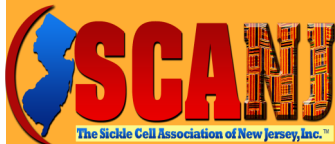


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



### Calendar Listings

**September 1 Mission Day** 3rd Year Anniversary of The Sick Cell Association of New Jersey.

**8 New York Mets Game.** 4:05pm. Sick Cell Awareness Night. For tickets go to [www.mets.com/sicklecell](http://www.mets.com/sicklecell)

**14 at noon SCANJ 2012 Road Trip Teleconference** All interested in going to Baltimore are encouraged to Dial into 1 712 775-7200 passcode 379831#.

**15 Donna T. Darrien Memorial For SCD Let's Walk About It.** Weequea Park Newark. 10am For more information go to [dtdsicklecell.org](http://dtdsicklecell.org)

**15 Health Fair with New Hope Baptist Church (of Metuchen)** at JFK Medical & Rehabilitation Center 65 James Street in Edison 10 am to 1pm.

**22 Sick Cell Walk A Thon to benefit SCANJ.** 9:00am registration and 10:00am Walk. Irvington Park in Irvington. [www.walkforthecure.org](http://www.walkforthecure.org)

**25-28, SCANJ Road Trip to the National SCDAA Convention Marriott Waterfront Hotel, Baltimore MD.** The SCANJ Road Trip is FREE, however, you must show proof of registration for the SCDAA convention in order to participate. To register for the Road Trip go to [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org) or [www.eventbrite.com](http://www.eventbrite.com)

**SCDAA 40th National Convention Marriott Waterfront Hotel, Baltimore MD.** To register for the SCDAA convention go to [www.sicklecelldisease.org](http://www.sicklecelldisease.org).

**30 Embrace Kids Walk for Cancer and Blood Disorders.** Johnson Park, Piscataway. 9 am. For more information go to [Embracekids.org](http://Embracekids.org)

**Beginning at 5pm October 19-20**  
**SCANJ 24Seven**

**Line Dance Marathon Fundraiser**  
24 Hours 7 Fun Events  
New Jersey City University  
Jersey City

[2012scanj24sevenmarathon.eventbrite.com](http://2012scanj24sevenmarathon.eventbrite.com)



Volume 3  
Issue 9

# Say It Loud!

September 2012

Sickle Cell News You Can Use

The Sick Cell Association of New Jersey

## A Note From the Executive Director...



Mary Bentley LaMar

**It's National Sick Cell Awareness Month!** Lend your voice to raising awareness and funds to kick sickle cell disease to the curb.

This newsletter is filled with activities you can get directly involved in to make it happen (calendar listings). We especially encourage you to support our 2nd Annual Line Dance Marathon October 19-20th at New Jersey City University. You can register now!

Here's a special shout out to the New York Mid Atlantic Consortium For Genetic and Newborn Screening Services (NYMAC). Thanks to their grant, we have a new awareness PSA. Stay posted for it's debut on our SCANJ Youtube channel. We're also thrilled to thank world renowned jazz vocalist, Dianne Reeves for allowing us to use her song EYES ON THE PRIZE for the PSA's soundtrack. I can't wait for you to see and hear it. I think you will find it uplifting.

On Wednesday September 26th at the SCDAA convention I will give a lecture on "Opportunities and the Importance of Community

Based Outreach." I am honored and happy to share that our community is coming together to make a difference in the lives of the families suffering with sickle cell disease.

### Mission Statement

*In concordance with the mission of The Sick 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."*

This mission is possible with your support!

~ Mary



## September is Sick Cell Awareness Month!

### What Is Sick Cell Disease?

Sickle cell disease is an inherited blood disorder affecting the red blood cells. People with sickle cell disease have red blood cells that become hard and pointed instead of soft and round. Sickle cells can cause blocked blood flow, anemia, and pain episodes, resulting in lung tissue damage, strokes and damage to most internal organs. Damage to the spleen makes sickle cell patients, especially children, easily overwhelmed by bacterial infections, resulting in hospitalization.

**Who Is Affected by Sick Cell Disease?** While it primarily affects persons of African descent, it is also present in Caucasians, mostly of Mediterranean descent and Hispanics. Sickle cell disease also appears in Middle Eastern countries and Asia. It is estimated that over 80,000 people have sickle cell disease in the United States and over 4,000 people live with sickle cell disease in New Jersey.

**How Does A Person Get Sick Cell Disease?** The gene that causes sickle cell disease is called hemoglobin (Hb) S. If a person inherits one HbS gene from one parent and one HbS gene from the other parent, they will have two abnormal hemo-

globin genes, in this case HbSS. This is referred to as sickle cell anemia, sickle cell disease SS, or HbSS. If the person gets an HbS gene from one parent and a gene for a different abnormal hemoglobin from the other parent, he or she would have another form of sickle cell disease. There are many different types of sickle cell disease, but HbSS is the most common in the United States.

**Is There A Cure?** There is hope for a universal cure through the bone marrow transplant which has been successful with a few patients, including our teen spokesperson. Bone marrow transplants are not yet widely available.

