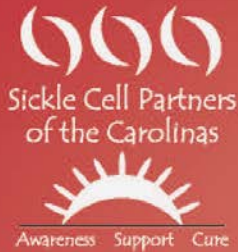


Sickle Cell Partners of the Carolinas Presents



Sickle Cell Disease

“let’s talk
about it”

day conference

Saturday, October 25, 2014 • 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

**CVS
CAREMARK**



Sickle Cell Partners
of the Carolinas



Awareness Support Cure

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 disease.

Sickle Cell Partners of the Carolinas (SCPOC) was formed in January of 2009. We are patients, moms, dads, healthcare providers and social workers who care deeply about the sickle cell community. SCPOC 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 disease.

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

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



facebook.com/SCPOC09



@sicklecellpartn

City of Charlotte, North Carolina Proclamation

WHEREAS, Sickle Cell Disease 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 an inherited blood disorder that causes intense pain, infections, bone deterioration, organ damage, disability, economic strain, and in some instances death; and

WHEREAS, while there is no definite cure for this disease, treatment is available to help those with Sickle Cell Disease to lead productive and rewarding lives; 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 provides a network of support for patients and families affected by Sickle Cell Anemia and is charged with raising awareness, educating the community, and advocating 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, an opportunity will be provided today to come together and have conversations to discuss the trials and tribulations 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, Daniel G. Clodfelter, Mayor of Charlotte, do hereby proclaim
October 25, 2014 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

SICKLE CELL PARTNERS OF THE CAROLINAS PRESENTS:

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

Saturday, October 25, 2014

Friendship Missionary Baptist Church, Charlotte, North Carolina

ADULTS, PARENTS & CAREGIVERS

AGENDA

Conference Room A

Conference Room C

Conference Room D

8:00-8:45 am	Registration and Continental Breakfast		
8:45-9:00 am	Welcome and Opening Remarks (Joey Popp, Dagny McDonald, and Kimberly Leathers-Raynor)		
9:00-9:50 am	Plenary Session & Video Presentation (Dr. Ify Osunkwo and Dr. James Eckman)		
9:50-10:15 am BREAK	<i>Special Guest ...</i>		
10:15-11:05 pm	Parents of Pediatric Patients: Ask the Docs (Dr. Paulette Bryant and Dr. Daniel McMahon)	Nutrition: Healthy Eating for the Sickle Cell Patient (Dr. Jacqueline Hibbert)	Workplace Laws and Sickle Cell Patients (Attorney Charles Everage)
11:05-11:15 am BREAK			
11:15-12:05 pm	Parents of Pediatric Patients: Ask the Docs (Dr. Paulette Bryant and Dr. Daniel McMahon)	Working with Disability and Vocational Rehabilitation (Kelandra R. Anthony and Chanda Daye)	“Where Do I Fit in With Sickle Cell Disease: Understanding Stages of Development in Your Child and How they Cope” (Dr. Amii Steele)
12:05-12:15 pm BREAK			
12:15-1:30 pm	Lunch and Tributes		
1:30-1:40 pm BREAK			
1:40-2:40 pm	Adults Coping... What’s on your Mind “Let’s Talk About It”	Nutrition: Healthy Eating for the Sickle Cell Patient (Dr. Jacqueline Hibbert)	Working with Disability and Vocational Rehabilitation (Kelandra R. Anthony and Chanda Daye)
2:40-2:50 pm BREAK			
2:50-3:40 pm	Art Expression -- Rm. 139 and 135	“Where Do I Fit in With Sickle Cell Disease: Understanding Stages of Development in Your Child and How they Cope” (Dr. Amii Steele)	Social Security Benefits: Applications & Eligibility (Attorney Charles Everage)
3:40-4:00 pm	Closing Remarks and Surveys		

TEENS (12 - 18 yrs. old), Childcare provided in room 133 (3 - 11 yrs. old)

