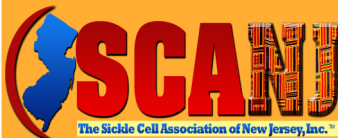


Sickle cell disease is the most common inherited blood disorder in the USA.. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



## Calendar Listings for SICKLE CELL AWARENESS MONTH

**10th Phi Beta Sigma Fraternity  
SCD Awareness Program**  
(Science Bldg) 3:00pm-4:00pm 185  
So. Orange. Ave. in Newark

**13th Sickle Cell Twitter Party.** To  
join the party register at  
[www.sicklecelldisease.org](http://www.sicklecelldisease.org). Follow  
@scdaa.org and use #Stand4SDC

**16th Top Ladies of Distinction  
Trenton Chapter** presenting "A  
Cabaret Supporting Sickle Cell  
Awareness. Ewing Councilman  
Hon. Kevin Baxter is the featured  
speaker. 7:00pm-12:00pm. Am-  
bassador Banquet & Catering 610  
New York Ave, Trenton. **Tickets**  
**are \$25.00.** Call Vivian Price at 609  
882-4851 for more information.

**17th Donna T. Darrien Memorial  
Foundation Walk for SCD.**  
8:30am. Weequahic Park in New-  
ark, NJ. For more information go to  
[www.dtsicklecell.org](http://www.dtsicklecell.org)

**26th SCANJ Open House and  
Presidential Debate Watch Party.**  
7:00pm. 1016 Broad St. Newark.

**Sept. 28-Oct 1 SCANJ Road Trip  
to the SCDA National Con-  
vention.** SCANJ will present on our  
PCORI Project. Hyatt Regency  
Hotel, Baltimore MD.

**ALL EVENTS ARE FREE  
UNLESS OTHERWISE NOTED**  
**REGISTER** via the events tab on  
[sicklecellnewjersey.org](http://sicklecellnewjersey.org)  
or call 973 482-9070

SCANJ is the  
New Jersey Chapter of the



"Break The Sickle Cycle"  
Sickle Cell Disease Association  
of America



Volume 7  
Issue 8

# Say It Loud!

September 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

## SEPTEMBER Is Sickle Cell Awareness Month...Say It Even Louder!!!



**Mary Bentley LaMar**  
Founder  
Executive Director

Oh yes! We are shouting even louder  
this month to raise sickle cell aware-  
ness. Don't let this month go by without  
your active involvement. In case you  
need help in thinking of ways to support,  
just take your pick from the calendar  
listings. You'll see that there are many  
organizations championing the cause of  
sickle cell disease that need your help.  
We thank them all.

We are actively seeking teams now for  
the upcoming 24 Seven Line Dance  
Marathon. This is the only non-stop 24 hour line dance Party with  
a Purpose in support of sickle cell disease in the world. That's 24  
hours with 7 major events within that time frame. Don't get  
scared...you can come for as long, or as little, as you like.

### 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.*

We will share more about the 24 Seven at the Open  
House and Presidential Debate Watch Party on Septem-  
ber 26th at 7pm. Learn about sickle cell advocacy and  
all programs offered by the SCANJ. And join in a lively  
discussion about the presidential candidate's positions  
on health policy.

Looking forward to hearing your voice **Say it Loud!**  
~Mary

## Afterwords Part 5: Teen To Transition



**Konstantinos**  
Child Ambassador

At what age do you get your  
child ready to "transition" into  
adult care? This thought would  
not have occurred to parents of  
children with sickle cell disease  
as recently as the 1960's since  
relatively few patients survived  
into adulthood. Thankfully, those  
days are over. We now have

individuals living well into their adulthood and senior years,  
thanks to improvements in medical care.

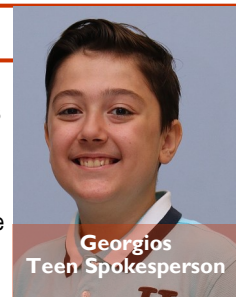
Pediatric medical services are generally well organized and  
comprehensive. On the other hand, most hospitals lack  
sufficient services for adults with sickle cell disease.  
Consequently, there is a great need for more adult providers  
to treat individuals living with sickle cell disease. And, there  
is a need to focus on educating about treatment options and  
available resources for all involved; health care providers,  
patients and extended family.

At the SCANJ we are fortunate to have our Child and Teen  
Ambassador's to help educate about sickle cell disease.  
One way they accomplish this is by leading the Youth  
Research Expedition during the annual Statewide Sickle  
Cell Symposium at the Liberty Science Center (Nov. 19).

This workshop organizes the  
youth into fun exploration groups  
where they solve questions that  
lead to greater understanding of  
sickle cell disease. This is also  
an opportunity for the youth to be  
engaged and active with other  
youth who have shared interests  
in learning about sickle cell  
disease.

When patients stay connected between pediatric and adult  
care through programs that educate and bring them  
together, it helps support the goal of coordinated continuity  
of care throughout life. Successful transition will lead  
individuals with SCD to live more productive and  
independent lives as adults. So at what age do you get your  
child ready to transition? We say from day one. Happy  
Birthday!! And many more to come.

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



**Georgios**  
Teen Spokesperson

**JOIN THE PARTY**  
**SHARE LEARN WIN**

## SICKLE CELL

### twitter PARTY

**TUESDAY, SEPTEMBER 13, 2016**  
**12-1:30PM**

**WWW.SICKLECELLNEWJERSEY.ORG**





**The Sick 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)

**SCANJ OPEN HOUSE & DEBATE WATCH PARTY**

**Monday September 26 at 7pm.**

Get updated on Advocacy and other programs offered such as our

Patient Centered Outcomes Research Institute Tier II Award  
1016 Broad St. Newark (NBCS)

Refreshments provided. Free Parking Available.

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



THE SICKLE CELL ASSOCIATION OF NEW JERSEY

PRESENT



# 24 HOURS SEVEN EVENTS

## LINE DANCE MARATHON

### RAISING FUNDS AND AWARENESS FOR SICKLE CELL DISEASE!

**FRIDAY, OCTOBER 21, 2016 @ 5:00 PM THROUGH**  
**SATURDAY, OCTOBER 22, 2016 @ 5:00 PM**  
**HOST SPONSOR: NEW JERSEY CITY UNIVERSITY**

**eventbrite**  

**Coming Soon...**

**OCTOBER**  
**October 4-5th** New York Mid Atlantic Consortium for Genetic and Newborn Screening Services Summit. SCANJ will present on our PCORI Project. Baltimore MD.

**October 21-22nd.**  
**24 SEVEN Line Dance Marathon.**  
Teams forming now to fundraise.

**November 11th** Newark Beth Israel Hospital Valerie Fund SCD Awareness Blood Drive.

**November 19th** 5th Annual Statewide Sickle Cell Symposium. Liberty Science Center, Jersey City, NJ. 9:30am-2:00pm.

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

**NEW JERSEY CITY UNIVERSITY**

# 24<sup>th</sup> ANNUAL seven line dance marathon

