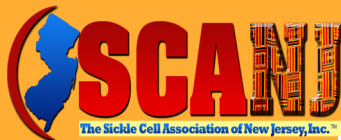


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Volume 7  
Issue 5

# Say It Loud!

May 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

## Calendar Listings:

**May 10th Get Connected; SCANJ Orientation and Voter Registration Training Meeting.** Volunteers needed to help raise SCD awareness and conduct voter registration drives. 6pm at 1016 Broad St. in Newark. RSVP 973 482-9070

**18th Liberty Science Center Community Evening.** 5:30pm-8:30pm. 222 Jersey City Blvd in Jersey City.

**SCANJ POP Up Event! Advocacy and Awareness at the UniverSoul Circus Tour in Newark.**

- **18-30th.** SCANJ will provide sickle cell disease information and conduct voter registration drives during the Newark run.
- **19th** Newark Boys Chorus School Concert Chorus song tribute for Sickle Cell Awareness at the 6:30pm Pre-Show
- **22nd** Sickle Cell Awareness Friends and Family Day at the UniverSoul Circus Newark. Ayoola Ogunyinka, Teen Spokesperson is guest Ringmaster at the 6:30pm show.

**25th Take Control of Your Health Workshop.** 6 week session Chronic Disease Self Management begins. 1016 Broad St. Newark. Wednesday's at 6pm. Through June 29th.

**ALL EVENTS ARE FREE UNLESS OTHERWISE NOTED IN RSVP**

**REGISTER** via the events tab on [sicklecellnewjersey.org](http://sicklecellnewjersey.org) or call 973 482-9070

SCANJ is the  
New Jersey Chapter of the



Sickle Cell Disease Association  
of America

## We're Advancing to Tier II With the PCORI Award!



**Mary Bentley LaMar**  
Founder  
Executive Director

I'm thrilled to report that SCANJ was selected to advance from Tier I to a Tier II Pipeline 2 Proposal Patient Centered Outcomes Research Institute (PCORI) award. This award will help to fund our research development project; We'll Take The Village; Engaging The Community To Better Health.

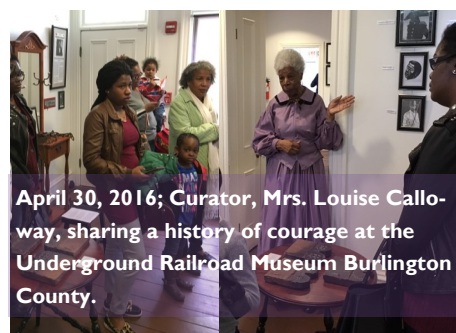
PCORI is an independent, non-profit research institution authorized by Congress, but it is not a federal agency. They provide awards through contracts, not grants.

For those of you who have been following our journey with PCORI, you know that we have been working on developing research questions that will have a real world impact for the sickle cell community. Please come out on May 10th (calendar listings) and get more information on our programs including the PCORI project. We want you to be involved.

So much is going on this month, I couldn't fit everything in this newsletter. Check our facebook and eventbrite pages and stay posted for the June Newsletter. It's already on and poppin! ~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.*



**April 30, 2016; Curator, Mrs. Louise Calloay, sharing a history of courage at the Underground Railroad Museum Burlington County.**

## Afterwords Part 3: Telemedicine in Sickle Cell Disease

The telemedicine workshop presented by Kunal Sanghavi at SCANJ's Annual Symposium in 2015 was aimed at continuing to promote awareness and education for SCD telemedicine services as well as identify barriers and strategies for implementing telemedicine services in the New York-Mid-Atlantic Consortium for Genetics and Newborn Screening (NYMAC) region.

Patients with sickle cell disease (SCD) who live long distances from their specialty care center can have difficulty with clinic visit compliance. Consistent with its goal of ensuring timely access to quality care, NYMAC supported the launch of a telemedicine program for sickle cell disease (SCD) at the Children's Hospital of Pittsburgh. Since its inception in 2013, 11 families with SCD have completed a total of 80 telemedicine clinic sessions. These sessions have allowed the SCD specialist to prescribe hydroxyurea and monitor treatment progress and access to genetic counseling.

An onsite telemedicine training program has been established for pediatric hematologists and allied health professionals. Two training programs have been completed so far with teams from DE, NJ, NY, and VA.

Telemedicine is a cost effective model of delivering and improving SCD services.

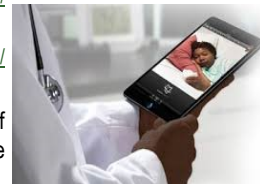
NYMAC strives to integrate the views of parents, family members, and advocates in ongoing and future activities. For more information, please contact Kunal Sanghavi at [ksangha1@jhmi.edu](mailto:ksangha1@jhmi.edu).

