

2016

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



Sponsored in part by



SICKLE CELL PARTNERS OF THE CAROLINAS
AWARENESS SUPPORT CURE



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 the 3rd annual conference, "Sickle Cell Disease... Let's Talk About It." As chair of this non-profit organization, I invite you to engage and help empower the participants for whom this conference was designed – patients and families affected by Sickle Cell Disease. "Sickle Cell Disease... Let's Talk About It" presents a platform to create open discussion and an ongoing dialog as patients and families share their own unique experiences about Sickle Cell Disease.

We all know how this hereditary condition can lead to terrible episodes of pain; cause life-threatening consequences; lead to endless stays in the hospital; and sometimes unsettling experiences with our families, peers, and others throughout the community who do not comprehend the vast toll Sickle Cell Disease can have on one's life. The planning team hopes the keynote address delivered today and the various sessions throughout the day bring better understanding to what patients and their loved ones endure as they cope with their hereditary illness.

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. This daunting task needs you and I personally invite each of you to join us and share your gifts and talents to help us continue to achieve the goals set forth in our mission. I tell everyone we have "partners" in our name because we cannot do it alone.

I'd like to thank each of you for attending our conference this year and our deepest gratitude to our conference facilitators for providing information and insight throughout 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!"

With Sincere Gratitude,

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 the most common genetic disorder 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, Jennifer Watson Roberts, Mayor of Charlotte, do hereby proclaim
September 10, 2016 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.




Jennifer Watson Roberts
Mayor



CONFERENCE AGENDA
Saturday, September 10, 2016
Friendship Missionary Baptist Church

“SICKLE CELL DISEASE.... LET’S TALK ABOUT IT”
Sickle Cell Partners of the Carolinas
AWARENESS SUPPORT CURE

General Session:

8:00 am to 8:45 am	Registration and Vendor Opportunity Continental Breakfast	Lobby Gymnasium
8:45 am to 8:55 am	Welcome and Opening Remarks Joey Popp, Conference Host Dagny McDonald, Chair, Sickle Cell Partners of the Carolinas Sandra Boyd, MA, Sickle Cell Program, Division of Public Health, North Carolina Dept. Of Health and Human Services	Gymnasium
8:55 am to 9:30 am	Keynote Address Let’s Talk: Transition and Sickle Cell Patients Ifeyinwa Osunkwo, MD, MPH, Medical Program Director Sickle Cell Program, Levine Cancer Institute/Carolinas Healthcare	Gymnasium
9:30 am to 9:40 am	Yoga Mini Session: Restore Yourself with Breath Kiesha Battles, ERYT and Candace Jennings	Gymnasium
9:40 am to 9:50 am	Break and Vendor Opportunity	
<u>Round One Adult Sessions:</u> (Each participant should choose one to attend)		
9:50 am to 10:30 am	Let’s Talk: Sickle Cell Disease and Depression Cossondra Miller, Safe Haven Child & Family Counseling	Room 360
9:50 am to 10:30 am	Let’s Talk: Sickle Cell Disease and Reproductive Health Rochelle Brandon, MD, Brandon Gynecology Associates, P.A.	Room 359
9:50 am to 10:30 am	What to Expect from Vocational Rehabilitation and Your Vocational Evaluation Chanda Daye, Vocational Rehabilitative Services	Room 358
9:50 am to 10:30 am	Let’s Talk: The Sickle Cell Parent Panel Nikki Johnson, Ebonee Lockett, Kia Hilton, Leron Ford and Tiffany Rush-Ford	Room 125





CONFERENCE AGENDA
Saturday, September 10, 2016
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“SICKLE CELL DISEASE.... LET’S TALK ABOUT IT”

Sickle Cell Partners of the Carolinas

AWARENESS SUPPORT CURE

Round One Teen & Pediatric Sessions:

