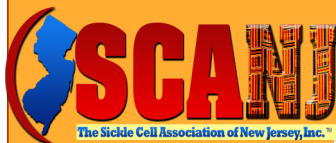


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



### Calendar Listings:

#### June

3rd-4th SCANJ Video presented at NYMAC Meeting. Baltimore, MD

6th Frances Thompson Walton Scholarship application deadline. [scanjscholarship.eventbrite.com](http://scanjscholarship.eventbrite.com)

9th. Tackle Sickle Cell 5K Walk with Embrace Kids and the NFL McCourt Twins.



Walk with SCANJ's "Walk the Talk" Team. BBQ and Kids Carnival for all registered. 9:00am Liberty State Park, Jersey City

18th Volunteers Meeting. We need your help for Sickle Cellabration. 4:30pm Garden State Discovery Children's Museum 2040 Springdale Ave in Cherry Hill.

21st NOBLE NNJ honors SCANJ Founder, Mary Bentley LaMar with Service Award at their Scholarship Dinner Dance. Tamara Tunie of NBC's Law & Order SVU Mistress of Ceremony. Visit [noblej.org](http://noblej.org) or call 908 227-6601 7 pm Pines Manor-Edison.

22nd Annual Sickle Cellabration and Red Cross Blood Drive Garden State Discovery Children's Museum in Cherry Hill. 9:30am-2:00pm.

25-26th Sickle Cell Disease Association of America (SCDAA) Advocacy Day in Washington DC.

For updates, or to register call 973 482-9070 SCANJ programs are listed on [sicklecellnewjersey.org](http://sicklecellnewjersey.org) and [www.eventbrite.com](http://www.eventbrite.com)



Volume 4  
Issue 6

# Say It Loud!

June 2013

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

PO Box 9501 Newark, NJ 07104

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

## A Note From The Executive Director



Mary Bentley LaMar  
Executive Director

I'm writing to you on the heels of returning from a fascinating gathering in Baltimore. The occasion was the New York Mid Atlantic Consortium on Genetics and Newborn Screening Services (NYMAC) Advisory Council Meeting. I had the honor of showing SCANJ's Say It Loud video to an audience of health care professionals from 7 states and the District of Columbia. Our video was made possible thanks to a grant from NYMAC.

It was great to be in the company of so many passionate professionals working to improve the health of those effected by genetic conditions. It was especially great to meet the research scientists and genetics specialists who want to hear more from the sickle cell community.

If you have sickle cell disease, and are interested in lending your voice to help in our NYMAC efforts, please contact

our office. You can help effect change for the better.

On a different note, don't blink when you read this newsletter...you might miss something. Many activities are time sensitive, so please respond accordingly.

Here's a shout out of thanks to the McDonalds at 425 Grand St. in Jersey City, owned by Lois and Mitch McGuire. They have gone above and beyond in allowing us to raise sickle cell awareness and promote the Tackle Sickle Cell Walk.

Gratitude is also in order to Ortho Clinical Diagnostics of J & J, for donating Build A Bears and tricycles, and raising sickle cell awareness. When you come on June 22nd to A Sickle Cellabration you'll see how we put those bears and trikes in motion.

I pause to appreciate being recognized for public service by the National Organization of Black Law Executives Northern New Jersey Chapter

(NOBLENNJ). My hope is that this recognition shines a brighter light on the work that is yet to be done in sickle cell disease.

As I write this note, I'm preparing for many events that take place this month. One of which is the SCDA Advocacy Day in Washington DC. Just last week, the first legislative office to confirm our visit was the office of Senator Frank Lautenberg. You may know that Senator Lautenberg died Monday June 3rd. The senator exemplified the finest in public service. We sadly note his passing. He was a friend to the SCANJ. ~Mary

SCANJ is the  
New Jersey Chapter of the



## A Sickle Cellabration for World Sickle Cell Disease Day!

Commemorate World Sickle Cell Disease Day at the 4th Annual A Sickle Cellabration; a world festival of food, fun and learning on Saturday June 22nd at 9:30am at the Garden State Discovery Museum in Cherry Hill. For this this year's celebration, we're excited to team up with neighboring affiliate chapter; the SCDAA Philadelphia/Delaware Valley.

The festivities include full access to the museum, activities for the whole family, international cuisine, presentations on the latest treatments for sickle cell disease, awarding of the Frances Thompson Walton Scholarship, selection of the NJ Poster Child and Teen Spokesperson and an American Red Cross Sickle Cell Blood Drive. It's all FREE, but you must register. Space is limited. You don't want to miss this!

Our guest presenter is Dr. Alice Cohen, hematologist and the head of Newark's Beth Israel Medical Center Barnabas Health, Adult Sickle Cell Center. Dr. Cohen is dedicated to improving the care of adult patients living with sickle cell disease. She's been instrumental in the improvement of protocols to expedite emergency room services and pain management.

We welcome your help for A Sickle Cellabration. Come to the volunteers meeting on Tuesday June 18th at 4:30pm at the Garden State Discovery Children's Museum 2040 Springdale Ave in Cherry Hill.

World Sickle Cell Disease Day was first established on June 19, 2006 by the United Nations to raise awareness about sickle cell disease. Come out and celebrate the courage and strength of the sickle cell community.



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## The Sickle Cell Association of New Jersey

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**Phone: 973 482-9070 Fax: 973 485-6591**

**email: sicklecellanj@gmail.com**

It's not too late ... join us for  
**NATIONAL  
SICKLE CELL ADVOCACY DAY  
2013**

Hilton Alexandria Mark Center Hotel  
5000 Seminary Road.  
Alexandria, VA 22311

**ADVOCACY TRAINING @ HOTEL**  
*Tuesday, June 25th*  
6:00pm

**PROGRAM DAY & HILL VISITS @ CAPITOL**  
*Wednesday, June 26th*  
9:00am



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

Beverly Lucas-Editor

**Tax deductible donations to SCANJ  
accepted online and by mail  
[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)**

1. **Haywood Barnes**, Program Manager of the Adult SCD Center of Newark's Barnabas Health speaks at HRSA's Regional Sickle Cell Learning Collaborative in Bethesda, MD.
2. **Lois and Mitch McGuire**, owners of McDonalds 425 Grand St. Jersey City, host sickle cell awareness.
3. **Employees at Ortho Clinical Diagnostics of Johnson and Johnson (OCD)** invite SCANJ to raise sickle cell awareness for Take Your Child to Work Day.
4. **Children of employees at OCD** build tricycles and teddy bears for children with sickle cell disease.
5. **Members of Alpha Kappa Alpha Sorority, Omicron Xi Omega Chapter** help with sickle cell outreach and voter registration at the Montclair Heritage Parade and Festival

**These individuals are captured in "not so random" acts of caring.**

***They cared to make a difference! Be intentional!***



### Coming Soon:

**September 24-27th. SCDAA National Convention,** Baltimore, MD. SCANJ Road Trip.

**October 25-26\* 24/Seven Line Dance Marathon,** New Jersey City University, 24 hours with 7 major events. Jersey City

**November 23 Statewide Sickle Cell Symposium**

**December Holiday Parties with Kenta Klaus 7th Montclair** (Central and Southern NJ locations TBA)

### Did You Know...

SCANJ has a Calling Post Program that can send an occasional message to your phone with reminders of related activities. If you would like to receive our calling posts, just send us your name and the phone number you would like us to use. Stay Connected!