Conference Room A

Room 135

Room 139

8:00-8:45 am	Registration and Continental Breakfast		
8:45-9:00 am	Welcome and Opening Remarks (Joey Popp, Dagny McDonald, and Kimberly Leathers-Raynor)		
9:00-9:50 am	Plenary Session & Video presentation (Dr. Ify Osunkwo and Dr. James Eckman)		
9:50-10:15 am BREAK	<i>Special Guest ...</i>		
10:15-11:05 pm		Young Females Coping with Sickle Cell Disease (Sheena Simpson, Dr. Anya Griffin, Mia McLeod, and Ishia Washington)	Young Males Coping with Sickle Cell Disease (Howard Estell, James Rogers, and Dr. James Eckman)
11:05-11:15 am BREAK			
11:15-12:05 pm		Young Females Coping with Sickle Cell Disease (Sheena Simpson, Dr. Anya Griffin, Mia McLeod, and Ishia Washington)	Young Males Coping with Sickle Cell Disease (Howard Estell, James Rogers, and Dr. James Eckman)
12:05-12:15 pm BREAK			
12:15-1:30 pm	Lunch and Tributes		
1:30-1:40 pm BREAK			
1:40-2:40 pm			Teens Together, Males and Females Let’s Talk About It... (Conf. Room D)
2:40-2:50 pm BREAK			
2:50-3:40 pm		Art Expression	Art Expression
3:40-4:00 pm	Closing Remarks and Surveys		



Sickle Cell Partners
of the Carolinas



Awareness Support Cure

Sickle Cell Partners of the Carolinas

Kelandra R. Anthony, MS, CRC
Vocational Rehabilitation Counselor
NC Division of Vocational Rehabilitation Services
“Working with Disability and Vocational Rehab”

Paulette Bryant, M.D.
Blume Pediatric Hematology & Oncology
Novant Health
“Let’s Talk About It – Ask Dr. McMahon and Dr. Bryant”

Chanda Daye
Vocational Rehabilitation Evaluator
NC Division of Vocational Rehabilitation Services
“Working with Disability and Vocational Rehab”

James Eckman, M.D.
Professor Emeritus of Hematology and Medical Oncology
Emory University School of Medicine
“Sickle Cell Disease... Let’s Talk About It”

Howard Estell, IV, BSW, MSW Candidate
Educator/Counselor
Piedmont Health Services and Sickle Cell Agency
“Presentation for Teen Males on Priapism”

Attorney Charles Ali Everage
Everage Law Firm, PLLC Disability Advocates
**“Reasonable Accommodations in the Workplace:
Workplace Laws Sickle Cell Patients Should Know”**
**“Am I Entitled to Social Security Benefits: Exploring
the Application & Eligibility Process”**

Holly Flood, Host and Producer
“Turning Point International”
Christian Broadcast Network
Conference Host

Sharon Green, Child Life Specialist
Levine Children’s Hospital/Carolinas Healthcare System
Pediatric Host

Anya Griffin, PhD.
Pediatric Psychologist
Aflac Children’s Cancer and Blood Disorders Service
“Sickle Cell Disease and Teen Transition”

Jacqueline Hibbert, PhD.
Associate Professor
Morehouse School of Medicine
“Nutrition and the Sickle Cell Patient”

Hassan Kirkland, MFA
Visual and Performing Arts
Johnson C. Smith University
“The Art of Expression”

Representative Mia McLeod
SC House of Representatives, District 79
“Young Females and Sickle Cell Disease”

Daniel P. McMahon, M.D.
Pediatric Hematologist/ Sickle Cell Specialist
Levine Children’s Hospital/Carolinas Healthcare System
“Let’s Talk About It – Ask Dr. McMahon and Dr. Bryant”

Ifeyinwa (Ify) Osunkwo, M.D. MPH
Medical Director, Sickle Cell Program
Levine Cancer Institute/Carolinas Healthcare System
**“Sickle Cell Disease... Let’s Talk About It” Video
Introduction**

Joey Popp, Producer, Writer, Media Consultant
Conference Host

Sheena Maria, Actor, Writer, Make-up Artist
Sheena Maria, Inc.
“I Think Therefore I Am... the Power of the Mind”

Amii C. Steele, Ph.D.
Pediatric Psychologist
Levine Children’s Hospital/Carolinas Healthcare System
“Where Do I Fit In Living with Sickle Cell Disease?”
**“Understanding Stages of Development in Your Child and
How They Cope”**

Ishia Washington, Author, “Meet Camden”
“Young Females and Sickle Cell Disease”

Katy F. Wind, Certified Child Life Specialist
Novant Health
Pediatric Host

A Tribute to Mrs. Ivestia Heggie “Peggy” Beckwith



Sickle Cell Partners of the Carolinas is proud to announce the establishment of a scholarship in honor of Mrs. Ivestia “Peggy” Beckwith. This scholarship will honor her long-standing commitment, service and work on behalf of sickle cell patients across North Carolina and beyond. Mrs. Beckwith passed away last September. Here is an excerpt from her obituary on her efforts on behalf of those affected by sickle cell disease: “In the 1970's, she began to ponder the inequality of health care, specifically health disparities, in the black community. She witnessed a mother grieving over the death of her child with sickle cell disease which prompted her to seek answers.

