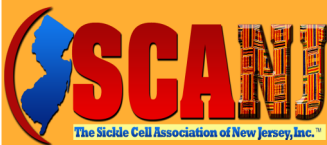


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



### Calendar Listings:

**JUNE 6th Montclair African American Heritage Parade (10am) & Festival (1pm).** Nishuane Park, Montclair. Visit SCANJ's table.

**10th Village Partnership Conference Call.** This is a PCORI initiative. Call SCANJ 973 482-9070.

**11th Frances Thompson Walton Scholarship applications due.**

**13th Eleventh Annual Unified Pre Ramadan Health Fair.** Rutgers NJ Medical School 185 South Orange Ave. Newark. 10am-3pm. SCANJ presentation at noon.

**20th World Festival on fun and learning for the whole family.**

## WORLD SICKLE CELL DISEASE DAY SICKLE CELLABRATION

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

**20th McCourty Twins Tackle Sickle Cell 5K Benefit for Embrace Kids Foundation.** Liberty State Park in Jersey City 9:00am



SCANJ is the  
New Jersey Chapter of the



Sickle Cell Disease Association  
of America



Volume 6  
Issue 6

# Say It Loud!

June 2015

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

## June 20th...It's ON! The 6th Annual Sickle Cellabration!



**Mary Bentley LaMar**  
Founder  
Executive Director

other the latest developments in sickle cell disease.

We use the term "Cellabration in commemorating World Sickle Cell Disease Day because we celebrate the success and courage of individuals all over the world living with sickle cell disease.

This year's featured workshop is Advocacy Training and will be given by the SCANJ Road Trip Attendees to the National SCD Advocacy Day in Washington DC.

Can you believe it's been six years since SCANJ's first *Sickle Cellabration*? Time flies when you're having fun. And that is just what the *Sickle Cellabration* is about.

We'll have fun learning and sharing with each

The workshop presenters are Quacian McEnough, Sireca Gregory, Darlene Young, Wendy Adi-Darko, Keema Givens and Olga Barnwell. This is just a hint of what is in store when you come to the 6th Annual *Sickle Cellabration*. The complete schedule is listed below. We look forward to seeing you and your family on the 20th in Cherry Hill.

In last month's newsletter we reported on our recent award from the Patient Centered Outcomes Research Institute (PCORI). Our project is *We'll Take The Village: Engaging the Community To Better Health*. At our Research Invitational Dinner on May 15th attendees were introduced to the initiative.

SCANJ's project is on <http://www.pcori.org/research-results>

Please help in our PCORI initiative by joining the "Village." Learn more during the Village Partnership Conference call on June 10th (calendar listing).

For those of you who regularly read our monthly newsletter you know that this month is no exception. We have many programs for you to get involved in. When you are **IN...**the awareness about sickle cell disease is **OUT! SAY IT LOUD!!**

~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."

## World Sickle Cell Disease Day. We Honor Your Advocacy!

When SCANJ was founded on September 1, 2009 we wanted to do whatever we could to bring awareness to the challenges of living with sickle cell disease. And just as important, we wanted to celebrate the successes in a way that would foster an environment that yields support and more positive results for the sickle cell community. SCANJ's *Sickle Cellabration* was born out of this mandate.

We host this event each year to commemorate World Sickle Cell Disease Day (June 19th).

Over the years we have enjoyed great support from partners including Embrace Kids Foundation, Robert Wood Johnson Pediatric Hematology, Newark Beth Israel Medical Center Adult Sickle Cell Center and the Valerie Fund, Be The Match, The American Red Cross, Dr. Wanda Shurney/Michigan Chapter SCDA, SCDA Philadelphia/Delaware Valley Chapter and Cooper Hospital Pediatric Sickle Cell Unit.

We have given over \$3,000.00 in scholarships and selected seven Child and Teen Ambassadors. World Sickle Cell Disease Day began in 2006 as an initiative of the United Nations. You are invited to join us in this great day for the whole family. The World is yours!

### PASSPORT TO THE WORLD TOUR ITINERARY:

**9:30am** Welcome Assembly and Cellabration Drum Call

**10:00am** Say It Loud! Awareness for SCD

Awarding of the Frances Thompson Walton Scholarship

Advocacy Training Workshop

**11:00am** Passport To the World Opens

Museum exhibits

Genes Genius Teen Game Show

**12:30pm** Cuisine from Around The World

**1:30pm** Child and Teen Ambassadors Selection

**2:00pm** Sickle Cellabration Closing

(you may continue to enjoy the museum)

**To RSVP for Sickle Cellabration or for any other SCANJ events just call us at 973 482-9070 or visit our events tab on [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)**

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





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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




# WORLD SICKLE CELL DISEASE DAY

# SICKLE

# CELL ABRAATION

## SATURDAY, JUNE 20, 2015

### 9:30 AM TO 2:00 PM



**FUN ACTIVITIES FOR THE FAMILY, ADVOCACY WORKSHOP  
A BONE MARROW DRIVE, INTERNATIONAL CUISINE  
AWARDING OF THE FRANCES THOMPSON WALTON SCHOLARSHIP**

**SELECTION OF THE 2015-2016 NEW JERSEY SICKLE CELL CHILD AMBASSADOR AND TEEN SPOKESPERSON**

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

**GARDEN STATE DISCOVERY CHILDREN'S MUSEUM  
2040 SPRINGDALE RD. CHERRY HILL, NJ**

#### **Coming Soon:**

*Attention Community Organizations:*

**July 31st Kente Carpet Movies Under The Stars** outside in the gardens of the Van Vleck House. 21 Van Vleck Street, Montclair. Join our "Village" as an Awareness Partner Call 973-482-9070 to sign up.

**August 29th SCDAA Walk With The Stars.** Join SCANJ's "Walk The Talk Team" or be a virtual walker. Baltimore MD.



**September SCANJ's 24 Seven Fundraiser.** Stay posted for updates.

**September 22-26th** SCANJ Road Trip to the SCDAA Convention Baltimore, MD

