and concerns facing many patients and families battling Sickle Cell Disease; and

WHEREAS, Sickle Cell Partners of the Carolinas envisions a world that will one day be free of Sickle Cell Disease and other related inherited blood disorders and where an open, honest and continuing dialogue for a cure will continue for those who suffer from Sickle Cell Disease:

NOW, THEREFORE, I, Vi Alexander Lyles, Mayor of Charlotte, do hereby proclaim September 21, 2019 as

"SICKLE CELL PARTNERS OF THE CAROLINAS DAY"

in Charlotte and commend its observance to all citizens.

WITNESS MY HAND and the official Seal of the City of Charlotte.

Vi Alexander Lyles
Mayor

Selena Webster-Bass, MPH
Voices Institute, LLC
CEO/LEAD INNOVATOR
Sickle Cell Disease Advocate: Passages from Pain to Purpose

Selena Webster-Bass, M.P.H., is a Jacksonville, Florida native with more than 20 years of experience in cultural competency, health equity and community health. Selena has an undergraduate degree in Biology from the University of North Florida and a Masters of Public Health from the University of South Florida. She has facilitated over 200 professional learning and community-based health education sessions with health and human services professionals, organizational leaders and the general community-at-large.

She has worked in a variety of professional settings as Community Medicine Director with the pediatrics and family medicine residency programs at UF/Shands Jacksonville, Manager of the Pediatric Sickle Cell Clinic at Shands Jacksonville/ Nemours Children's Clinic, Adjunct Professor at University of North Florida – College of Public Health, Science Teacher at Northwestern Middle School and developing national disease education campaigns for pharmaceutical companies focusing on multicultural populations. Recently, Selena Webster-Bass served over five years with the Jacksonville System of Care Initiative as the Mental Health and Cultural Competency Educator.

In 2016, she launched *The Voices Institute*; a premiere training, curriculum development, public speaking and research firm focused on multicultural consciousness, health equity and well-being. Selena facilitates on a variety of topics; sickle cell disease/trait education, health equity, mental health literacy and spiritual development with faith-based partners. She is a core partner and consultant with the Substance Abuse and Mental Health Services Administration (SAMHSA) National Technical Assistance-Cultural and Linguistic Competency Team, the National Sickle Cell Disease Association of America and The Partnership for Child Health. Certified in Adult and Youth Mental Health First Aid, she trains with a variety of community organizations.

Selena shares her personal message ***Passages: From Pain to Purpose*** as a caregiver of a child with sickle cell disease, Richard Webster-Bass, who transitioned due to SCD complications (sepsis anti-resistant streptococcal infection) in 1999. A soulful encourager, motivator and advocate Selena brings a message of *health, hope and healing* to families overcoming sickle cell disease. Co-authors Selena and her brother, F. Anthony Webster who has a daughter, Fredrianna Webster, with SCD are launching a children's book, ***Rainbows***, a book of hope and SCD awareness.

Selena Webster-Bass is eternally tied to her husband, Circuit Court Judge Lester B. Bass and they have four wonderful children: Spencer, Trinity, Micah and Richard in spirit. Her life statement is: "We must be the change, we want to see in the world."– Gandhi

We are one world, many voices – Amplifying and equipping the voices of the voiceless.

"SICKLE CELL DISEASE…. LET'S TALK ABOUT IT"

SATURDAY, SEPTEMBER 21, 2019

FRIENDSHIP MISSIONARY BAPTIST CHURCH CONFERENCE CENTER

CONFERENCE AGENDA

General Session:

9:00am to 9:30am	**Registration and Vendor Opportunity**	**Lobby**
9:00am to 9:30am	**Continental Breakfast**	**Conference Room A**
9:30am to 9:45am	**Welcome and Opening Remarks** Dagny McDonald, Conference Host Chair, Sickle Cell Partners of the Carolinas Sandra Boyd, MA, Sickle Cell Program, Division of Public Health, NC Department of Health and Human Services	**Conference Room A**
9:45am to 10:00am	**Yoga Mini Session** Kiesha Battles, 500 ERYT and Candace Jennings	**Conference Room A**
10:00am to 10:10am	**Break and Vendor Opportunity**	**Lobby**

Conference Agenda

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Friendship Missionary Baptist Church

