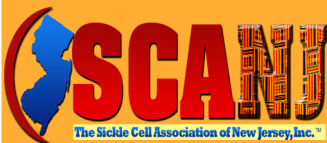


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



## Calendar Listings: October

**2nd Research Invitational Dinner**  
6:30pm. 21 Van Vleck St. in Montclair  
SCANJ's project is on <http://www.pcori.org/research-results>

**8th Take Control of Your Health Chronic Disease Self Management Workshop.** 6 week session begins. Hickory Corner Public Library in East Windsor. 6:30pm. RSVP

**Take Control of Your Health Diabetes Self Management Workshop.** 6 week session begins. Living Springs Delanco, NJ 10:00am

**29th NEW DATE! New Approach! 24 Seven Kick Off Party!**  
6:30pm-9:00pm.

This is the beginning of fundraising for the **2016 24Seven Line Dance Marathon**. Teams, organizations and individuals...let's get this party started!! RSVP by calling our office or via the events tab on

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

**November 5th SCANJ's Research Project: "We'll Take The Village Engaging The Community To Better Health. Meeting 7:00pm**

SCANJ is the  
New Jersey Chapter of the



Sickle Cell Disease Association  
of America



Volume 6  
Issue 8

# Say It Loud!

October 2015

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

## Back From the Road and We're Ready to Get Connected!



**Mary Bentley LaMar**  
Founder  
Executive Director

We're fresh off the 43rd Annual SCDAA Convention trail and ready to Get Connected! In Baltimore, MD from September 23rd-26th, SCANJ joined with hundreds of others from around the country and different parts of the world to gain knowledge on how we can improve the lives of individuals living with sickle cell disease in our country and globally. The convention did not disappoint.

I had the honor of conducting the convention's opening ceremony. In SCANJ style, I began with a Zulu chant and had everyone in the audience singing to Mary Mary's "It's Our Time." With that start, attendees were off to take part in over 75 convention offerings including lectures, forums, workshops, and poster sessions. Workshops ranged

from "Innovations in Stem Transplant and Gene Therapy" to "The Role of the Patient in Empowering Change." We presented a workshop on our SCANJ Statewide Sickle Cell Symposium (held annually on the Saturday before Thanksgiving). Presenter slides are available on the SCDAA website so check it out.

During the convention several presentations were centered on aspects of the SCDAA's Sickle Cell Disease Newborn Screening Program (see below). I'm excited that our agency has been named as a Co-Lead for the North East Region on this important program. This gives us an opportunity to work more closely with our New York colleagues and also Community based organizations throughout the SCDAA network in bringing a change for the better for the families we serve.

Prior to Baltimore, Ediom Utuk, Co-Chair of The Village, and I attended the Patient Centered Outcomes Research Tier 1 Convention in Minneapolis, MN.

Thanks to all who supported our SCANJ "Walk The Talk" Team for the national SCDAA Walk. We raised \$1,800.00!!

Let's keep the momentum going. **On Thursday October 29th from 6PM -9PM, come to the 24 Seven Line Dance Marathon Kick Off Party!** We're doing something new this year in cooperation with New Jersey City University. So come out and be a part of efforts to bring about a change. One step at a time we fulfil 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.*

## Highlight from the SCDAA Convention...

A highlight of the convention was the report on the new Sickle Cell Disease Newborn Screening Project (SCDNBSP); a cooperative agreement awarded to the SCDAA by the Health Resources and Services Administration (HRSA). The SCDNBSP is a 2-year collaborative that utilizes the SCDAA's alliance with 10 regional community-based organizations and stakeholders across the nation to improve sickle cell care for a broader population of patients. The award total to the SCDAA is \$2,679,000 a year for a period of two years ending in May of 2017.

