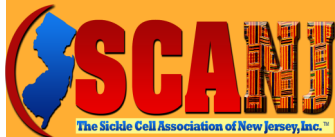


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Volume 3  
Issue 10

# Say It Loud!

October 2012

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey



## Calendar Listings

### October

#### 9 Red Cross Blood Drives:

##### New Jersey Institute of Technology

Laurel Hall, 12:00 PM - 5:00 PM

Sponsor Code: 12335

Location 150 Bleeker St. in Newark

##### 9 Rutgers University 12:00 PM -

5:00 PM Sponsor code 10492

Location 350 MLK Blvd. Paul Robeson Center, Newark

##### 11 SCANJ Meet and Greet at Cooper University Hospital 5PM-

6:30PM in the Pavillion Room 1014.

One Cooper Plaza, Camden

##### 14 Red Cross Blood Drive: Projeto

Mantena Ajuda Corporation 10:00

AM - 3:00 PM Sponsor Code: 13729

Location 109 Monroe St, Newark

##### 15 Bowl with NY Jets Santonio

Holmes. 7 PM in Linden For Kids with

SCD and their chaperone. Must

RSVP through SCANJ online or call

us 973 482-9070. No walk ins

### October 19-20

### SCANJ 24Seven

#### Line Dance Marathon Fundraiser

5 PM to 5 PM Student Union Building

New Jersey City University (NJCU)

2039 Kennedy Blvd. Jersey City, NJ

Registration online or in person

\$24.00 General and \$7.00 Student

SCANJ is the

New Jersey Chapter of the



Sickle Cell Disease Association of America

Make Your Voice Heard!



Turn for Page 2...

## A Note From the Executive Director...



Mary Bentley LaMar

### The 24 Seven ain't nothing but a Party with a Purpose!

The purpose is to raise awareness and funds for our programs and services that fight sickle cell disease.

Judging from our outreach you may notice that education is a big focus with the SCANJ. Research shows that the more educated one is about their health, the better their health outcomes.

Just last week SCANJ was recognized at the SCDAA national convention in Baltimore, for being the member organization with the most attendees at the convention. That is thanks to our Road Trip Program

that supports those affected by sickle cell disease to attend scientific conferences.

Road Trip Attendees will be sharing their convention reflections on Saturday of the 24 Seven. Make sure you are there to hear about this as well as other programs offered by the SCANJ.

You can learn while having a good time supporting our mission. That's why it's a 24 hour "Party with a Purpose!"

Here's a shout out to WeCarePartners in cooperation with the Township of Irvington Mayor's Wellness Program for hosting a Sickle Cell Awareness Walk September 22. Kudo's to all who participated including Irvington Mayor, Wayne Smith.

### SCANJ Mission Statement

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

### See you at the 24 Seven!

Wobble baby...

wobble baby...

wobble baby!

~ Mary



Sanaa, 2011 Poster Child, at the first 24 Seven

## Is There a Cure?

Here are a few facts that you may not be aware of. From birth, people with sickle cell disease live with this often excruciatingly painful potentially life-threatening disease 24 hours a day, 7 days a week.

There is a cure for sickle cell disease—a bone marrow transplant—but few people are candidates for the operation and many of those who are, don't have a good "match" (a person whose bone marrow is more likely to be compatible with the genetic makeup of the person receiving it). Such a match is critical if the operation is to be successful because the

best matches come from people of the same ethnic group.

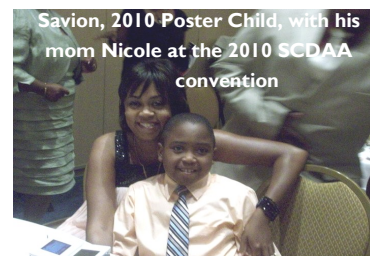


Walking for the cure

Sickle cell disease is most common among African-Americans and Hispanics in the United States, however it affects people of all ethnicities. One of the most famous persons currently undergoing a bone marrow transplant (for myelodysplastic syndrome) is ABC news anchor, Robin Roberts.

SCANJ's Teen Spokesperson, Amanda Salazar, was cured with the bone marrow transplant.

We are partnering with Be the Match® to find a suitable bone marrow donor for Savion, our very first Poster Child. You have an opportunity during the 24 Seven to find out if you're the one—it only takes a simple swab of your cheek. Even if you don't match Savion, you might be the match for someone else in need.



Savion, 2010 Poster Child, with his mom Nicole at the 2010 SCDAA convention

# ONE COMMUNITY ONE CAUSE *Campaign...*

Text the words **BREAK-NJ** to the number **52000** to donate \$10.00 to support programs, services and research, that help the SCANJ in the fight against sickle cell disease. **Your donation makes a difference. Please 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 it's 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.

# 24<sup>ANNUAL</sup> Seven line dance marathon

**24 HOURS 7 EVENTS**

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

Made possible thanks to our host sponsor  
**NJCU's Gothic Knights!**

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



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

For the latest updates on SCANJ go to the home page  
"SCANJ News"-events calendar or contact us...

Phone: 973 482-9070 Fax: 973 485-6591  
SCANJ PO Box 9501 Newark, New Jersey 07104  
e-mail: [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com)

## SCANJ Research Spotlight...

SCANJ encourages teens and young adults, ages 13 to 21, to participate in the dissertation study entitled "Factors Related to the Sexual Behaviors of Adolescents with Sickle Cell Disease." Participants would complete a 10-30 minute survey on sex, health, and related issues. (Parental consent is required for minors) 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.

To learn more, please contact: Sejal Patel, M.A. [Patels9@lasalle.edu](mailto:Patels9@lasalle.edu)  
860.729.3155. Information will also be available at the 24 Seven

At least one in ten participants will win a gift card until enrollment has ended.



This study has been approved by the IRB of

**Groundbreaking treatment begins with study.**

**We encourage informed participation in research and clinical trials.**

## 24 Seven Schedule

**Starts Friday October 19th**

4pm Check In/Registration

5pm Line Dancing begins

(24 Hrs)

Donations Collected

Bone Marrow Drive

Community Service Fair

Phone A Thon

7pm SCD Workshop

10pm Movies

11 pm Laugh A Thon

## MidKnight Maaaaaadness

**Through Saturday October 20**

Cards, Wii, Dominoes, Games

6am Stretch and Exercise

10am SCDAA Convention Recap

11:00am Genes Genius Game Show

12:00pm Lunch and Learn

4:30pm Awards Ceremony

5:00pm Closing Celebration

New Jersey City University (NJCU)  
2nd Fl. Student Union Building  
2039 Kennedy Blvd. Jersey City, NJ



**Jimmy**  
**2012 Poster Child**  
invites you to the  
**24 Seven**



## The "Say It Loud" newsletter

is published monthly with the exception of the *Summer Breeze* Edition that combines July and August. Archived copies can be downloaded from our website resource page. Beverly Lucas-Editor