"SICKLE CELL DISEASE… LET'S TALK ABOUT IT"

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AWARENESS SUPPORT CURE

Round One Conference Sessions: **(Adult participants choose one to attend)**

10:15am to 11:00am	**Let's Talk: Bone Marrow Transplant and Cure Options** Michael Kent, MD, Pediatric Hematology and Oncology, Pediatric Blood and Marrow Transplantation, Atrium Health	**Conference Room A**
10:15am to 11:00am	**Let's Move: "Dare to Chair… Yoga"** Kiesha Battle, 500 ERYT and Candace Jennings	**Room 133**
10:15am to 11:00am	**Let's Talk: Sickle Cell Disease… How Can CMS Support Your Child?** Dr. Harriet Ford, PhD, Section 504 and Homebound Program Specialist Dr. Yolanda P. Holmes, Community Partnership & Family Engagement Toni Rios, Exceptional Children Technology Coordinator	**Room 135**
10:15am to 1:00pm	**Let's Donate: One Blood Bloodmobile**	**Conference Room C**
101:15am to 11:45am	**Let's Watch: "Spilled Milk," Documentary Film** A film about Omar who lives with sickle cell disease and Jaqai, his friend who makes a documentary about him.	**Room 125**

Morning Pediatric Session: **(All pediatric participants attend)**

10:15am to 11:55am	**Pediatric Playroom** Let's Talk: "The Big Rig Kids Deal with Bullying" Balloon Twisting and Gaming Fun	**Room 139**
11:00am to 11:10am	**Break and Vendor Opportunity**	

Conference Agenda

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Round Two Conference Sessions: **(Adult participants choose one to attend)**

11:10am to 11:55am	**Let's Talk: Vocational Rehabilitation and Employment Services** Chanda Daye Griffin, MS, CRC Michelle Perry, MS, CRC, NC Dept. of Health and Human Services	**Conference Room A**
11:10am to 11:55am	**Let's Talk: Managing Life's Interruptions: Cultivating Emotional and Social Well-Being of Families Affected By Sickle Cell Disease** Selena Webster-Bass, MPH CEO/Lead Innovator, Voices Institute	**Room 135**
11:10am to 11:55am	**Let's Talk: REIKI, A Natural Treatment to Reduce Pain, Anxiety, Sleep Issues, & Support Deep Relaxation Without Negative Side Effects** Miri Klements, Reiki Master Teacher and Medical Reiki Master	**Room 139**
11:55am to 12:05pm	**Break, Vendor Opportunity, Special Guest Appearance**	
12:10pm to 1:30pm	**Luncheon and Keynote Address** Passages, A Sickle Cell Journey: From Pain to Purpose Selena Webster-Bass, MPH CEO/Lead Innovator, Voices Institute	**Conference Room A**
1:30pm to 1:45pm	**Closing Remarks and Surveys**	

Participant Survey Says….
Comments on 2017 "Sickle Cell Disease… Let's Talk About It"

"Great experience. I learned so much!" **"Awesome Event!"**

"Fantastic Event." ***"Thank You!"*** "Glad to be a part of it." **"I learned so MUCH!"**

"Glad to be a part of the event." "OUTSTANDING!" "Such a great event."

"Honored for the opportunity to present to patients and caregivers."

In Memory

To those we love affected by sickle cell disease who have transitioned…. Peace.

Sickle Cell Partners of the Carolinas

Awareness Support Cure

AWARENESS… SUPPORT… CURE!

SCPOC Events Raising Awareness About Sickle Cell Disease

Tee Up for Health with Steve Smith and the Steve Smith Foundation at Top Golf. -- September 2019

Wells Fargo Red Lights for Sickle Cell Awareness on World Sickle Cell Day, June 19, 2019.

Awesome tee shirts provided by Sickle Cell Partners of the Carolinas to the staffs at Atrium Health and Novant Health in honor of World Sickle Cell Day 2019. It's an example of SCPOC's partnership with hospital teams to support patients and families affected by sickle cell disease and to raise awareness about this hereditary condition. -- June 2019

Sip & Paint for adults. --March 2019

AWARENESS… SUPPORT… CURE!