SCANJ's Executive Director, Mary Bentley LaMar has been chosen as a Co-lead in the HRSA Northeast Region. She serves alongside Stanley Simpkins, Executive Director of SCDAA-Philadelphia/Delaware Valley Chapter and Andrea Williams, Executive Director of the Children's Sickle Cell Foundation of Pittsburgh. The SCDNBSP will support SCANJ's collaboration with colleagues at the Queens Sickle Cell Advocacy Network led by Gloria Rochester as the NY State Lead Agency and the Sickle Cell Thalassemia Network led by Donnette Carol as a NY State Partner.

A goal of the SCDNBSP is to strengthen the infrastructure that overcomes obstacles linking people with SCD to quality care. This will be done with the Get Connected Patient Powered Registry, Certified Community Health Workers, care coordination, SCD education, and working with key stakeholders to make a collective impact in the community. Stay posted for news as we work on this important program.



**SCANJ Road Trip Scholars to the SCDAA Convention; Dominique Goodson and Quacian McEnough enjoying the Unity Soiree Gala with Maze Runner Scorch Trials Movie Star, Dexter Darden.**

[WWW.SICKLECELLNEWJERSEY.O](http://WWW.SICKLECELLNEWJERSEY.O)

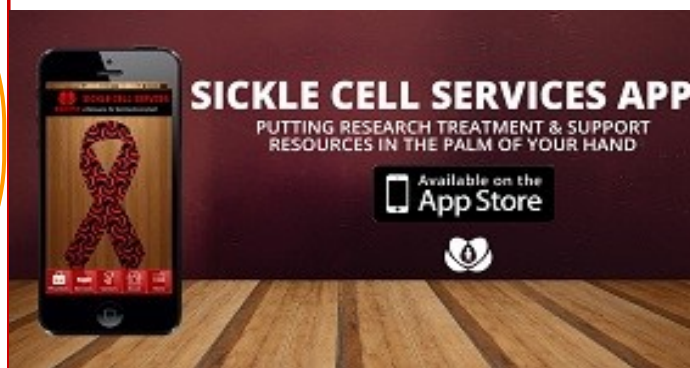




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*You asked for it...you got it!*



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

**THE SICKLE CELL ASSOCIATION OF NEW JERSEY**  
IN COOPERATION WITH HOST SPONSOR NEW JERSEY CITY UNIVERSITY

# 24<sup>th</sup> Annual Seven line dance marathon

## KICK OFF PARTY

**JOIN US IN  
RAISING FUNDS & AWARENESS FOR  
SICKLE CELL DISEASE!**

**THURSDAY OCT. 29, 2015 FROM 6PM - 9PM**

FOR INFORMATION TO REGISTER OR DONATE GO TO:  
[WWW.SICKLECELLNEWJERSEY.ORG](http://WWW.SICKLECELLNEWJERSEY.ORG)  
OR CALL **973.482.9070**



2ND FLOOR STUDENT UNION BUILDING 2039 KENNEDY BLVD. JERSEY CITY, NJ.

### *Coming Soon...*

**November 5th The Village Meeting.** Agenda: Conversations on research relevant to you. 7 pm-8:30pm in South Orange. Call 973 482-9070 for details.

**21st. 4th Annual Statewide Sickle Cell Disease Conference and Dr. Charles F. Whitten Award Ceremony.** 9:00am-3:00pm. Liberty Science Center in Jersey City

**December Join us for the Holiday Parties with Kenta Klaus.** Special Thanks to NOBLE our Toyland Sponsors These parties are FREE for families effected by sickle cell disease. All others are Merry-makers by making a donation of \$25. per adult and \$10.00 per child

**11th Holiday Party Central 6:30-9:00pm** Bradley Beach Bowling Center in Bradley Beach.

**17th Holiday Party South 6-8pm** Garden State Discovery Children's Museum in Cherry Hill

**19th Holiday Party North 3:00pm-5:00pm** Van Vleck House in Montclair

Register for SCANJ programs via events on [sicklecellnewjersey.org](http://sicklecellnewjersey.org) or call 973 482-9070.

*Dates are subject to change.  
Any changes will be posted.*