She began her work with sickle cell seeking answers by expressing her interest to the local County Health Director, Model Cities Health Educator and two local pediatricians. This group requested that she develop a plan which resulted in the creation of the Association for Sickle Cell Disease in October 1972. Joined by Dr. George Lowe, Dr. C. W. Williams, Dr. James Murphy and later Dr. Karen Burges, the mission to provide access to healthcare and extend the life of babies in Mecklenburg County seemed to be possible. That was not enough. She joined a statewide network fight to save the lives of those born with sickle cell disease and provided the voice for the underserved in healthcare. This began her passion as a health care professional and advocate.

In 1972 she submitted a federal grant to fund the Mecklenburg County Sickle Cell program which would expand the program to include eight surrounding counties which was approved. At the inception of the program, there was a dire need for well-trained volunteers to provide basic information about the disease. She worked with the Continuing Education Department at Central Piedmont Community College, and developed a three month “Lecture Laboratory Curriculum” for volunteers which launched in 1973.”

Sickle Cell Partners of the Carolinas salutes Mrs. Ivestia Beckwith, known fondly as “Peggy,” for her service to our community and we are proud to continue her legacy by establishing a scholarship in her honor.



Sickle Cell Partners of the Carolinas

Thank You ...

Sickle Cell Partners of the Carolinas (SCPOC), with sincere gratitude, would like to thank all individuals living with sickle cell disease for giving the core planning team the inspiration to plan “Sickle Cell Disease.... Let’s Talk About It.” This day conference was designed 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 grateful to all the doctors, nurses, and healthcare providers from Carolinas Healthcare System and Novant Health who have donated their time today to share their expertise. A special thank you to all of those who traveled to Charlotte for this conference and to all presenters for “Sickle Cell Disease.... Let’s Talk About It” who added to our day of success. It has been an awesome experience working with each of you to bring this conference to life. Thank you for your service and dedication to the sickle cell community.

A special thanks to CVS Caremark and Novartis Pharmaceuticals for working with SCPOC to implement this day conference. We also thank Friendship Missionary Baptist Church for the use of their conference facility and Mr. Edwin Holland, Ms. Cassandra Harding, and Ms. Chandra Pretty for securing everything needed for the venue to ensure a successful event.

Our sincerest gratitude and thanks to the Barnes family for their gracious support and Ms. Joanne Johnson for all her hard work on behalf of SCPOC to obtain grants to make this conference a reality. Lastly, SCPOC would like to thank Tammy Sherrod and Paulette Smith for their relentless push back in 2009 for parents to come together for support, thus making Sickle Cell Partners of the Carolinas a reality. Sickle Cell Partners of the Carolinas... we are you... and we thank you for your attendance and making “Sickle Cell Disease.... Let’s Talk About It” a success.