SCPOC Events Raising Awareness About Sickle Cell Disease

World Sickle Cell Day
Ice Cream Social.
– June 2019

Novant Health's Blume Clinic. – June 2019

Red carpet event for "Spilled Milk," a documentary film about life-long friends Jaqai & Omar. Omar lives with sickle cell disease and Jaqai documents his life on film. – February 2018

Sickle Cell Partners of the Carolinas Beckwith Scholarship

Sickle Cell Partners of the Carolinas continued its annual tradition in 2019 of awarding two scholarships to students living with sickle cell disease who are continuing their education at an accredited college, university or trade school.

The Beckwith Scholarship is named in honor of Mrs. Ivestia "Peggy" Beckwith to honor her commitment to the sickle cell community. Mrs. Beckwith was instrumental, along with others, in securing a federal grant in 1972 that established the Mecklenburg County Sickle Cell program which spanned several North Carolina counties. The blueprint of that program remains in operation across the state.

Sarah Joergensen

Shayna Smith

Since 2015, Sickle Cell Partners of the Carolinas has awarded **twelve (12) scholarships totaling $6,000** to deserving students living with sickle cell disease and continuing their education at an accredited college, university or trade school.

For more information, an application or if you would like to contribute to the Beckwith Scholarship, designed to assist students living with sickle cell disease, please email sicklecellpartners@gmail.com.

2019

UNIVERSITY CITY

Turkey Trot 5k

THANKSGIVING DAY

NOV. 28, 2019 8:00 AM

WAKE... RUN.... FEAST!

3024 PROSPERITY CHURCH ROAD CHARLOTTE, NC

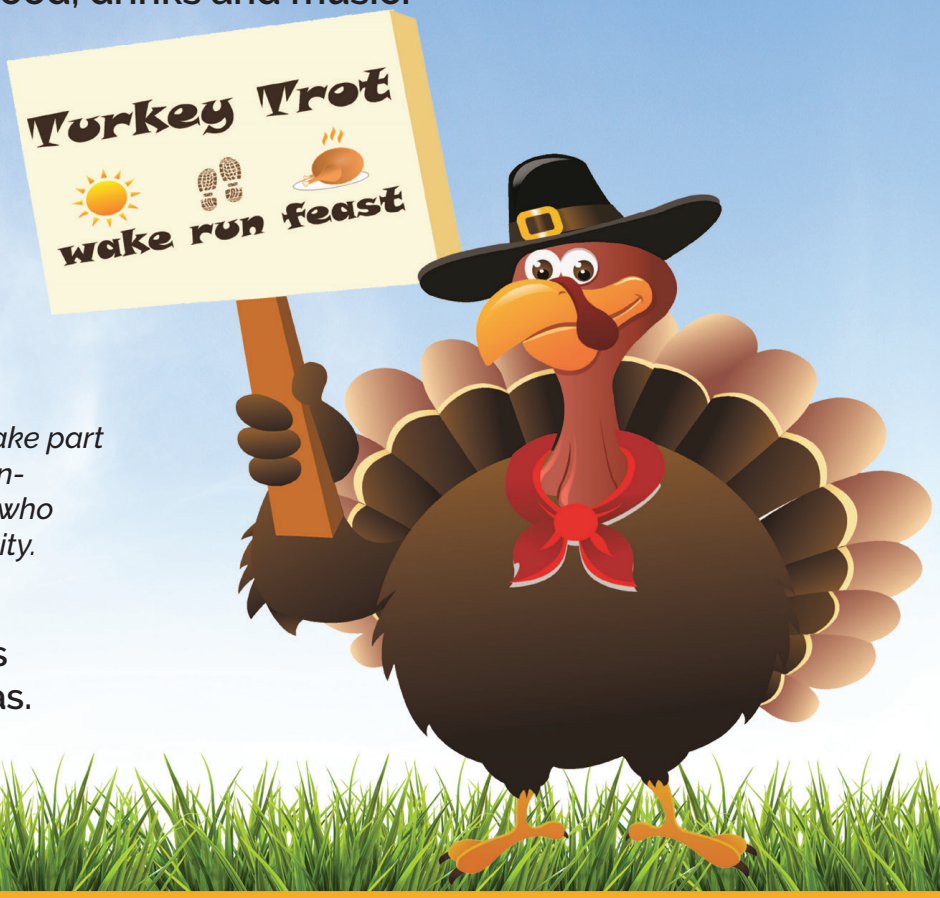
The University City Turkey Trot is a 5K race/walk sponsored by Sickle Cell Partners of the Carolinas on Thanksgiving Day.