9:50 am to 10:30 am	Let’s Talk: Teen Truth Booth and Open Mic Karla Robinson, MD & Robert Robinson, III, MD, Urban Housecall Magazine	Room 357
9:50 am to 10:30 am	Pediatric Playroom Kai Burkins, MSW, Johnson C. Smith University Justina Williams, MSW Candidate, Johnson C. Smith University Danielle Ellis, MSW Candidate, Johnson C. Smith University Racquel Linton, MSW Candidate, Johnson C. Smith University	Room 304

10:30 am to 10:40 am Break and Vendor Opportunity

Round Two Adult Sessions: (Each Participant should choose one to attend)

10:40 am to 11:15 am	Yoga: Restore Yourself with Breath Kiesha Battles, EYRT and Candace Jennings	Room 360
10:40 am to 11:15 am	Working and How It Affects Your Benefit Denise Horton, Vocational Rehabilitative Services	Room 358
10:40 am to 11:15 am	Let’s Talk: Why You Should “Get Connected” Azizi Coleman, Piedmont Health Services & Sickle Cell Agency	Room 357
10:40am to 11:15 am	Let’s Talk: Are You Where You Want and Need to Be? Karla Robinson, MD & Robert Robinson, III, MD, Urban Housecall Magazine	Room 125

Round Two Teen & Pediatric Sessions:

10:40 am to 11:15 am	Let’s Talk: Why You Should “Get Connected” Azizi Coleman, Piedmont Health Services & Sickle Cell Agency	Room 357
10:40 am to 11:15 am	Pediatric Playroom Kai Burkins, MSW, Johnson C. Smith University Justina Williams, MSW Candidate, Johnson C. Smith University Danielle Ellis, MSW Candidate, Johnson C. Smith University Racquel Linton, MSW Candidate, Johnson C. Smith University	Room 304
11:15 am to 11:30 am	Break and Vendor Opportunity	
11:30 am to 12:30 pm	Lunch Special Dedication: Dagny McDonald, Chair Sickle Cell Partners of the Carolinas Beckwith Scholarship Presentation: Tammy Sherrod, Founding Advisor, Sickle Cell Partners of the Carolinas Quilt Presentation: Diane Hamilton, Friendship Missionary Baptist Church Quilting Ministry	Gymnasium
12:30 pm to 12:35	Closing Remarks & Surveys	

DUSK: The Wells Fargo Lights go **RED** at the Duke Energy Building in support of Sickle Cell

Sickle Cell Partners of the Carolinas Program Dedication



Ms. Joanne Johnson, Founding Advisor, Sickle Cell Partners of the Carolinas

The 2016 “Sickle Cell Disease... Let’s Talk About It” conference is dedicated in loving memory to Ms. Joanne Johnson. Ms. Johnson provided a wealth of knowledge and direction for Sickle Cell Partners of the Carolinas when the organization was in its infancy. She helped secure our tax-exempt status; gave countless hours of advice on what direction our organization should go in; and was instrumental in helping Sickle Cell Partners of the Carolinas plan just about every event we undertook.

Ms. Johnson transitioned in December 2015 and Sickle Cell Partners of the Carolinas lost that calming voice of wisdom when our team would ponder, “what to do next.” She was mother to Nikki, an SCPOC founding member and grandmother to Nicholas, whose bold words you have all read in the poem, “I’m Small, But I’m Strong.” Prior to her passing, she worked passionately and with purpose as a Community Educator at the James R. Clark Memorial Sickle Cell Foundation in Columbia, South Carolina. She was an advocate for the disenfranchised and a leader in her community.

Sickle Cell Partners of the Carolinas owes its deepest gratitude to Ms. Joanne Johnson for her guidance, strength and wisdom since our humble beginning in January 2009. Her strong voice for advocacy on behalf of patients and families affected by Sickle Cell Disease and her matter of fact demeanor have been greatly missed.

Friendship Quilting Ministry Benefits Sickle Cell Patients

The beautiful quilts you see adorning the Friendship Missionary Baptist Church gymnasium were made by Friendship's Quilting Ministry to raise awareness about Sickle Cell Disease. The quilts will be donated to hospitalized patients with Sickle Cell Disease to provide comfort and to let them know there is a community of hands praying for their recovery.

