

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 serious health problems. Your involvement makes the difference in overcoming this disease.



Volume 7  
Issue 11

# Say It Loud!

November 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



## So What is Your Point of View?

### Calendar Listings

#### NOVEMBER

##### 1st SCANJ Pop Up Event

Disney On Ice Prudential Center 7:00pm Newark

##### 1st-2nd PCORI Annual Meeting

SCANJ selected to present a poster on Patient Engagement. Crystal City, VA.

##### 3rd 24Seven Line Dance

**Marathon.** 5:00pm-Midnight at New Jersey City University in Jersey City. Seven Hours with 24 exciting events. Line dancing with Douglas Hawkins of Step4Step, SCD Awareness, Facebook Live moments, Food and Fun. 24Seven fundraising continues through Giving Tuesday so please keep those donations coming.

##### 7th Connections Support

**Group** 7:00pm -8:30pm JFK Center Willingboro.

##### 18th 5th Annual Statewide Sickle Cell Symposium.

Liberty Science Center, Jersey City 11:00am-3:30pm.

**SCANJ EVENTS ARE FREE UNLESS**

**OTHERWISE NOTED**

**REGISTER** via the events tab on [sicklecellnewjersey.org](http://sicklecellnewjersey.org)

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America



**Mary Bentley LaMar**  
Founder  
Executive Director

How do you deal with sickle cell disease? I believe it depends on your point of view. Are you looking at it as an individual who is living with the challenges of having SCD? Are you a health care professional who is trying to understand how to better treat individuals living with the disease? Perhaps you are seeking ways to be of greater support to your loved one who is living with sickle cell disease.

Whatever your perspective, we can all make a positive difference when dealing with SCD when we increase our understanding of different points of view. Our annual Statewide Sickle Cell Symposium allows you to experience those differing points of view by bringing

## Statewide Sickle Cell Symposium

**It's ON! The 5th Annual Statewide Sickle Cell Symposium!** There is no better event in New Jersey that allows you to learn the latest information on so many aspects of sickle cell disease from a cross section of the medical and patient community. **Join us!**

### SYMPOSIUM AGENDA

**10:00AM**

Judging of Pre-Symposium Research Fair Posters

**11:00AM**

**Drum Assembly Call to Order and Welcome**

Black Circle Symphony

**Panel Discussion: Hope for SCD**

Dr. Ansley LaMar,

SCANJ Board President & Panel Moderator

**Bone Marrow Transplants for Adults**

Dr. Jennifer Krajewski, Pediatric Hematologist

Hackensack Meridian Health UMC

**The 411 on SCANJ's PCORI Research Development Project**

Mary Bentley LaMar, Project Co-Lead

### Workshops

**Youth Research Expedition & Teen To Transition**

Ayoola Ogunyinka, Rutgers University Student & Lateasha Grant-Mack, Social Worker, The Valerie Fund RWJBarnabas Health Newark Beth Israel

**Kente Carpet Movies (video loop of SCD PSAs)**

### 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.*

together a diverse cross section of the sickle cell community with one focus—to improve conditions for individuals living with sickle cell disease. I hope you see my point.

~Mary



### Lunch & Learn Panel Discussion:

**Current Happenings in SCD**

**Understanding Diagnostic Tests**

Cathi Rubin Franklin, MS, LCGC, Genetic Counselor with Quest Diagnostics

**The Effects of New Opioid Laws on Pain Management**

Dr. Alice Cohen, Director of RWJBarnabas Health Newark Beth Israel Adult SCD Center

**SCANJ's PCORI Project from a Patient's Perspective**

Sakiyyah Burwell-Darden, Advisory Committee member

**Big Apple Playback Theatre**

**Research Fair Presentation of Poster Winners.**

**Closing Remarks**

**SCANJ PCORI Project Town Hall**

**Afterword's Networking**

**3:30PM SYMPOSIUM ADJOURNS**

**Until November 17, 2018**

Registration in advance is FREE.



Register now for this exciting and informative symposium.

[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

1016 Broad St. Newark, NJ  
 Phone: 973 482-9070 Fax: 973 485-6591  
 email: [info@sicklecellnewjersey.org](mailto:info@sicklecellnewjersey.org)  
 or [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com)



**Connections Support Group** Meets the first  
 Tuesday of each month at 7:00PM North and South  
 Jersey Locations alternate by  
 month. *Topic: Dealing With  
 Holiday Stress*



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, INC.  
 INVITES YOU TO

# Celebrate the Holidays

**CENTRAL**  
**FRIDAY DEC. 8<sup>TH</sup> 6:00PM TO 9:00PM**  
**i Play America**  
 110 SCHANCK ROAD • FREEHOLD NEW JERSEY

**SOUTH**  
**THURSDAY DEC. 14<sup>TH</sup> 6:00PM - 8:00PM**  
**GARDEN STATE DISCOVERY CHILDRENS MUSEUM**  
 2040 SPRINGDALE ROAD, CHERRY HILL, NJ 08003

**NORTH**  
**SATURDAY DEC. 16<sup>TH</sup> 3:00PM - 5:00PM**  
**VAN VLECK HOUSE & GARDENS**  
 21 VAN VLECK ST, MONTCLAIR, NJ 07042

**FESTIVE GAMES • CAROLING • TOYLAND • GIFTS • FOOD**

SPECIAL APPEARANCE BY  
**"Kenta Klaus"**

THIS EVENT IS FREE FOR FAMILIES AFFECTED BY SICKLE CELL DISEASE  
 ALL OTHERS ARE MERRY MAKERS \$25 ADULTS

FOR MORE INFORMATION CALL 973-482-9070  
 RSVP - [WWW.SICKLECELLNEWJERSEY.ORG](http://WWW.SICKLECELLNEWJERSEY.ORG)

OR VISIT  
**Eventbrite**

Happy  
 Thanksgiving!

Remember to  
**RSVP** for the  
 Holiday Party  
 most convenient  
 for you.

Please donate  
 to **SCANJ** on  
**Giving Tuesday**  
 November 28th  
 online or via  
 our  
**Facebook  
 Page**

Thanks for  
 Giving!

