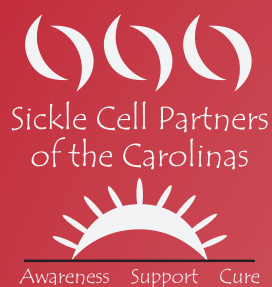


Sickle Cell Partners of the Carolinas Presents



Sickle Cell Disease

“let’s talk
about it”

day conference

Sponsored in part by

N **NOVANT**
HEALTH

On behalf of Sickie Cell Partners of the Carolinas, I welcome all of you to the 4th 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, Sickie 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

**ABBREVIATED BIOGRAPHY OF DR. WAYNE A. I. FREDERICK, M.D., MBA, F.A.C.S.,
PRESIDENT, HOWARD UNIVERSITY,
WASHINGTON, D. C.**



After serving Howard University as interim president for more than a year, Wayne A. I. Frederick was appointed the 17th president of Howard University on July 21, 2014 by unanimous vote of the search committee.

Dr. Frederick is a scholar, surgeon, and researcher. The focal point of his research is to narrow the disparity in cancer care outcomes between African-Americans and the larger population, particularly in the area of breast cancer. Dr. Frederick enrolled at Howard University when he was only sixteen years old and earned his Bachelor of Arts degree and a medical degree in 1992 and 1994 respectively.

He is most grateful that his matriculation, as a triple alumnus of Howard allowed him to commit himself to the mission of Howard University.

In January 2017, The Federal Reserve System Board of Governors elected Dr. Frederick to the Federal Reserve Bank of Richmond's Baltimore Branch. In May 2016, he was appointed to the Board of Advisors for the White House Initiative on Historically Black Colleges and Universities (HBCUs). Dr. Frederick was also elected to the Board of Advisors for the White House Initiative on HBCUs to provide the president and secretary of education advisory support and program and strategy recommendations to strengthen HBCUs.

Named by the Washington Business Journal as one of the Power 100 of 2015 Innovators, Dr. Frederick has received the National Association of Health Services Executives' Congressional Black Caucus Distinguished Leadership in Health Care Award; The Minority Business Leader Award by The Washington Business Journal; Congressional Citation for Distinguished Service presented by the Honorable Barbara Lee on the Occasion of Caribbean-American Heritage Month; been named the 2015 Male President of the Year by HBCU Digest; and in 2014 he was awarded the Howard University Bison Pride Award. In 2013, he was named "Super Doctor" by The Washington Post Magazine.

Dr. Wayne A. I. Frederick is a true son of Howard University—a proud and loyal exemplar of Howard University's motto, Veritas et Utilitas: Truth and Service.

About Howard University:

Founded in 1867, Howard University is a private, research university that is comprised of 13 schools and colleges. Students pursue studies in more than 120 areas leading to undergraduate, graduate and professional degrees. Over the last 20 years, the University has produced four Rhodes Scholars, 10 Truman Scholars, two Marshall Scholars, over 80 Fulbright recipients, 22 Pickering fellows and one Schwarzman Scholar. Howard also produces more on-campus African-American Ph.D. recipients than any other university in the United States. For more information on Howard University, call 202-238-2330, or visit the University's website at www.howard.edu.

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 9, 2017 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 W. Roberts
Jennifer Watson Roberts
Mayor



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

**Saturday, September 9, 2017
Friendship Missionary Baptist Church**

General Session:

8:00 am to 8:45 am	Registration and Vendor Opportunity	Lobby
8:00am to 8:45 am	Continental Breakfast	Conference Center
8:45 am to 8:55 am	Welcome and Opening Remarks Fred Shropshire, News Anchor, NBC-6, Conference Host Sandra Boyd, MA, Sickle Cell Program, Division of Public Health, North Carolina Dept. Of Health and Human Services Dagny McDonald, Chair, Sickle Cell Partners of the Carolinas	Conference Center
8:55 am to 9:40 am	Morning General Session Address “The ‘Discovery’ of Sickle Cell Disease in 1910-1911” Todd L. Savitt, PhD, Department of Bioethics, Brody School of Medicine, East Carolina University	Conference Center
9:40 am to 9:50 am	Yoga Mini Session Kiesha Battles, 500 ERYT and Candace Jennings	Conference Center
9:50am to 10:05 am	Let’s Talk: Sickle Cell Interpersonal Communications Shawn M. Bediako, Ph.D., Associate Professor of Psychology, University of Maryland Baltimore County	Conference Center
10:05 am to 10:15 am	Break and Vendor Opportunity	Lobby



CONFERENCE AGENDA
Saturday, September 9, 2017
Friendship Missionary Baptist Church