Sickle Cell Partners of the Carolinas would like to thank the many hands of the Friendship Quilting Ministry that worked on behalf of patients affected by Sickle Cell Disease to provide such beautiful and comforting works of art. Sickle Cell Partners of the Carolinas has truly been blessed by this awesome partnership and ministry.

If there is a patient in need who would like a quilt, please contact Sickle Cell Partners of the Carolinas at sicklecellpartners@gmail.com or call 704-562-2760. Quilts will be provided to hospitalized patients only.



QUILTS MADE BY FRIENDSHIP QUILTING MINISTRY



Sickle Cell Partners of the Carolinas Beckwith Scholarship

Sickle Cell Partners of the Carolinas awarded three deserving students the Beckwith Scholarship which was established by Sickle Cell Partners of the Carolinas in 2014. The scholarship was established to honor the commitment of Mrs. Ivestia “Peggy” Beckwith to the sickle cell community. Along with others, Mrs. Beckwith was instrumental in securing a federal grant in 1972 that established the Mecklenburg County Sickle Cell program which went on to span across several counties in North Carolina. That foundation of programs remains in existence across the state.



Mrs. Ivestia “Peggy” Beckwith



Ms. Janay Lindsey, Scholarship Recipient



Ms. Celine Kisimba, Scholarship Recipient

Sickle Cell Partners of the Carolinas Beckwith Scholarship

The recipients were awarded their scholarships in August 2016. Below are a few quotes that show their determination and stamina to succeed despite their illness. Sickle Cell Partners of the Carolinas feels sure Mrs. Beckwith would be proud of their accomplishments thus far and all that they will go on to achieve.

From the Beckwith Scholarship Recipients:

"I have to take my health into my own hands, because I no longer had my parents motivating me to take my hydroxyurea everyday as well as other vitamins to improve my health. It is all on me. I know there are kids who are coming behind me who may need help too along the way with motivation to continue forward." -- **Beckwith Scholarship Recipient**

"Despite how my life began, and even considering what I still have to endure as a result of this disease, that's not how my story will end. I am working on a new story, a story that acknowledges the hardships and adversities that I have faced and uses them as a springboard to launch me into a bright future... a future spent helping others as others have helped me." -- **Beckwith Scholarship Recipient**

"I've always concealed my illness. I've always tried to formulate reasons to my classmates on why I missed three days of school. I was ashamed of sickle cell disease and wondered why I had to be different from everyone else. The isolation and stigma that comes with a chronic illness, especially sickle cell, prevented me from sharing details about my health to anyone other than my family and health care providers. After a panel discussion, I learned that instead of being ashamed of my illness and hiding it from the public, I should own up to sickle cell and use it as a platform to help others." -- **Beckwith Scholarship Recipient**

Mrs. Beckwith believed the strength of our people lies in our collective voice that speaks of ongoing change through action and commitment. Her leadership, vision, courage, competence, ability to build constituencies, set priorities, mobilize resources and promote political action served as a voice of change for our community (particularly those affected by sickle cell disease).

In honor of Mrs. Beckwith's memory, this scholarship will be awarded to two deserving students who are enrolled in an accredited college, university or trade school. Sickle Cell Partners of the Carolinas is proud to honor Mrs. Beckwith's long-standing commitment, service and work on behalf of sickle cell patients across North Carolina. The next awarding cycle for The Sickle Cell Partners of the Carolinas Beckwith Scholarship will be in the summer of 2017.

