

Greetings from Sickle Cell Partners of the Carolinas!

Greetings from Sickle Cell Partners of the Carolinas! Our winter hibernation is over and we hope you are ready for spring and all the beauty this season brings this time of year. SCPOC is preparing for another year of activities and as always we encourage you to participate in helping us plan and carry out ideas that you want to see in the sickle cell community across Charlotte and the Carolinas.

Please mark your calendars now for our two signature events that will be held this year. Our annual conference, "Sickle Cell Disease... Let's Talk About It" will be held during Sickle Cell Awareness month on Saturday, September 10, 2016. This conference is designed for patients – adults and pediatrics – families, caregivers, healthcare providers and the community at large to learn more about sickle cell disease. We want your ideas on how to make this event a success once again, so please email SCPOC at sicklecellpartners@gmail.com with your ideas. We welcome them! Registration for the conference is now open on Eventbrite.com. Register and bring your family and friends.

Also for the third year, SCPOC will build on the success of the University City Turkey Trot 5k race on Thanksgiving Day. This signature event helps SCPOC build more awareness about sickle cell disease to the broader community and is rapidly becoming the race to run in University City on Thanksgiving Day. Join us for the 5K and Family Fun Trot... WAKE, RUN, FEAST!



Sickle Cell Partners of the Carolinas seeks 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



Awareness



Support



Cure

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PHENOMENAL CONFERENCE: “SICKLE CELL DISEASE... LET’S TALK ABOUT IT” 2015

It was another successful year for Sickle Cell Partners of the Carolinas as the organization hosted its signature event, the day conference, “Sickle Cell Disease.... Let’s Talk About It.” The conference was held last November and was headlined by a dynamic and engaging sickle cell advocate from Florida, Dr. Lanetta Jordan. Dr. Jordan stepped from the stage into the audience for an intimate conversation to address patients and families about the disparities in sickle cell care but expressed to the audience that they have the power to change that. Jordan made herself right at home as she told the crowd her roots were in North Carolina and that she had ties to the medical community in the Raleigh-Durham area before moving to Florida where she is the President of the Foundation for Sickle Cell Research.

Dr. Jordan’s credentials and experience with the sickle cell community proved to be a perfect fit for “Sickle Cell Disease.... Let’s Talk About It.” The day conference was designed specifically for the sickle cell community which is her specialty. With Dr. Jordan’s medical background and expertise in the field of sickle cell disease and research, the conference offered a flow of emotionally-charged conversations among patients and families; information to help adult and pediatric patients in school and on the job; and a forum to talk about sickle cell disease in a manner where people truly understood. The conference brought together adults and pediatric patients, families, healthcare providers, the medical community, local agencies, the school system and businesses who have a vested interests in seeing people with sickle cell disease succeed at every level.



In addition to Dr. Jordan’s keynote address, the conference featured expert-led breakout sessions on the psychological and emotional challenges of living with sickle cell disease; a bone marrow transplant session; break-out sessions for teens living with sickle cell disease; an adult talk-back session; yoga; and art for participants. SCPOC is planning to host “Sickle Cell Disease... Let’s Talk About It” on Saturday, September 10, 2016 at Friendship Missionary Baptist Church in Charlotte. Please plan to attend this event and get to know other patients and families affected by this hereditary illness, share your experience and learn more about the latest research surrounding sickle cell disease. If you have ideas for the conference, please submit them to sicklecellpartners@gmail.com.





LET'S END THE CONFUSION



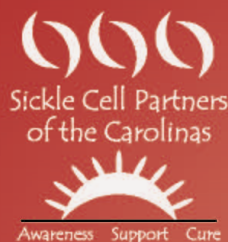
SICKLE CELL PARTNERS OF THE CAROLINAS **AWARENESS SUPPORT CURE**

Although the sign above indicates someone being unsure, puzzled, confused, lost, unclear and baffled, Sickle Cell Partners of the Carolinas would like to end the confusion. Often, members of the core team of Sickle Cell Partners of the Carolinas are asked, “what does your organization do? Who do you serve? What is this group about? Is SCPOC for children or adults? Do you provide financial assistance?” The list goes on and on. Please take a good look at our mission statement and rest assured that this is what we strive to do.

SCPOC was designed to provide a network of support for patients and families affected by sickle cell anemia. We reach out to families when asked and provide support in many ways. Sometimes, that’s a conversation with a parent whose child may be in the hospital. Sometimes, that is taking part in a health fair and sitting at a table answering questions from children, adults or families. We raise awareness about sickle cell disease and do our best to educate the community. Sometimes, that awareness comes from SCPOC lending our support to one of your ideas -- like lighting up a skyscraper along the Charlotte skyline to give every family affected by sickle cell disease recognition and a voice (see article below). Sometimes, that awareness and education comes from your participation at our annual conference, “Sickle Cell Disease... Let’s Talk About It” where we provide patients and families, young and old, a platform to express what this condition means to them, what it has done to them, and how they live each day.