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

Sickle Cell Partners of the Carolinas
AWARENESS SUPPORT CURE

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

10:15 am to 11:00 am	Let's Talk: Raising Your Child with Sickle Cell Disease and News Parents Should Know Paulette Bryant, M.D., Blume Pediatric Hematology & Oncology, Novant Health Daniel McMahon, M.D., Pediatric Hematologist / Sickle Cell Specialist, Levine Children's Hospital	Room 123
10:15 am to 11:00 am	Let's Talk: Sickle Cell Disease and Pain Management Options to Consider Yvette Marie Miller, M.D., Executive Medical Officer, American Red Cross Donor and Client Support Center	Room 123
10:15 am to 11:00 am	Let's Talk: Demystifying Clinical Trials Lori Luck, M.D., Medical Director, Sickle Cell Disease, Pfizer Inc.	Room 123
10:15 am to 11:00 am	Let's Talk: What to Expect from Vocational Rehabilitation Chanda Daye, MS, CRC, N.C. Dept. of Health and Human Services Michelle Perry, MS, CRC, N.C. Dept. of Health and Human Services	Room 123
10:15 am to 11:00 am	Inhale, Exhale, Move and Pause – Yoga for Caregivers and Ones They Love Kiesha Battles, 500 ERYT and Candace Jennings	Room 123

Round One Teen Session: *(All teens should attend)*

10:15 am to 11:00 am	Let's Talk: Teen Truth Booth and Open Mic Brandon McCoy, Sickle Cell Patient and Author Shawn Bediako, Associate Professor of Psychology, University of Maryland, Baltimore County	Room 123
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Round One Pediatric Session:

10:15 am to 11:00 am	Pediatric Playroom Torie Leslie, Digi-Bridge Jamie Stepanek, Twisted Turtle of Charlotte	Room 123
11:00 am to 11:10 am	Break and Vendor Opportunity	Lobby



CONFERENCE AGENDA
Saturday, September 9, 2017
Friendship Missionary Baptist Church

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

Sickle Cell Partners of the Carolinas
AWARENESS SUPPORT CURE

Round Two Conference Sessions: *(Teen and adult participants choose one to attend)*

- | | | |
|-----------------------------|---|-----------------|
| 11:10 am to 11:55 am | Let's Talk: "When Providers Say X, Do They Really Mean Y? Interpersonal Communications in the Clinical Setting"
Shawn M. Bediako, Ph.D., Associate Professor of Psychology,
University of Maryland, Baltimore County | Room 123 |
| 11:10 am to 11:55 am | Let's Talk: The Power of Common Ground among Parents and Caregivers Living with Sickle Cell Disease
Ken Mitten, MSW, Pediatric Sickle Cell Social Worker, Levine Children's Hospital | Room 123 |
| 11:10 am to 11:55 am | Ticket to Work Program: How Working Will Affect Your Disability Benefits
Lisa Oakley, North Carolina Department of Health and Human Services | Room 123 |
| 11:10 am to 11:55 am | Let's Talk: Exceptional Children 101
Marianna Sartin, EC Program Specialist for High Schools, CMS
Toni Rios, EC Technology Coordinator for Exceptional Children Programs, CMS | Room 123 |
| 11:10 am to 11:55 am | Inhale, Exhale, Move and Pause – Yoga for Caregivers and Ones They Love
Kiesha Battles, 500 ERYT and Candace Jennings | Room 123 |

Round Two Teen & Pediatric Sessions:

- | | | |
|-----------------------------|--|--------------------------|
| 11:10 am to 11:55 am | Pediatric Playroom
"Aunt Polly and the Big Rig Kids," Renee Brown, Author | Room 123 |
| 11:55 am to 12:05 pm | Break, Vendor Opportunity, Special Guest Appearance | |
| 12:10 pm to 1:30 pm | Luncheon and Keynote Address
"Sickle Cell is a Journey, Not a Destination"
Wayne A.I. Frederick, M.D., MBA, Howard University President | Conference Center |
| 1:30 pm to 1:45 pm | Special Dedication and Beckwith Scholarship Presentation
Dagny McDonald, Chair Sickle Cell Partners of the Carolinas
Tammy Sherrod, Founding Advisor, Sickle Cell Partners of the Carolinas | Conference Center |
| 1:45 pm to 2:00 pm | Closing Remarks & Surveys | |

Survey Says....
Participant Comments About 2016 "Sickle Cell Disease...
Let's Talk About It" Conference



"Very educational." *"I come every year and really enjoy this event."*
"Life changer!" **"More workshops please."**
"Awesome experience!" *"Keep up the good work!"*
"More people need to get involved."



"This was my first conference and I truly enjoyed the event."
"This should be two days." **"Very Informative."**
"Gym was quite cold but I enjoyed it."
"Excellent conference, thoroughly enjoyed it."
"GREAT JOB, SO ORGANIZED." *"Too cold!"* **"Excellent job!"**

AWARENESS.... SUPPORT.... CURE!