Criteria for Applicants:

- Applicants must be enrolled in an accredited college, university or trade school
- Applicants must be a graduating high school senior or currently enrolled at an accredited institution
- Applicants must have a "B" overall average at the time of application
- Applicants must be a sickle cell patient
- Applicants must provide a certified academic transcript
- Applicants must submit an essay and provide a record of community service (if applicable)

For more information, please email sicklecellpartners@gmail.com

If you would like to make a donation to the Beckwith Scholarship Fund, please go to Sickle Cell Partners of the Carolinas website and click on the Contact & Donate page. Checks for donations can be made out to Sickle Cell Partners of the Carolinas and mailed to SCPOC at P.O. Box 480714 Charlotte, North Carolina 28269.

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What You Should Know About Sickle Cell Disease



What Is Sickle Cell Disease?

Sickle cell disease (SCD) is a group of inherited red blood cell disorders.

- Healthy red blood cells are round and they move through small blood vessels carrying oxygen to all parts of the body.
- In SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a “sickle”.
- Sickle cells die early, which causes a constant shortage of red blood cells.
- Sickle cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These blockages cause repeated episodes of severe pain, organ damage, serious infections, or even stroke.

What Causes Sickle Cell Disease?

SCD is inherited in the same way that people get the color of their eyes, skin, and hair.

- A person with SCD is born with it.
- People cannot catch SCD from being around a person who has it.

Who Is Affected By Sickle Cell Disease?

- It is estimated that SCD affects 90,000 to 100,000 people in the United States, mainly Blacks or African Americans.
- The disease occurs among about 1 of every 500 Black or African-American births and among about 1 out of every 36,000 Hispanic-American births.
- SCD affects millions of people throughout the world and is particularly common among those whose ancestors come from sub-Saharan Africa; regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.

What Health Problems Does Sickle Cell Disease Cause?

Following are some of the most common complications of SCD:

“Pain Episode” or “Crisis”: Sickle cells don’t move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

Infection: People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis.

Hand-Foot Syndrome: Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.

Eye Disease: SCD can affect the blood vessels in the eye and lead to long term damage.

Acute Chest Syndrome (ACS): Blockage of the flow of blood to the lungs can cause acute chest syndrome. ACS is similar to pneumonia; symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.

Stroke: Sickle cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.

How Is Sickle Cell Disease Treated?

The goals of treating SCD are to relieve pain and to prevent infections, eye damage, and strokes.

- There is no single best treatment for all people with SCD. Treatment options are different for each person depending on the symptoms. Treatments can include receiving blood transfusions, maintaining a high fluid intake (drinking 8 to 10 glasses of water each day), receiving IV (intravenous) therapy (fluids given into a vein) and medications to help with pain.
- For severe SCD, a medicine called hydroxyurea might be recommended. Research suggests that hydroxyurea can reduce the number of painful episodes and the recurrence of ACS. It also can reduce hospital stays and the need for blood transfusions among adults who have SCD.

Is There A Cure For Sickle Cell Disease?

To date, the only cure for SCD is a bone marrow or stem cell transplant.

- A bone marrow or stem cell transplant is a procedure that takes healthy stem cells from a donor and puts them into someone whose bone marrow is not working properly. These healthy stem cells cause the bone marrow to make new healthy cells.
- Bone marrow or stem cell transplants are very risky, and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match.

For more information visit: www.cdc.gov/sicklecell



I'M SMALL, BUT I'M STRONG

By: N. Hampton

When you see my stature, don't doubt my strength

When you see my pain, don't doubt my endurance

When you see my crisis, don't doubt my peace

When you see my face, remember this...

I'm Small, but I am Strong.

I am an Overcomer

I am a Conqueror

I am a Hero

I am Healed

I have Sick Cell Disease... It doesn't have me!