Join fellow runners and walkers Thanksgiving Day for the 6th annual race designed for all of University City to enjoy!

After the race, cool down and enjoy a post-race mini-feast featuring food, drinks and music!

FEATURING:

- **5k Walk/Run**
- **One Mile Kid's Fun Run**
- **Costume Contest with Prizes**



FOOD DRIVE

Participants are encouraged to take part in our food drive by bringing a non-perishable item to support those who are less fortunate in our community.

Participation in this event supports Sickle Cell Partners of the Carolinas.

Runsignup.com/race/NC/Charlotte/UniversityCityTurkeyTrot5K

5 FACTS YOU SHOULD KNOW
ABOUT SICKLE CELL DISEASE

A child gets sickle cell disease (SCD) when he or she receives two sickle cell genes*—one from each parent.

A child who inherits only one sickle cell gene has sickle cell trait (SCT). If both parents have either SCD or SCT, it is important for them to discuss this information with each other and with a doctor when making decisions about family planning.

*Genes, which are passed down from a parent to child, are instructions in each of our cells that determine a person's traits such as eye color, blood type, and risk of disease.

SCD has many faces.

The disease affects millions of people worldwide and is especially common among people who come from and whose ancestors come from the following regions highlighted in red:

SCD can be cured for certain patients.

A bone marrow transplant, which involves collecting healthy cells from a donor's bone marrow and transferring them into a patient, can cure SCD. However, a bone marrow transplant may not be the best choice for all patients because it comes with serious risk. A bone marrow transplant expert can advise patients about whether or not it is a good choice for them.

Anemia is a common effect of SCD, but it can be treated.

In someone with SCD, red blood cells die early and not enough are left to carry oxygen throughout the body, causing anemia. Infection or enlargement of the spleen, an organ that stores red blood cells, may make anemia worse. Blood transfusions are used to treat severe anemia.

A person with SCD can live a long and high quality life.

More than **95%** of newborns with SCD in the United States will live to be adults. People with SCD can lower their chances of difficulties from the disease and enjoy many normal activities by

✓Getting regular checkups with their doctor.

✓Following treatments prescribed by their doctor, such as taking medication called hydroxyurea.

✓Preventing infections by taking simple steps including washing their hands.

x 8

✓Practicing healthy habits like drinking 8 to 10 glasses of water per day and eating healthy food.

For more information about SCD, visit: **www.cdc.gov/ncbddd/sicklecell**

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

CS267164A

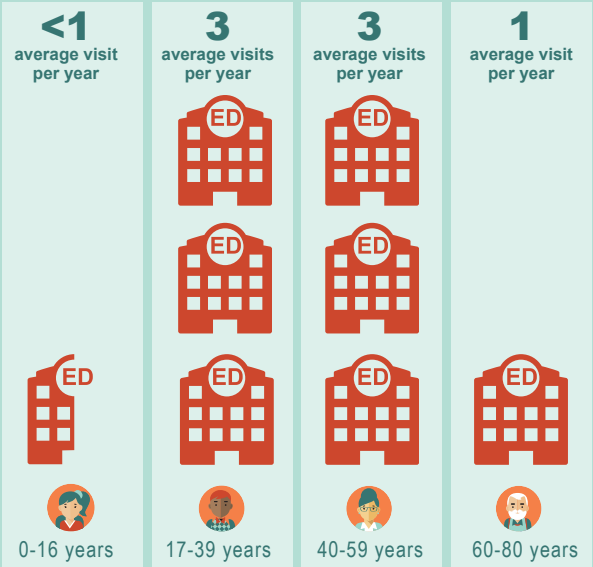
DO YOU USE THE EMERGENCY DEPARTMENT FOR CARE OF SICKLE CELL DISEASE?

WHAT TO KNOW BEFORE YOU GO.

Children and adults with sickle cell disease (SCD) often require care in the emergency department (ED) of hospitals or clinics for health issues related to SCD. The ED may be your only option for health care when symptoms, such as pain crises, cannot be managed at home or when you do not have access to a healthcare provider who specializes in treating SCD.