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

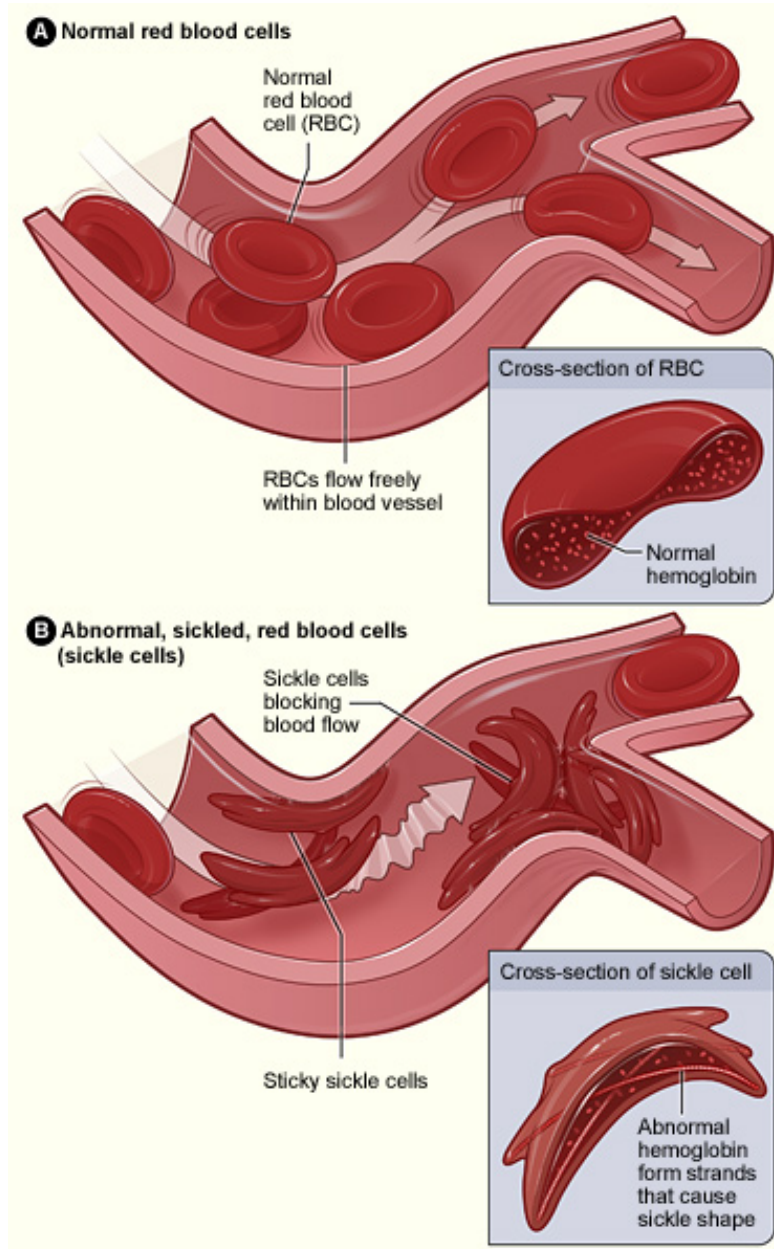


[facebook.com/SCPOC09](https://www.facebook.com/SCPOC09)



[@sicklecellpartn](https://twitter.com/sicklecellpartn)

Sickle Cell Anemia



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

What is Sickle Cell Disease?

Sickle Cell Disease (SCD) is a group of inherited blood cell disorders.

- Healthy blood cells are round and carry oxygen to all parts of the body.
- When someone has SCD, the red blood cells become hard and sticky and take on a crescent or sickle shape.
- Sickle cells die early, which causes a constant shortage of red blood cells in a sickle cell patient.
- Sickle cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These blockages are called pain crises and cause severe pain, organ damage, serious infections or a stroke.

What Causes Sickle Cell Disease?

SCD is inherited in the same way people get their eye color, hair color, and other traits from their parents.

- A person with SCD is born with it.
- Both parents of a child with SCD carry the sickle cell trait.
- People cannot catch SCD by being around someone who has the disease.
- With each pregnancy for parents who have the sickle cell trait, there is a 25% chance the child will have SCD, a 50% chance the child will have sickle cell trait and a 25% chance that the child will have nothing at all. The chances are with EVERY pregnancy.

Who is Affected by Sickle Cell Disease?

There are thousands of people affected by SCD across the United States and millions more worldwide.

- It is estimated that SCD affects 90,000 to 100,000 people in the United States.
- SCD occurs in about one out of every 500 African-American births and among Hispanic-Americans, one out of every 36,000 births.
- SCD knows no boundaries and affects not only African Americans and Hispanics but also Caucasians, and those with ancestors from South America and the Caribbean; Central America; Saudi Arabia; India; Turkey, Greece; and Italy.

What Health Problems Does Sickle Cell Disease Cause?

- **“Pain Episode” or “Crises”:** Sickle cells do not move easily through one’s bloodstream and get stuck and clog the blood flow. This causes pain that can start suddenly which can be mild or 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 with a fever, is caused by sickle cells getting stuck in the blood vessels and blocking the flow of blood 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:** Blockage of the flow of blood to the lungs can cause acute chest syndrome. This condition is similar to pneumonia and symptoms include chest pain, coughing, difficulty breathing and fever. Acute Chest syndrome 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 life-long disabilities and learning problems.

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

CVS Health

www.cvshealth.com

Enroll America

www.enrollamerica.org

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

Piedmont Health Services and Sickle Cell Agency

www.piedmonthalthservices.org

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, Joanne Johnson, Nikki Johnson and Rhonda Rickenbacker-Johnson

Conference Planning Committee:

Dagny McDonald, Hans McDonald, Paulette Smith, Tammy Sherrod, LaNae Wade, Joanne Johnson, Nikki Johnson, Rhonda Rickenbacker-Johnson
Althea Bogues, James Rogers, Tristan Samson, Dr. Ify Osunkwo, Shirley Miller, Tonya Brailey

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.