

Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.

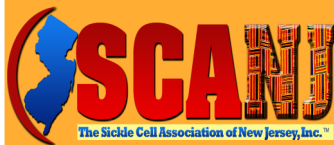


Volume 5
Issue 5

Say It Loud!

May 2014

Sickle Cell News You Can Use
Sickle Cell Association of New Jersey
P.O. Box 9501 Newark, NJ 07104



Calendar Listings:

May

12-16th Peer Leader Certification Course for Take Control of Your Health Chronic Disease Self Management Workshops. JFK Center Willingboro.

21 SCANJ attends SCD Learning Collaborative in cooperation with the CNNJSC Network. St. Barnabas Health, Bethesda, MD

21 Liberty Science Center Community Evening. Visit the SCANJ table and sign up for the Tackle Sickle Cell 5K Run/Walk 6:00 pm

SCANJ partners to offer FREE CDSMP Take Control of Your Health Six Week Community Workshops beginning:

- **19th Shiloh Baptist Church** 99 Davenport Ave in Newark. Monday's at 6:30pm
- **24th Independent Club of Colonia** Saturday's at 10:00am

28th Nomination Action Day: Stay posted for details...

June

14 NFL McCourty Twins Tackle Sickle Cell 5K Benefit for Embrace Kids Foundation. Liberty State Park Jersey City 9:00am

21 Sickle Cellabration Garden State Discovery Children's Museum in Cherry Hill 9:30am-2:00pm

For updates or to register for SCANJ programs, call 973 482-9070 or go to our event link via

www.sicklecellnewjersey.org

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America

Can We Get a Little Help In Here?



Mary Bentley LaMar
Founder
Executive Director

And the answer is YES! Join us in welcoming the Morning Star Community Christian Church of Linden to our volunteer family. We are grateful to be able to call on them for support.

We also welcome our new Chronic Disease Self Management Program (CDSMP) Master Trainers, Ediom Utuk and Phillip Hall. They just completed the Master Trainer course through the Stanford School of Medicine's Patient Education. And we have additional Peer Leaders who have recently been certified.

With this added support, SCANJ will be able to deliver more high quality workshops that help individuals to become better self managers of their health challenges.

Thank you so much to all of our wonderful volunteers who have stepped up to the plate to support our programs and services. And it's a good thing too considering all that is coming up.

Please read through this newsletter and then get your walking shoes on. Perhaps you can start off with SCANJ's *Walk the Talk* Team for the NFL McCourty Twins Tackle Sickle Cell 5K Run/Walk on June 14th. This is a benefit for Embrace Kids Foundation. We partner with Embrace Kids on many programs that benefit the sickle cell community.

Keep moving and you will run into the Sickle Cellabration on June 21st. This is our way of commemorating World Sickle Cell Disease Day. And we are in the planning stages for the 24 Seven Line Dance Marathon which takes place September 19-20th. All of these programs need you to make a difference in the sickle cell disease community. If you would like to help, please give us a

call or send us an email. A prayer, a donation, your time, your expertise...we appreciate all that you do to further our mission.

~Mary

SCANJ Mission Statement

To advocate for and enhance our membership's ability to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease."



Teen Ambassador
Ayoola Ogunyimika

Afterwords Part 5: Youth Connection

During the inaugural Statewide Sickle Cell Symposium held last November, we conducted a Youth Connection Treasure Hunt. It was facilitated by Dr. Ansley LaMar, SCANJ Board Chair and Ayoola Ogunyimika, SCANJ Teen Spokesperson.

The youth attendees participated in an ice-breaker. Then they were broken up into teams, given a treasure hunt map and challenged to "hunt" through the exhibit floors of the Liberty Science Center. The Youth Connection was a way to engage children and teens in interacting with each other and learning more about their health. The Liberty Science Center sparked a sense of adventure, intellectual engagement and fun.

When we think of our youth, we want them to become more knowledgeable and aware of programs that will foster their well-being. Additionally, we want them to support each other through what can be a difficult journey with sickle cell disease. The treasure hunt was just one way to foster this outcome. At the SCANJ we have several programs to support youth facing sickle cell

We encourage you to take advantage of these opportunities. A few that you may want to check out are:

- **The Frances Thompson Walton Scholarships for higher education**
- **The Snowflake Awards; funding support for youth in extra-curricular programs, tutoring, summer camp and after school programs**
- **SCANJ Child and Teen Ambassador Program**
- **Sickle Cellabration Commemorating World SCD Day**

Registration for the above SCANJ programs is on the events page of our website www.sicklecellnewjersey.org. And please check out other programs for youth living with sickle cell disease such as summer camps and scholarships that are offered by other agencies.

Afterwords is a six part newsletter series to shed insight on the topics covered during the 2013 SCANJ Statewide Sickle Cell Symposium. This year's Statewide Sickle Cell Symposium will be November 22nd at the Liberty Science Center in Jersey City.



The Sickle Cell Association of New Jersey
Mailing Address

P.O. Box 9501 Newark NJ 07104
EIN# 80-0474935 SCANJ is a 501c 3 agency

Phone: 973 482-9070 Fax: 973 485-6591
email: info@sicklecellnewjersey.org

Reserve These Dates:
June 21st Annual Sickle Cellabration
& September 19th -20th



24 HOURS 7 EVENTS
RAISING FUNDS & AWARENESS FOR
SICKLE CELL DISEASE!

The Say It Loud Newsletter is published monthly. Archived copies are available for download from our website.

Beverly Lucas-Editor

www.sicklecellnewjersey.org
Join SCANJ's Walk The Talk Team



TACKLE SICKLE CELL 5K

IN PARTNERSHIP WITH THE
JERSEY CITY DEPARTMENT OF RECREATION

- 1 in 500 African Americans and 1 in 1400 Latinos are born with Sickle Cell Disease
- If also affects people of Caribbean, Middle Eastern, Indian and Mediterranean descent

The Tackle Sickle Cell Campaign aims to educate the public, increase blood donation, raise money & awareness for the fight against sickle cell disease.

This 5K Run/Walk is the major fundraising component of the Tackle Sickle Cell Campaign. The Run/Walk is for all ages and will be followed by a celebration including music, food, and fun at the park.

SATURDAY, JUNE 14, 2014
REGISTRATION STARTS AT 9AM
LIBERTY STATE PARK, JERSEY CITY, NJ

Twin brothers Jason & Devin McCourty were football standouts at Rutgers University before moving on to the NFL where they both currently starting defensive backs.

Jason & Devin McCourty will be joined on this day by fellow members of the NFL & Rutgers football community.

All proceeds from this campaign will go toward emergency financial assistance, scholarships for young adult sickle cell patients and to fund educational programming on how families can best manage their child's disease.

To register or for more information, please visit www.tacklesicklecell.org/events



MAYOR
STEVEN M. FULOP



City of Jersey City
Official Government Page
JC.GOV

Coming Soon:

American Red Cross
Community of Giving Blood
Drives:

July 12 Bethany Baptist
Church 1115 Gibbsboro Rd.
Lindenwold & July 13th
Bethel AME Church 512 N.
Church St. Mooresville.
Schedule now 1 800 RED
CROSS or redcrossblood.org

August TBA Kente Karpel
Movie Gala

September 19-20 SCANJ's
24 Seven Line Dance
Marathon. New Jersey City
University, Jersey City

October 1-4 Sickle Cell
Disease Association of
America (SCDAA) National
Convention & SCANJ Road
Trip to the SCDAA National
Convention Baltimore, MD

November 22 Statewide
Sickle Cell Symposium
Liberty Science Center
Jersey City.

December Holiday Parties
TBA