**What is Sick Cell Trait?** Sick Cell Trait means that you carry the gene for sickle cell disease that can be passed on to your children, if your partner also has sickle cell trait or the trait from another hemoglobin disorder. A person gets sickle cell trait the same way they inherit the color of their eyes or hair...through the genes that their mother and father pass on to them. Sickle cell trait is not an illness. People with sickle cell trait are generally healthy. Sickle Cell trait can never turn into Sick Cell Disease.

**What Should a Person with Sick Cell Trait Do?** In planning a family it is wise to ask your partner to be tested in order to understand what the possibilities are for your baby to have sickle cell disease. Teens and adults should be tested to see if they carry the gene for sickle cell disease.

**What Can You Do To Help?**  
*Please support our mission.*

SCANJ is the New Jersey Chapter of the



**SCDAA**

"Break The Sick Cell Cycle"

**Sickle Cell Disease Association of America**

**DO you WANT YOUR VOICE to BE HEARD this ELECTION?**



Turn for Page 2...

**A Call to Action!**  
**Join the Mobile Giving**



Text the words **BREAK-NJ** to the number **52000** to donate \$10.00 to support programs, services and research, that help the SCANJ and the SCDA in the fight against sickle cell disease. Your donation makes a difference so text now! A one-time donation of \$10.00 will be added to your mobile phone bill or deducted from your prepaid balance. Donor must be age 18+ and all donations must be authorized by the account holder (e.g. parents). By texting YES, the user agrees to the terms and conditions. All charges are billed by and payable to your mobile service provider. Service is available on most carriers. Donations are collected for the benefit of the Sickle Cell Disease Association of America and its member chapters (including the Sickle Cell Association of New Jersey) by the Mobile Giving Foundation and subject to the terms found at [www.hmgf.org/t](http://www.hmgf.org/t). Message & Data Rates May Apply. You can unsubscribe at anytime by texting STOP to short code 52000; text HELP to 52000 for help.

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

For the latest updates go to the home page  
"SCANJ News"-events calendar

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SCANJ's "Say It Loud" newsletter  
is published monthly with the exception of the *Summer Breeze* Edition that  
combines July and August

Archived copies are available on the resource page of our website  
[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)  
Beverly Lucas-Editor.

**SCD Awareness Walk**

**9:00am September 22nd Irvington Park, Irvington, NJ!**  
Special thanks to the Township of Irvington Mayor's Wellness Campaign  
for support of WeCarePartners Inc., organizers of this walk for SCANJ

**SCANJ Supports the Work of Student Researchers on Sickle Cell Disease and Related Factors.**

To improve the quality of life for individuals living with sickle cell disease it's imperative that we encourage and support research on sickle cell disease. High School student and SCANJ volunteer, Taylor Wilson, created an excellent Power Point presentation on sickle cell disease that was shared with her fellow students at Montclair High School. We felt it was of such great quality that we are pleased to use it as part of our outreach at Health Fairs and other appropriate venues.

Doctoral student, Sejal Patel has a dissertation study entitled "Factors Related to the Sexual Behaviors of Adolescents with Sickle Cell Disease." The objective is to understand similarities and differences in risky sexual behaviors among adolescents and young adults with and without sickle cell disease. Prior research has indicated that risky behaviors may be higher than expected among youth with chronic illness in southern and more rural locations. This is a pilot study investigating whether these patterns may also exist in the Philadelphia/New Jersey region and whether this is an area in which additional research and clinical focus could positively impact the psychosocial care of youth with sickle cell disease. The study uses a survey-based, 2-group design (n = 29 for "sickle cell" and n = 29 for "non-sickle-cell"). All individuals ages 13 to 21 recruited from events associated with SCANJ and SCDA/Philadelphia Delaware Valley are eligible to participate and will constitute the majority of the "sickle cell" group. Individuals recruited from Delaware Valley Charter School and La Salle University will comprise the majority of the "non-sickle-cell" group. ALL participants will receive the same survey and, in order to participate, ALL participants under age 18 must have parental consent.

If you are between the ages 13 to 21 and are interested in participating by completing this 10-30 minute survey on sex, health, and related issues or, to learn more, please contact: Doctoral Candidate Sejal Patel, M.A. 860.729.3155 or email: [Patels9@lasalle.edu](mailto:Patels9@lasalle.edu). At least one in ten participants will win a gift card until enrollment has ended. This study has been approved by the Internal Review Board of



**Groundbreaking treatment begins with study. SCANJ is glad to support these scholars and we encourage informed participation in research and clinical trials.**

**The Fun Begins at 5pm on October 19th!**



**24 HOURS 7 EVENTS**

**RAISING FUNDS & AWARENESS FOR  
SICKLE CELL DISEASE!**

Get your dancing shoes ready for the Electric slide, Cupid Shuffle, Macarena, the Wobble and other line dances including "The Sickle Cell Stomp." So we don't drive everybody crazy listening to the same songs, we have many activities planned including Comedians, Game tournaments, Live and Learn Health and Community Fair, Midnight Maaaadness, Great Food and FUN!

**It all happens at New Jersey City University in Jersey City!**  
The 24 Seven is THE major fundraiser for The Sickle Cell Association of New Jersey (SCANJ). We ask for YOUR support to make it successful!

Call us at 973 482-9070 or register online  
<http://2012scanj24sevenmarathon.eventbrite.com> or via  
[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org) by clicking "donate."