Our awareness effort spills over into our annual University City Turkey Trot 5K race which engages a segment of the population who may not be affected by sickle cell disease whose only connection to this condition is running a race. We advocate on behalf of sons, daughters, mothers, fathers, every human being affected by this crippling illness. Let’s end the confusion and partner to make a better world for those affected by sickle cell disease. Sickle Cell Partners of the Carolinas... we are definitely all of YOU!

Sickle Cell Partners of the Carolinas Presents



Sickle Cell Disease

"let's talk about it"

day conference

Saturday, September 10, 2016 • 8am to 1pm
Friendship Missionary Baptist Church Conference Center

3400 Beatties Ford Road Charlotte, North Carolina 28216

Sickle Cell Partners of the Carolinas Presents



Sickle Cell Disease

"let's talk about it"

day conference

Saturday, September 10, 2016 • 8am to 1pm

Conference will include:

- ▶ Continental Breakfast, Lunch, & Snacks
- ▶ Childcare (ages 3-11)
- ▶ Pediatric, Teen & Adult Sessions
- ▶ Information on Social Security Benefits
- ▶ Open Forum for Adult Patients & Caregivers
- ▶ And Much More!

**Friendship Missionary Baptist
 Church Conference Center**

3400 Beatties Ford Road Charlotte, North Carolina 28216

How to Register

Register and pay online at
<http://scpoconference2016.eventbrite.com>

Mail-in:

Sickle Cell Partners of the Carolinas
 P.O. Box 480714 Charlotte, NC 28269

Make Check Payable to:
 Sickle Cell Partners of the Carolinas

Registration:

\$5 for All Ages

No on-site registration

For more information:

Call 704-562-2760 or Text sickle to 24587



Giving Back Christa's Style & Beauty



We honor Christa Hayes for her beauty, style and determination to empower young women affected by sickle cell disease. Christa left our presence last fall when she transitioned. In her passing, she left behind a wonderful project that SCPOC and her family plan to continue, the annual prom make-over. Christa used her love for style and fashion to spark conversations with young women in high school going through exactly what she endured... the pain of living with sickle cell disease. Using her gifts and talent, she made young women look and feel awesome for one of the most magical nights of their high school years – prom night. Although Christa is no longer with us physically, we are honored to carry on something she started – her idea to provide make-overs for young girls for prom night. SCPOC is dedicated along with Christa's family to continuing the annual prom make-over for young girls affected by sickle cell disease. As the prom season approaches, look for your invitation to take part in Christa's gift to give back to the sickle cell community.

Sickle Cell Partners of the Carolinas Beckwith Scholarship

Sickle Cell Partners of the Carolinas has established a scholarship in honor of the late Ivestia "Peggy" Beckwith, a pioneering force in North Carolina for patients affected by sickle cell disease. Mrs. Beckwith, along with others, was instrumental in securing a grant in 1972 to establish and fund sickle cell programs across the state of North Carolina. She worked tirelessly for decades to heighten awareness about sickle cell disease; to bring attention to the plight of families affected; and to balance health disparities in the community she served.

In honor of her service and efforts in the sickle cell community, SCPOC is proud to continue her legacy and has established a scholarship in her honor. Two (2) \$500 scholarships will be awarded to two (2) deserving students. Candidates for the scholarship must be a sickle cell patient. Candidates must also be enrolled in a college, university or trade school.

If you would like to donate to the scholarship fund please visit our website's donate page at:

www.sicklecellpartnersofthecarolinas.org/donate.html

Please email sicklecellpartners@gmail.com for a scholarship application and additional guidelines for applying.

Sickle Cell Partners of the Carolinas Updates

Making it Better, One Meal at a Time

If you've ever been hospitalized, you know that hospital food is the last thing you may want to eat because you're not feeling your best. One patient who unfortunately had numerous trips to a local children's hospital teamed with others to make a difference in the menu and for patients to make healthier food choices when hospitalized. At Levine's Children's Hospital, you can find "Gerard's Sliders" on the menu. Gerard was among several teens who helped the hospital come up with better food choices that also included carbohydrate counts for those patients who need to watch their insulin dosing. Great job Gerard!



"I'm Seeing RED! Mommy is that for me?"

