

Sickle Cell Partners of the Carolinas Presents



Sickle Cell Disease

"let's talk
about it"

day conference

Saturday, November 7, 2015 • 8am to 4pm

Friendship Missionary Baptist Church Conference Center

3400 Beatties Ford Road Charlotte, North Carolina 28216

Sickle Cell Partners of the Carolinas

AWARENESS SUPPORT CURE

Sponsored in part by





Sickle Cell Partners of the Carolinas

Sickle Cell Partners of the Carolinas Mission Statement:

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.

Sickle Cell Partners of the Carolinas Vision:

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 suffer from 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.



We are moms, dads, families, health care providers and social workers who care deeply about the Sickle Cell community. Our start began with parents looking for support and for someone to explain this painful, often life-threatening condition that no one seems to want to talk about. Back in 2009, a support group was formed and we decided to call ourselves "Sickle Cell Partners of the Carolinas." We are "partners" in this mission to learn more about Sickle Cell Disease and how people cope with it. We hold meetings, host fun gatherings and do fundraisers all in an effort to engage the entire Sickle Cell community. Sickle Cell Partners of the Carolinas is an entire community working together to better the lives of those who have Sickle Cell Disease. We have "partners" in our name because we cannot do that alone. Sickle Cell Partners of the Carolinas.... we are you!

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

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

WHEREAS, Sickle Cell Disease is a chronic but treatable illness although there is no single best treatment for people with Sickle Cell Disease, treatment options are different for each person depending on symptoms which can range 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 medical community; 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, 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:

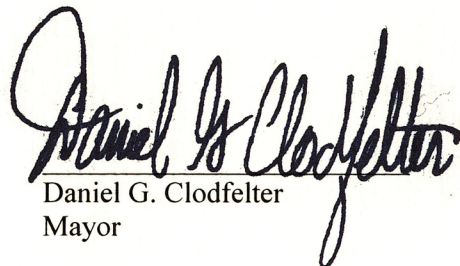
NOW, THEREFORE, I, Daniel G. Clodfelter, Mayor of Charlotte, do hereby proclaim
November 7, 2015 as

"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.




Daniel G. Clodfelter
Mayor



CONFERENCE AGENDA

“SICKLE CELL DISEASE.... LET’S TALK ABOUT IT”

General Session:

8:00 am to 8:45 am	Registration and Continental Breakfast	Lobby/Conference Room A
8:45 am to 9:00 am	Welcome / Opening Remarks Joey Popp, Conference Host Dagny McDonald, Chair, Sickle Cell Partners of the Carolinas	
9:00 am to 9:50 am	Keynote Address Lanetta Jordan, MD, MPH, MSPH University of Miami, Miller School of Medicine	Conference Room A
9:50 am to 10:05 am	“Yoga, Let’s Talk About It... Breathe It, Feel It” Keisha Battle, Yoga-Me	Conference Room A
10:05 am to 10:15 am	Break & Vendor Opportunity	Conference Room A
<u>Morning Adult Sessions:</u>	“Adult Patients Living with Sickle Cell Disease”	Conference Room A
10:15 am to 11:05 am	Lanetta Jordan, MD, MPH, MSPH, University of Miami, Miller School of Medicine	
10:15 am to 11:05 am	“Pediatric Parents Ask the Docs” Paulette Bryant, MD, Blume Pediatric Hematology & Oncology, Novant Health Daniel McMahon, MD, Pediatric Hematologist / Sickle Cell Specialist, Levine Children’s Hospital	Friendship Choir Room
10:15 am to 11:05 am	“School Education Plans: Does Your Student Need One?” Dr. Yolanda P. Holmes, Community Partnerships Coordinator, Charlotte-Mecklenburg Schools Dr. Harriett Ford, Section 504 Facilitator, Charlotte-Mecklenburg Schools Corrine Turner, Itinerant Coordinating Teacher, Charlotte-Mecklenburg Schools	Conference Room D
11:05 am to 11:15 am	Break & Vendor Opportunity	

Morning Teen Break-out & Pediatric Sessions:

10:15 am to 11:05 am	"Managing the Psychological and Emotional Challenges of Sickle Cell Disease" Sandra Barnes, MA, Clinical Psychology, Fielding Graduate University Tammy Sherrod, RN	Room 135
10:15 am to 11:05 am	"Prepare: What Young Men Can Expect in Living with Sickle Cell Disease" Craigie Sanders, Esq., North Carolina Council on Sickle Cell Syndrome James Rogers, Public Health Sickle Cell Educator, North Carolinas Sickle Cell Syndrome Program	Room 139
10:15 am to 11:05 am	"Pediatric Patients Learn About Sickle Cell Disease" Katy F. Wind, Certified Child Life Specialist, Novant Health Kelly Campbell, RN, CPN, Carolinas Healthcare	Room 133



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

CONFERENCE AGENDA

Mid-Morning Adult Sessions:

11:15 am to 12:05 pm	"Pediatric Parents Ask the Docs" Paulette Bryant, MD, Blume Pediatric Hematology & Oncology, Novant Health Daniel McMahon, MD, Pediatric Hematologist / Sickle Cell Specialist, Levine Children's Hospital	Friendship Choir Room
11:15 am to 12:05 pm	"Stem Cell Transplants to Cure Sickle Cell Disease" Michael J. Eckrich, MD, MPH, Director of Non-Malignant Stem Cell Transplantation, Levine Children's Hospital Craigie Sanders, Esq., North Carolina Council on Sickle Cell Syndrome	Conference Room D
11:15 am to 12:05 pm	"Social Security Work Incentives: How Working will Affect Your Disability Benefits" Lisa M. Oakley, Certified Community Work Incentive Coordinator, Vocational Rehabilitation Services Chanda Daye, Vocational Rehabilitation Evaluator, Vocational Rehabilitation Services	Conf. Room C
11:15 am to 12:05 pm	"Adult Art Expression" Hasaan Kirkland, MFA, Visual and Performing Arts, Johnson C. Smith University	Room 139

Mid-Morning Teen Break-out & Pediatric Sessions:

11:15 am to 12:05 pm	"Yoga, Let's Talk About It... Breathe It, Feel It" Keisha Battle, Yoga-Me	Room 135
11:15 am to 12:05 pm	"Pediatric Patients Learn About Sickle Cell Disease" Katy F. Wind, Certified Child Life Specialist, Novant Health Kelly Campbell, RN, CPN, Carolinas Healthcare	Room 133
12:05 pm to 12:15 pm	Break & Vendor Opportunity	
12:15 pm to 1:30 pm	LUNCH Advocacy & Tributes	Conference Room A
1:30 pm to 1:40 pm	Break & Vendor Opportunity	



“SICKLE CELL DISEASE.... LET’S TALK ABOUT IT”

CONFERENCE AGENDA

Afternoon Adult Sessions:

1:40 pm to 2:40 pm	Adult Talkback: “Sickle Cell Disease.... Let’s Talk About It” Robert Robinson III, MD, Urban Housecall Magazine	Conference Room A
1:40 pm to 2:40 pm	“Stem Cell Transplants to Cure Sickle Cell Disease” Michael J. Eckrich, MD, MPH, Director of Non-Malignant Stem Cell Transplantation, Levine Children’s Hospital Jasmine DeBerry, Bone Marrow Donor	Conference Room D
1:40 pm to 2:40 pm	“Social Security Work Incentives: How Working will Affect Your Disability Benefits” Lisa M. Oakley, Certified Community Work Incentive Coordinator, Vocational Rehabilitation Services Chanda Daye, Vocational Rehabilitation Evaluator, Vocational Rehabilitation Services	Conf. Room C

Teen Afternoon Sessions:

1:40 pm to 2:40 pm	Teen Talkback: “Sickle Cell Disease.... Let’s Talk About It” Sandra Barnes, MA, Clinical Psychology, Fielding Graduate University Craigie Sanders, Esq., North Carolina Council on Sickle Cell Syndrome	Room 135
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All Conference Participants:

1:40 pm to 3:40 pm	Heart to Heart Healing Therapy (afternoon pre-scheduled 15 minute mini-sessions)	Room 133
2:40 pm to 2:45 pm	BREAK	

All Conference Participants:

2:45 pm to 3:40 pm	Art of Expression	Room 139
2:45 pm to 3:40 pm	“Yoga, Let’s Talk About It... Breathe It, Feel It”	Room 135
3:40 pm to 4:00 pm	Closing Remarks & Surveys	Conference Room A

SICKLE CELL PARTNERS OF THE CAROLINAS
AWARENESS SUPPORT CURE

SICKLE CELL PARTNERS OF THE CAROLINAS BECKWITH SCHOLARSHIP

In 2014, Sickle Cell Partners of the Carolinas established a scholarship in honor of the late Mrs. Ivestia “Peggy” Beckwith, a true sickle cell pioneer. Mrs. Beckwith was instrumental, along with others, in securing a federal grant in 1972 that established the Mecklenburg County Sickle Cell program which went on to span across several counties across North Carolina.



Ivestia “Peggy 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 and 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 Sickle Cell Partners of the Carolinas Beckwith Scholarship will be awarded in the spring of 2016.

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



Sickle Cell Partners
of the Carolinas



Awareness Support Cure

Sickle Cell Partners of the Carolinas

With Sincere Gratitude

Sickle Cell Partners of the Carolinas (SCPOC), with sincere gratitude, would like to thank all patients and families affected by sickle cell disease for making the day conference, **"Sickle Cell Disease.... Let's Talk About It"** an event that we can all be proud of. This conference was designed again this year for pediatric patients, adult patients, their families, care givers, care providers and the at-large community to provide an open forum to raise the level of awareness and educate everyone about sickle cell disease. We hope the information shared today will empower all those affected by sickle cell disease to learn more, embrace their condition and live their life to its fullest extent.

We are eternally grateful to the talented medical staffs at Carolinas Healthcare System and Novant Health for donating their time and expertise to the sickle cell patient population, their families and the at-large community. Our special thanks is extended to those who traveled to Charlotte to ensure the success of **"Sickle Cell Disease... Let's Talk About It."** The contributions from all of you will make a lasting impression on our audience and the patient population. Thank you for your tremendous service and dedication to the sickle cell community.

SCPOC would like to especially thank Pfizer and Novartis for their input in helping to implement this day conference. We are also grateful to our many donors who helped to ensure that our non-profit had all the resources necessary to bring this day of education and awareness to the Charlotte community. Our sincere thanks again is extended to Friendship Missionary Baptist Church for the usage of their awesome conference center and for securing everything needed for a successful event.

Lastly, I would like to thank the parents of children with sickle cell disease who took time away from their busy lives to help plan this conference; the nurses and child life specialists at Novant Health and Carolinas Healthcare who gave ideas on what would work best for the patient population they work with; and to the others on our core team who guided conversations and gave their input. This was challenging work done in the spirit of the mission of Sickle Partners of the Carolinas which at the core is to raise awareness and educate the community about sickle cell disease. Let's keep the conversation going! **"Sickle Cell Disease.... Let's Talk About It!"**

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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



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

Conference Notes

This image shows a single sheet of white paper with horizontal blue 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 presenters' 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 Sickle Cell Partners of the Carolinas disclaim all liability in connection with the specific personal use of any and all information provided during this conference.

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 Sickle Cell Disease... It doesn't have me!

AWARENESS SUPPORT CURE

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

Heart to Heart Healing – heart2hearthealing@yahoo.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

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

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

Sickle Cell Partners of the Carolinas Team:

Dagny McDonald, Hans McDonald, Paulette Smith, Tammy Sherrod, LaNae Wade, Montae Monroe, Bettye Monroe,
Joanne Johnson and Nikki Johnson

Conference Planning Committee:

Dagny McDonald, Hans McDonald, Paulette Smith, Tammy Sherrod, LaNae Wade, Montae Monroe, Bettye Monroe,
James Rogers, Elizabeth Lineberger, Katy Wind, Carla Jones, Kathy Staley, Althea Bogues

