

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 3

# Say It Loud!

March 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



## Calendar Listings:

### March 9th SCANJ POP Up Event!

Ringling Bros. Barnum and Bailey Circus at Prudential Center Newark. FREE. Pick up tickets at 6:30pm Sharp! You must RSVP online or call Mary at 908 247-9130.



16th SCANJ Raises Awareness at the Liberty Science Center Community Evening. Play *Genes Genesis* and raise your Sickle Cell Awareness. 5:30pm-8:30pm. 222 Jersey City Blvd in Jersey City.

## Support Group Exploratory

Meetings: Are you interested in starting a Support Group? Well let's get this going!

- **19th (South Jersey)** at The Underground Railroad Museum. 4:00pm-6:00pm. 803 Smithville Rd. in Eastampton.
- **22nd (North Jersey)** Newark Boys Chorus School (next to Symphony Hall). 1016 Broad St. Newark 6:00pm-8:00pm

Frances Thompson Walton Scholarship Applications Accepted through June 1st. Apply online.

ALL EVENTS ARE FREE UNLESS OTHERWISE NOTED.

## REGISTER

via the events tab on  
sicklecellnewjersey.org  
or call 973 482-9070

SCANJ is the  
New Jersey Chapter of the



Sickle Cell Disease Association of America

## Be Flexible and Let the Blessings Flow...



Mary Bentley LaMar  
Founder  
Executive Director

So what am I talking about? Well, we at the SCANJ are always working on finding resources that will support families who are affected by sickle cell disease.

We call on our network of agencies, organizations, schools and volunteers to make great things happen. One example is the SCANJ POP Up Event this month (see calendar listing). You may ask, how come such short notice? I heard about it today and BOOM! From my ears to yours. This POP UP is the first of what we hope will be many family events that get you connected

to fun and support through the SCANJ. If you can't make this one, we hope you can make the next.

Be sure to read the entire newsletter for details on other programs. And check out the new Comcast News PSA on SCANJ programs.

*Blessings flow... ~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.



Thanks Cedarbrook Elementary!

## Cedarbrook Elementary School in Plainfield Raises SCD Awareness!

Cedarbrook Elementary School in Plainfield knows how to make a difference for sickle cell disease! On March 6th the staff, students and parents came together under the leadership of their Principal, Ms. Gwynetta Joe, to host a successful American Red Cross Sickle Cell Awareness Blood Drive. They partnered with the Central New Jersey Chapter of Delta Sigma Theta Sorority to recruit donors and volunteer support for the blood drive. And they partnered with the SCANJ to raise awareness and provide educational materials for the attendees.

Some individuals living with sickle cell disease must have blood transfusions as treatment so having enough blood available to meet the need is critical. According to the Red Cross; because of the need for regular transfusions over a patient's lifetime, it is critically important that blood transfused to Sickle Cell patients be as closely matched as possible. If the blood is not closely matched, the patient may build antibodies against the donated blood, and the transfusions will be ineffective in treating the symptoms of the disease. Like other genetic factors, blood is similar among people of the same ethnic group, that is why the closest match for a Sickle Cell patient will most likely come from an African American donor

blood is similar among people of the same ethnic group, that is why the closest match for a Sickle Cell patient will most likely come from a donor of the same ethnic group.

We're thrilled that the Cedarbrook Elementary School Blood Drive exceeded their goal and brought the community together to support individuals living with sickle cell disease.



Thanks Blood Donors!



Students learn about sickle cell disease...

WWW.SICKLECELLNEWJERSEY.ORG



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**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**  
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**There is power in numbers!** We want the New Jersey sickle cell community to be well represented. Your input through "Get Connected" will help us to identify critical needs. But more importantly, your voice can inform and support vital research and lead to the development of much needed care improvement guidelines. [www.getconnectedscd.org](http://www.getconnectedscd.org) is FREE and confidential. Register, complete your profile and choose to connect with The Sickle Cell Association of New Jersey (SCANJ). SCANJ gives priority for resources to those in the Get Connected registry.

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

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



## Support Groups? What Do You Think??

**A definition of Support: That which upholds, sustains, or keeps from falling as a prop, pillar, or a foundation of any kind.**

We invite you to explore the feasibility of starting a Sickle Cell Support Group. Help us to shape it's foundation. We want the group to be relevant to your needs. We can only do that with your input. Think about your definition of a support group? What should it include?

Support groups have been shown to provide many benefits to those who participate. They can create a safe environment to discuss feelings, increase education, network and become personally empowered. Dr. David Spiegel conducted a landmark study on support groups in the 1980's. In his book *Living Beyond Limits* he concluded that support groups can improve the quality of life—reduce anxiety and depression, increase coping skills and help symptom management.

At the SCANJ we conduct 6 week Chronic Disease Self Management (CDSMP) and Diabetes Self Management (DSMP) Workshops. We also conduct Peer Leader Trainings to cultivate workshop leaders. The CDSMP and DSMP are evidence based programs certified and licensed through Stanford School of Medicine's Patient Education. While they are not traditional support groups; we have found these to workshops to be beneficial to the well being of our participants. They also serve as a great way to strengthen the group facilitation skills of our Peer Leaders, many of whom have sickle cell disease.

We'd love to build on our success and experience with the self management workshops by starting a Support Group program specifically for the sickle cell community.

**Join the conversation** to share your thoughts as we begin a supportive network of individuals and families living with sickle cell disease. Currently we have a surveymonkey survey asking for feedback. We also invite you to come to one of the exploratory meetings to weigh in with your ideas.



### South Jersey-March 19th from 4pm—6pm

Underground Railroad Museum  
 803 Smithville Rd. in Eastampton

### North Jersey March 22nd 6pm - 8pm

Newark Boys Chorus School  
 1016 Broad Street in Newark

RSVP online (Eventbrite registration)

**Coming Soon...**

**April is Minority Health Month**

**April 20th SCANJ Raises Awareness at the Liberty Science Center Community Evenings**

**Dates TBA**

**Take Control of Your Health**

- Certification in Stanford School of Medicine's 4 Day Diabetes Peer Leader (DSMP) Training.
- And Chronic Disease Self Management (CDSMP) 4 Day Peer Leader Training.
- 6 Week CDSMP and DSMP Community Workshops

**Stay posted for Afterwords; a six part newsletter series to shed insight on the topics covered during the SCANJ Statewide Sickle Cell Symposium. The symposium is held annually on the Saturday before Thanksgiving at the Liberty Science Center.**