SCPOC Events to Raise Awareness about Sickle Cell Disease



Wells Fargo Red Lights for
Sickle Cell Awareness
September 2016



2nd Annual Sickle Cell
Disease Symposium:
OPIODS -- The Big
Elephant in the Room



Promoting the University City Turkey Trot (sponsored by SCPOC) at the
Prosperity Village Area Association Food Truck Rally in October 2016.



Family Fun
Day @
Google Fiber

October 2016



Sickle Cell Partners of the Carolinas Beckwith Scholarship

Sickle Cell Partners of the Carolinas was proud to award three deserving students with the Beckwith Scholarship to continue their educational studies. This scholarship fund was established by Sickle Cell Partners of the Carolinas in 2014 to honor the commitment to the sickle cell community of Mrs. Ivestia “Peggy” Beckwith. 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 North Carolina counties. The blueprint of that program still remains in operation across the state today.



Mrs. Ivestia “Peggy” Beckwith

Scholarship Winners



Andre’ Harris



Sarah Joergensen



Max Monroe

Sickle Cell Partners of the Carolinas Beckwith Scholarship

The Beckwith Scholarship recipients were awarded their scholarships in August 2017. They will go on to begin or continue their studies across North Carolina and in Pennsylvania. Below are a few quotes that show their determination and stamina to succeed despite their battles with sickle cell disease.

From the Beckwith Scholarship Recipients:

"Sickle cell disease will try to dictate to you how your life will go and will try to place limitations on what you can do. From an early age, my parents instilled in me an attitude that no matter what, I could/can achieve anything I want to achieve. With any chronic, life threatening illness, not just sickle cell, it will run your life if you allow it to. There have been so many experiences and opportunities I missed out on because at the time, I allowed my disease to have me. I have arrived at the place where I have it, or in other words, I have it just where I want it." -- **Andre' Harris, Beckwith Scholarship Recipient**

"I no longer allow the shape of my red blood cells to limit what I am able to achieve. When I was three month's old, I was diagnosed with sickle cell anemia. As a result, my childhood was filled with hospital stays, blood tests, and blood transfusions. Despite the countless needles and doctors' appointments, I am grateful that I was born with sickle cell anemia because it has allowed me to gain a new appreciation for the world of healthcare and helping others." --**Sarah Joergensen, Beckwith Scholarship Recipient**

"I was placed on the operating table and given the anesthesia. The doctor told me to count to ten but I was already unconscious after I said 3. When I woke up my stomach was bloated like an inflated balloon and I was surrounded by my surgeons and my family. I was told that the surgery went perfect and I was shown a series of pictures of my gallbladder in and out of my body. I was so ecstatic that I would finally recover that the only words I could mutter were "thank you" as tears of joy rolled down my face. This experience shaped me into who I am today because it taught me to appreciate the good times and to never take advantage of the good health you have because there are times that are much worse than you ever expected." -- **Max Monroe, 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 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).

Criteria for Applicants:

- Applicants must be enrolled in an accredited college, university or trade school
- Applicants must be a graduating high school senior or 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)
- Scholarship will be awarded in the summer of 2018

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

Get Screened to Know Your Sickle Cell Status

TO FIND OUT WHETHER YOU OR YOUR LOVED ONE

has sickle cell disease (SCD) or sickle cell trait (SCT), blood tests must be done to screen for these conditions. Arming yourself with this information is referred to as knowing your sickle cell status.

What is sickle cell screening?

Screening for sickle cell means testing a person's blood for abnormal types of hemoglobin:

- Hemoglobin is a substance inside the red blood cell that delivers oxygen to all organs in the body.
- There are many types of altered hemoglobin, but people with SCD or SCT make a form of hemoglobin which is abnormal and it is called hemoglobin S or sickle hemoglobin.
- A blood test for hemoglobin S or sickle hemoglobin can tell you if your hemoglobin is normal, you have SCD or SCT (carrier status) or if you have another type of abnormal hemoglobin.

Why should I (or my child) get screened for sickle cell?

- Getting screened to know your sickle cell status is extremely important at child-bearing age because SCD and SCT can be passed down to children through their parents' genes (Visit <http://www.cdc.gov/ncbddd/sicklecell/facts.html> for more information).
- Knowing if you have sickle cell trait is important because you could have a baby with SCD if your partner also has SCD, SCT or another abnormal hemoglobin gene (like hemoglobin C or Beta-thalassemia).
- All newborns should be screened for sickle cell, even if they look healthy. If left undetected and untreated, SCD can lead to severe health problems and even death, early in childhood.