Dr. James Eckman, 2014 Conference Keynote Speaker, Nicholas Hampton and Nikki Johnson



Dr. Lanetta Jordan, 2015 Conference Keynote Speaker

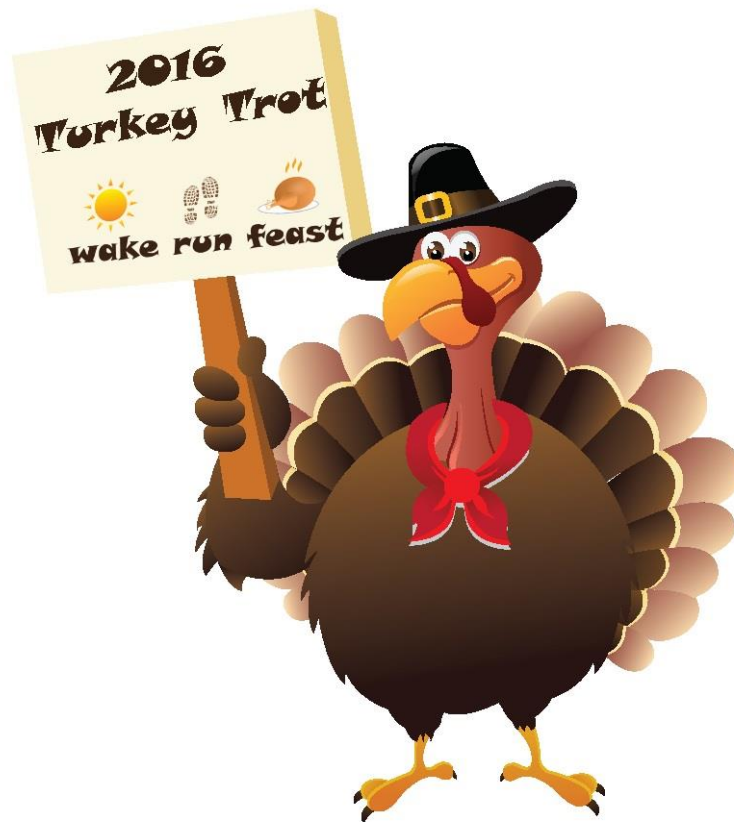
The University City Turkey Trot is a 5K race sponsored by Sickie Cell Partners of the Carolinas to raise awareness and educate the community about Sickie Cell Disease and to help with fundraising efforts.
Join us Thanksgiving Day 2016

Register: runsignup.com Volunteer: universitycityturkeytrot@gmail.com

UNIVERSITY CITY

Turkey Trot 5k

NOVEMBER 24, 2016 8:00 AM



THE FRESH MARKET Prosperity Church Road
GOBBLE UP DETAILS @runforyourlife.com



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

Conference Notes

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The information discussed at this conference is true and complete to the best of the presenter's and sponsor's knowledge. This conference is intended only as an information source and should not replace, countermand, or conflict with the advice given to you by your physicians, medical team and/or legal counsel. The presenters, sponsors and Sickie Cell Partners of the Carolinas disclaim all liability in connection with the specific personal use of any and all information provided during this conference.

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

Conference Notes

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

The information discussed at this conference is true and complete to the best of the presenter's and sponsor's knowledge. This conference is intended only as an information source and should not replace, countermand, or conflict with the advice given to you by your physicians, medical team and/or legal counsel. The presenters, sponsors and Sick Cell Partners of the Carolinas disclaim all liability in connection with the specific personal use of any and all information provided during this conference.

Sickle Cell Partners of the Carolinas sincerely thanks Friendship Missionary Baptist Church for their invaluable assistance in supporting our conference, "Sickle Cell Disease... Let's Talk About It."

RESOURCES:

Be the Match – www.bethematch.org

Carolinas Healthcare – www.carolinashealthcare.org

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

Community Blood Center of the Carolinas – www.cbcc.us

InnerVision, Inc. -- www.innervisionnc.org

Juice Plus – www.juiceplus.com

Levine Children's Hospital – www.carolinashealthcare.org/levine-childrens-hospital

North Carolina Sickle Cell Syndrome Program – www.ncsicklecellprogram.org

Novant Health – www.novanthealth.org

Novartis Pharmaceuticals – www.novartis.com

Pfizer – www.pfizer.com

Piedmont Health Services & Sickle Cell Agency – www.piedmonthhealthservices.org

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

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

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