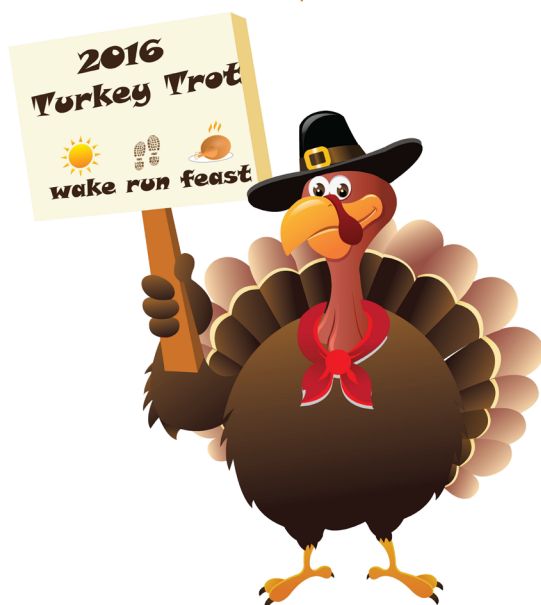


The credit for the Wells Fargo skyscraper going red on September 23, 2015 is owed to a South Carolina man who works for Wells Fargo and has a young child affected by sickle cell disease. For those of you who are familiar with the Charlotte skyline, the city's latest skyscraper often dons a different color each night to support a charity or another endeavor. You'll see Panther Blue to support Cam and the home team or pink to support breast cancer awareness and every color in between for other charities. On September 23rd however, the red displayed was for Sickle Cell Awareness month and the Duke Energy building never looked better. SCPOC thanks the family for this awesome idea to raise awareness about sickle disease, to encourage those who live with sickle cell and to allow a mommy to say, yes... that was for you.

Sickle Cell Partners of the Carolinas is proud to present The University City Turkey Trot! Join us on Thanksgiving Day 2016 for the 3rd annual 5K run/walk.

Wake.... Run.... Feast!

UNIVERSITY CITY
Turkey Trot 5k
NOVEMBER 24, 2016 8:00 AM



GOBBLE UP THE DETAILS AT RUNFORYOURLIFE.COM



Register for the race at : <https://runsignup.com/Race/NC/Charlotte/UniversityCityTurkeyTrot5K>



Is your son or daughter in need of volunteer hours for school requirements? Would you like to volunteer in any way with the Sickle Cell Partners of the Carolinas conference, "Sickle Cell Disease... Let's talk About It" or the University City Turkey Trot being sponsored by Sickle Cell Partners of the Carolinas?

Please email sicklecellpartners@gmail.com to sign up as a volunteer.

Sickle Cell Partners of the Carolinas Updates

SCPOC Community Meet & Greet



Come mingle with others affected by sickle cell disease. Lunch will be served.

Date & Time: Saturday, May 14, 2016 1pm to 4pm

Location: Francis Auditorium, Main Library Uptown Charlotte

RSVP: sicklecellpartners@gmail.com

"Sickle Cell Disease.... Let's Talk About It" 2016 Conference



Registration is now open for "Sickle Cell Disease.... Let's Talk About It." Please help Sickle Cell Partners of the Carolinas build on the success of last year's event. Your input and that of your family and friends will make this an awesome day of conversation and learning as we bring to you once again a great line-up of speakers, fun activities and even the microphone to express how you feel about sickle cell disease. This conference is designed for you to have an open and honest dialog about how this hereditary illness affects you. Save the date now and join us.

Register at : <http://scpoconference2016.eventbrite.com>



Every Drop Stays Here.
Saving Local Lives.

SCPOC Encourages Blood Donations

Sickle Cell Partners of the Carolinas encourages everyone who is eligible to donate blood to help sickle cell patients and others in need. Many patients depend on blood products to manage their sickle cell disease. The Community Blood Center of the Carolinas has a unit dedicated to sickle cell patients. Join their campaign #StepUp4Sickle and donate to help those in need today.

Donors, Thanks For Your Support!

Thank you to all the donors who have supported Sickle Cell Partners of the Carolinas. In addition to donating through your employee giving program, direct mail and PayPal on our website, you can now donate to SCPOC through AmazonSmile. While shopping on Amazon.com, please choose SCPOC as the charity of your choice. After your online purchase, Amazon will send a small donation to Sickle Cell Partners of the Carolinas! It's a great way to shop and donate to an awesome organization that supports patients and families affected by sickle cell disease. Go to: <https://smile.amazon.com/ch/27-1636109>



SOCIAL MEDIA HELP

Do you love social media and can't go a day without updating your status, tweeting your whereabouts or snapping a picture? Help Sickle Cell Partners of the Carolinas stay in the mix on the various social network platforms. Send us an email at sicklecellpartners@gmail.com if you can help.

Contact Sickle Cell Partners of the Carolinas:

Mail: SCPOC P.O. Box 480714 Charlotte, NC 28269 Email: sicklecellpartners@gmail.com

Website: www.sicklecellpartnersofthecarolinas.org



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