When should sickle cell screening occur?

At birth:

- Newborn babies should be screened for sickle cell status (SCD or SCT), as early as 24-48 hours after birth.
- In the U.S. (all 50 states and the District of Columbia), babies are screened for sickle cell status as part of the newborn screening program.
- A positive newborn screening test means your baby likely has a condition reported but you need more testing by your baby's doctor to know for sure.

Both SCT and SCD are conditions that are genetically inherited or passed down from your parents.



SCD is different from SCT; one cannot turn into the other. SCD causes many disabling symptoms like anemia (causes a person to feel tired, weak or short of breath), severe pain, or even stroke. SCT does not make you sick. In fact, screening tests might show that you have SCT and yet you usually never have physical symptoms.



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



In adulthood:

- Screening for sickle cell status may be done as part of the care you and your partner receive before or during pregnancy, or after your baby is born.

What tests should be done?

The best tests to tell you whether you or your child is at risk for having SCD or SCT are:

- Complete blood count (CBC) – this test screens for anemia, a condition that occurs when not enough oxygen is delivered to the cells of the body due to the presence of abnormal hemoglobin

AND;

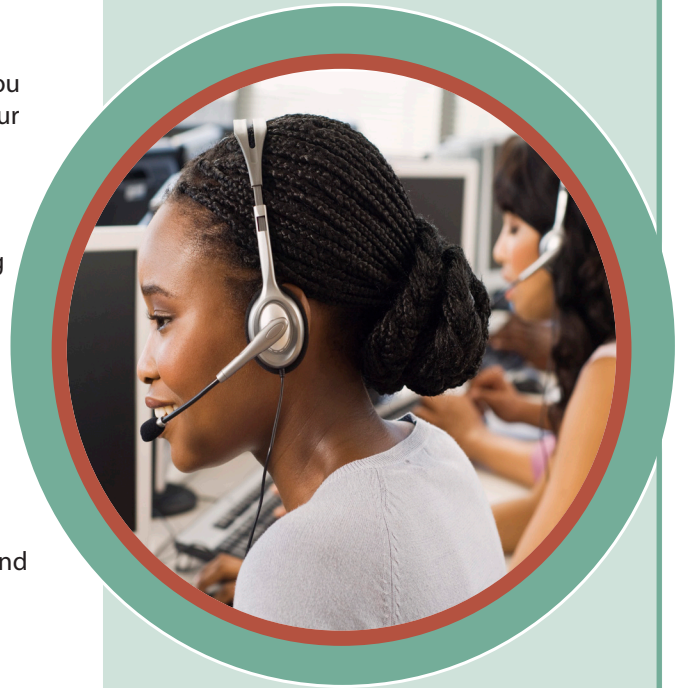
- Hemoglobin electrophoresis, high performance liquid chromatography (HPLC), or DNA testing which may be used to find out the type of hemoglobin present in a person's blood.

What tests should not be used?

- Results from sickle cell solubility tests may be misleading and SHOULD NOT be used to determine sickle cell status.

Where can I get tested?

- All infants born in the United States after 2006 should have their newborn screening information as part of his or her medical record, including sickle cell status. Contact your child's physician for more information.
- Ask your physician, local health-clinic, or community based sickle cell disease organization for testing locations near you.
- You may also contact the Sickle Cell Disease Association of America (SCDAA) at (800) 421-8543 or visit their website at www.sicklecelldisease.org to find testing locations in your community.



Where can I find more information about sickle cell disease and sickle cell trait?

For more information about sickle cell, visit: <http://www.cdc.gov/ncbddd/sicklecell/index.html>



2017

UNIVERSITY CITY

Turkey Trot 5k

THANKSGIVING DAY

NOV 23, 2017

8:00 AM

WAKE... RUN.... FEAST!

THE FRESH MARKET 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 4th 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

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

Conference Notes

[illegible]

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 Sickel Cell Partners of the Carolinas disclaim all liability in connection with the specific personal use of any and all information provided during this conference.

RESOURCES:

Be the Match – www.bethematch.org

Carolinas Healthcare – www.carolinashealthcare.org

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

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

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

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, LaNae Wade, Tammy Sherrod, Paulette Smith,
James Rogers, Betty Monroe, Montae Monroe, Nikki Johnson

Conference Planning Committee:

Dagny McDonald, Hans McDonald, LaNae Wade, Tammy Sherrod, Paulette Smith,
James Rogers, Betty Monroe, Montae Monroe, Kathy Staley

Sickle Cell Partners of the Carolinas Scholarship Committee:

Tammy Sherrod, James Rogers, Dagny McDonald, Hans McDonald

SICKLE CELL PARTNERS OF THE CAROLINAS

AWARENESS SUPPORT CURE

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