The Sickle Cell Data Collection (SCDC) program found that in California, people with SCD seek care in the ED an average of three times a year from their late teens to their late 50s. *Excruciating pain, known as a sickle cell crisis, is the most common reason for these ED visits.*

Emergency Department (ED) Visits Among People with Sickle Cell in California, 2005-2014



Tips for receiving better care in the ED

Before you get sick or have a pain crisis, work with your regular doctor to

- Make sure that information in your electronic medical record (EMR) is updated, including your medical history and current pain medicines.

- Create a pain management plan and make sure it is entered into your EMR. Keep with you a printed copy of the plan and a list of all your medicines.

When you go to the ED

- Tell the ED staff right away that you have SCD.
- Share openly with your ED nurse and doctor

  - Your medical history, including a list of your medicines.
  - Your pain management plan. Ask the ED nurse or doctor to look up your plan in your EMR or share a printed copy.
  - Your regular doctor's contact information. If the ED nurse or doctor has concerns about your pain management, ask the ED staff to call your regular doctor.

PROTECTING PEOPLE

CDC's National Center on Birth Defects and Developmental Disabilities is committed to protecting people and preventing complications of blood disorders. Learn more about CDC's work to help people with SCD here: www.cdc.gov/ncbddd/sicklecell

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

SCDC
Sickle Cell Data Collection

"Sickle Cell Disease… Let's Talk About It" Conference Notes

Atrium Health employees sport their tee-shirts provided by Sickle Cell Partners of the Carolinas to Celebrate World Sickle Cell Day. – June 2019

“Sickle Cell Disease…. Let’s Talk About It”
Conference Notes

Sir Purr and conference attendees. September 2017

“Spilled Milk” Documentary viewing at the Epicenter
Charlotte. – February 2018

Sickle Cell Partners of the Carolinas

Awareness Support Cure

Sickle Cell Partners of the Carolinas

RESOURCES:

Atrium Health – **www.atriumhealth.org**

Be the Match – **www.bethematch.org** **800-627-7692**

Centers for Disease Control and Prevention – **www.cdc.gov**

Charlotte Mecklenburg Schools – **www.cms.k12.nc.us/cmsdepartments/ec**

North Carolina Sickle Cell Syndrome Program – **www.ncsicklecellprogram.org** **1-866-627-2355**

Novant Health – **www.novanthealth.org**

Novartis Pharmaceuticals – **www.novartis.com**

One Blood – **www.oneblood.org** **704-972-4700**

Sickle Cell Disease Association of America – **www.sicklecelldisease.org**

Sickle Cell Partners of the Carolinas – **www.sicklecellpartnersofthecarolinas.org**

Sickle Cell Partners of the Carolinas Conference Planning Team:

Kia Hilton, Eddie Love, Shapera Love, Dagny McDonald, Hans McDonald, Bettye Monroe, Montae Monroe,

Nilda Navedo, Tammy Sherrod, Kathy Staley

This program could not exist without the help of some very important entities. We offer our sincere appreciation to Friendship Missionary Baptist Church for the use of their facilities. We thank KSD Events for their awesome design ideas and making the Sickle Cell Disease… Let's Talk About It" conference exhibits come to life. We are very grateful to our donors who openly donate and anonymously donate to Sickle Cell Partners of the Carolinas.

Our Mission:

We seek to provide a network of support for patients and families affected by Sickle Cell Anemia; to raise awareness and educate the community; and to advocate for a cure.

AWARENESS SUPPORT CURE

P.O. Box 480714 Charlotte, NC 28269 sicklecellpartners@gmail.com sicklecellpartnersofthecarolinas.org

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SICKLE CELL PARTNERS OF THE CAROLINAS

- **We envision a world that will one day be free of Sickle Cell Anemia and other related inherited blood disorders.**

- **We envision an open, honest and continuing dialogue for a cure for those who are challenged with Sickle Cell Anemia.**

- **Sickle Cell Partners of the Carolinas is a non-profit 501c (3) tax exempt organization that exists to "partner" with any organization that is working to make a difference in the lives of patients and families affected by Sickle Cell Anemia.**

Sickle Cell Partners of the Carolinas

Awareness Support Cure