**About NYMAC:** New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services is one of the seven regional collaboratives funded by the Genetic Services Branch in the Health Resources and Services Administration (HRSA)'s Maternal and Child Health Bureau (MCHB). It includes DC, DE, MD, NJ, NY, PA, VA, and WV.

<http://www.wadsworth.org/newborn/nymac/>

<https://www.facebook.com/NYMACGenetics>

The Sickle Cell Association of New Jersey is a collaborative partner with NYMAC.



**Afterwords;** is a six-part newsletter series to shed insight on the topics covered during the most recent SCANJ Statewide Sickle Cell Symposium. The symposium is held annually on the Saturday before Thanksgiving at the Liberty Science Center in Jersey City, NJ.

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



**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](mailto:info@sicklecellnewjersey.org)  
or [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com)



Register Now

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

Have you always wanted to advocate for sickle cell disease? Perhaps you want to make a difference in policy, funding and research for sickle cell disease. If so, **RSVP** for the **SCANJ Orientation and Voter Registration Training Meeting on Tuesday May 10th at 6pm.** 1016 Broad St. Newark (NBCS)  
Voter Registration Drive training conducted in partnership with the Maplewood/Oranges NAACP. Refreshments served.

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)



## Get Connected to SCANJ's Pop Up Events



**SICKLE CELL AWARENESS  
FAMILY & FRIENDS DAY  
SUNDAY MAY 22 @ 6:30PM**

**GET TICKETS**

WHILE SUPPLIES LAST  
ADDITIONAL FEES MAY APPLY

GUEST RINGMASTER ON MAY 22ND IS SCANJ's  
TEEN SPOKESPERSON, AYoola OGUNYIMIKA

ACROSS FROM BROAD ST. NEWARK TRAIN STATION  
MAY 18-30

[universoulcircus.com](http://universoulcircus.com)

**WHAT:** SCANJ will host SCD Awareness and Voter Registration Drives during the Circus run in Newark.

**WHEN:** May 18-30, 2016

**WHERE:** 430 Broad St. Newark, NJ

The Sickle Cell Association of New Jersey (SCANJ) invites you to enjoy the *UniverSoul Circus*; a highly interactive combination of circus arts, theater, and music that spans genres including Pop, Classic R&B, Latin, Hip Hop, Jazz and Gospel. It embraces and celebrates the unique and familiar aspects of pop culture globally by bringing them center stage with a cast of international performers. *UniverSoul Circus* is rated as one of the top three circuses in America along with Ringling Brothers Barnum and Bailey and Cirque du Soleil. UniverSoul's fresh approach to family friendly live entertainment has garnered it a coveted spot as one of Ticketmaster's top ten most requested family events.

SCANJ is sponsoring a **limited** number of **FREE** tickets to the UniverSoul Circus for the SCD Friends & Family Day 6:30pm Show on May 22nd. These **FREE** tickets are for individuals who are directly affected by sickle cell disease **AND** who have completed profiles in the **Get Connected Registry**.

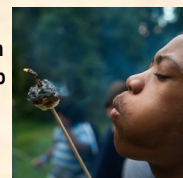
Register for SCANJ programs via events on [sicklecellnewjersey.org](http://sicklecellnewjersey.org) or call 973 482-9070.

### Coming Soon...

Our June newsletter will feature various camps. Here's a preview...

**Dragonfly Forest** is an overnight summer camp in the Poconos of PA for children ages 7-14 with Sickle Cell Disease and other medical diagnoses. **The hematology session for 2016 takes place August 5-10** at YMCA Camp Speers. Tiered Tuition starts at \$200 with additional camper scholarships available. 24/7 medical staff on site. Activities include ropes course, zip line, archery, tie dye, horses, basketball, canoeing, fishing and more! Transportation options available. **Register online at [dragonflyforest.org](http://dragonflyforest.org) or call 610-298-1820** with any questions.

**Frances Thompson  
Walton Scholarship**  
application deadline  
June 1st.



### Stanford School of Medicine's Self Management Certification Programs

- June 2,3, 6 & 7th Diabetes Self Management Peer Training in Fords
- June 16,17, 20 & 21st Chronic Disease Self Management Peer Leader Training in Newark

**June 25th Sickle Cellabration** at the Garden State Discovery Children's Museum Cherry Hill

**Join SCANJ's Walk The Talk Team for these upcoming walks:**

**June 18th Tackle Sickle Cell Walk**  
**August 27th SCDAA' Walk with the Stars**  
[www.sicklecellnationalwalk.org](http://www.sicklecellnationalwalk.org)