

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  
Issues 10

# Say It Loud!

October 2014

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



## Calendar Listings:

### October

Now until the 22nd. Sign the *White House Petition to declare SCD a national priority* (see pg. 2)

**1-4th SCANJ Road Trip** to the Sickle Cell Disease Association of America (SCDAA) National Convention, Hyatt Regency Inner Harbor, Baltimore, MD

**11th Humanity Baptist Church** -- SCANJ Sickle Cell Sabbath visit 10:30am 235 Bergen St. Newark

**18th Women's Health and Wellness Workshop** 12-4pm. Source of Knowledge 867 Broad Street. Newark. SCD information available. Register through 973 580-5028

**28th Sickle Cell Awareness Program hosted by Alpha Kappa Alpha Sorority, Rho Phi Chapter-** Montclair State University 8:00pm

### November

**Nov. 6, 7, 10 & 11th. Chronic Disease Self Management (CDSMP) Peer Leader Certification Course.** 9:30am- 4:00pm Shiloh Baptist Church Spain Center 107 Davenport Ave. Newark. Register now. Class size is limited.

**22nd STATEWIDE Sickle Cell Symposium** 8:30am-2:00pm at the Liberty Science Center (Jersey City)

### December

**Holiday Parties with Kenta Klaus**  
11th South (Cherry Hill)  
12th Central (location TBA)  
13th North (Montclair)

SCANJ is the  
New Jersey Chapter of the



Sickle Cell Disease Association  
of America

## A Word From The Executive Director...Grateful.



**Mary Bentley LaMar**  
Founder  
Executive Director

Sickle Cell Awareness Month concluded with a flurry of meaningful activities. Most impactful was the 24 Seven Line Dance Marathon- 24 hours with 7 major events raising funds and awareness for sickle cell disease.

A heartfelt thanks to our host facility New Jersey City University, under the

leadership of President Dr. Sue Henderson, VP Student Affairs Dr. John Melendez and Dean of Student Affairs, Dr. Lyn Hamlin. And special thanks to the Office of Campus Life and Community Service, Robert Quiñones, Mel Williams and Victor Devalle. They worked almost 24/7 to bring everything together.

Thanks also to Douglas Hawkins of the Step 4 Step Line Dancers for keeping us moving. And most importantly, the Student Government Organizations, Greek Council, fund-raising teams, volunteers and individuals who led us to raise over \$14,000.

Read through this newsletter and see how the funds raised help us to implement the programs and services you see offered. We are grateful that your involvement makes the mission come to life.

~Mary

### SCANJ Mission Statement

*In concordance with the mission of The Sickle Cell Disease Association of America; "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."*

## Our Road Trip to the SCDAA Convention

We had about 180 miles to go before we would enter the Hyatt Regency Inner Harbor in Baltimore Maryland. This was the site for the 2014 Sickle Cell Disease Association of America national convention.

From October 1-4th, our SCANJ attendees were immersed in a gathering of individuals from all walks of the sickle cell community... researchers, physicians, individuals living with sickle cell disease and their family members, students, pharmaceutical representatives, celebrities, community based agency executives and staff. Additionally, we would meet with attendees from the entire country and various parts of the world.

The vast array of workshops and lectures was as varied as the attendees. Topics covered clinical treatment of sickle cell disease, research, patient care, sickle cell history, health disparities and community based practices. And equally important was the networking and exchange of ideas and resources as attendees got together.

Ayoola Ogunyimika, Teen Spokesperson for the SCANJ, attended along with her parents' Olu and Labake. SCANJ provided Road Trip scholarships for 8 attendees from New Jersey. We also showcased our programs and services during the Poster Session with a poster titled "24 Seven-Our Journey Now with Sickle Cell Disease."

The SCDAA convention is an annual meeting established to bring health care professionals and individuals with sickle cell disease and related conditions together to learn the latest developments in research treatment and services related to sickle cell disease. We encourage you to make the trip.

**Dorothy C. Moore M.D.**  
1952 - 2014



We sadly note her passing, yet we joyously celebrate her time on earth.

She "fought a good fight and she won." Despite being born with sickle cell disease, Dr. Moore was raised in Newark and went on to become the 1st female African American Immunopathologist in the State of New Jersey.

She served as the Chief Medical Officer for the SCDAA. Dr. Moore lived a rich and active life, was supportive of her family, and was passionate about serving all under her care. She leaves a loving family and friends, and a grateful sickle cell community.

**Materials from the SCDAA Convention will be available at the SCANJ Statewide SCD Symposium November 22, 2014 Liberty Science Center, Jersey City, NJ**

WWW.SICKLECELLNEWJERSEY.ORG

Make a Difference!  
**DONATE**

**The Sickle Cell Association of New Jersey**

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

Beverly Lucas-Editor

[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)



**The Statewide Sickle Cell Disease Symposium is Coming!**

If you want to be empowered. If you want to increase your knowledge. If you want to connect with others who are passionate about making a difference in the sickle cell community, then you want to be at the Sickle Cell Association of New Jersey's 2nd Annual Statewide Sickle Cell Symposium. It's all happening Saturday, November 22nd from 8:30am to 2:00pm at the Liberty Science Center in Jersey City.



We're planning an exciting program suitable for individuals effected by sickle cell disease, health care professionals who provide care for patients with the condition from infancy to adulthood (including private practice physicians, hospitalists, ED staff, nurses, social workers), and the community at large.

You can experience several workshops on the latest clinical research and treatments including:

- Breakfast Meet and Greet & Poster Session
- Keynote Panel Presentation
- Bone Marrow Transplants, Dr. Alfred Gillio, Hackensack Medical Center-Presenter
- Caring For Your Child with Sickle Cell Disease, Dr. Jill Menell, St. Josephs Hospital-Presenter
- Introduction to Clinical Trials and Research, Dr. Alice Cohen, Newark Barnabas Medical, Adult SCD Center-Presenter
- Introduction to Chronic Disease Self Management- Darlene Young, Kay Robinson-Presenters
- Youth Research Excursion -Ayoola Oguymika Teen Spokesperson & Dr. Ansley LaMar -Presenters
- Kente Carpet Morning at the Movies-PSA's on SCD

And back by popular demand is a performance by New York's Big Apple Playback Theatre, the Lunch and Learn and museum admission to the exhibit halls. The Dr. Charles F. Whitten Awards for outstanding service will be presented to individuals and organizations. **Early Bird Registration is FREE via [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org) events Day of event registration is subject to a \$25.00 fee. You may also register by calling 973 482-9070.**

**Advocate!  
Please Sign  
Before October  
22nd!**

Sign the White House Petition to Declare Sickle Cell Disease a national health priority and support legislation to expand and establish SCD programs.



Sickle Cell Disease (SCD) is Real!  
SCD is a major public health concern causing critical healthcare impacts in the nation.

Reauthorization of the Sickle Cell Treatment Act – Bill H.R. 5124 will expand the national newborn screening program, develop a comprehensive adult transition program, continue public surveillance, expand research efforts and establish up to 25 sickle cell treatment centers throughout the US all in an effort to support the creation of a sustainable comprehensive model of care for individuals affected by SCD.

We request acknowledgement and declaration of SCD as a national health priority; support of legislative Bill-H.R. 5124 and return funding for SCD programs in the President's budget.

Currently we NEED over 60,000 signatures before October 22, 2014.

To sign go to:

<https://petitions.whitehouse.gov/petition/declare-sickle-cell-disease-national-health-priority-and-support-legislation-expand-and-establish/jFgQrMJ7>