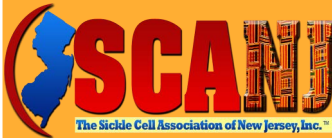


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings SCD AWARENESS MONTH

5th Connections Support Group
Tuesday 7:00pm – 8:30pm Topic Patient Centered Research. JFK Center Willingboro, NJ

Every Thursday in September, from 12:30 pm-1:30 pm, join in the **SCDAA Twitter Parties.** The theme is *Standing as One Voice in Advocacy & Awareness.* Use #SCDVICTORIES

September 6-October 11th CDSMP Workshop. 6 weeks 9:00am. First Baptist Church of Beverly.

9th Meet Move & Mingle Community Wellness 10:00am, Elmwood Park, East Orange

14th Bone Marrow Transplant Program. 3:00pm -5:00pm at RWJ Barnabas Medical Center Newark Beth Israel. Valerie Fund Room L-5Dr. Speaker- Jennifer Krajewski, MD of Hackensack Meridian Health.

16th Donna T. Darrien Memorial Foundation Walk for SCD. 8:30am. Weequahic Park Newark, For information visit www.dtsicklecell.org

27th RWJ Barnabas/ Valerie Fund Blood Drive. 12 noon -5:30PM at RWJ Barnabas Beth Israel Medical Center 210 Lehigh Ave. H-3 Conference Room. Newark.

ALL SCANJ EVENTS ARE FREE UNLESS OTHERWISE NOTED

REGISTER via the events tab on
sicklecellnewjersey.org

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America



Volume 7
Issue 9

Say It Loud!

September 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

Ten Ways To Make Some Noise. It's Sickle Cell Awareness Month!



Mary Bentley LaMar
Founder
Executive Director

1. **Say It Loud!** Share this newsletter with someone else.
2. Participate in any of the programs listed on the calendar.
3. Surf www.sicklecellnewjersey.org
4. Surf other websites dedicated to sickle cell disease.
5. Request an awareness packet from SCANJ to share with your community.
6. Share your personal story of dealing with sickle cell disease.
7. Learn three facts about sickle cell disease and share your learnings.

8. Donate blood at the Valerie Fund Blood Drive.
9. Post on our Facebook page how you are raising awareness
10. Volunteer!

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.

This month, I am short on words and long on action. As you move through Sickle Cell Awareness Month, please go beyond your own circumstances and actively do something to support our mission. Looking forward to hearing your voice...

Somebody make some noise!

~Mary

SCANJ Advances To A PCORI Pipeline To Proposal Tier III Award!

SCANJ has been approved for a \$50,000 Funding Award by the Patient-Centered Outcomes Research Institute (PCORI). We will use the funds provided through PCORI's Pipeline to Proposal (P2P) Awards program to build community partnerships, develop research capacity, and develop a comparative effectiveness research (CER) question that could become the basis of a research funding proposal to submit to PCORI or other health research funders.

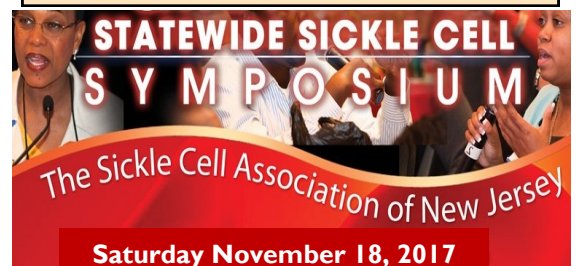
SCANJ's project is "We'll Take The Village: Engaging the Community To Better Health." We began with a P2P Tier I Award in 2015 and advanced to P2P Tier II in 2016. Our research ideas are centering around choices to deal with pain management. During Tier III which is from August 1, 2017-July 31, 2018, we plan to further refine our research questions, and ultimately design a scientifically robust comparative effectiveness research (CER) study proposal. We will accomplish this by continuing to conduct systematic literature reviews and increasing research/clinical partner involvement. Increased participation from these partners is critical to inform the design of the proposed study and to identify barriers to its implementation in a real-world clinical setting. We welcome continuing to engage the patient community through meetings, presentations, etc., to educate them on CER and PCORI methodology and seek their input on question revisions and study design.

Pipeline to Proposal Awards enable individuals and groups that are not typically involved in clinical research

to develop the means to develop community-led funding proposals focused on patient centered CER. "The Pipeline to Proposal Awards program is a manifestation of PCORI's commitment to the meaningful involvement of patients, caregivers, clinicians, and other stakeholders in all our research endeavors," said Jean Slutsky, PA, MSPH, PCORI's Chief Engagement and Dissemination Officer. "It provides support to those who may not otherwise have an opportunity to contribute to the field of comparative effectiveness research."

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work.

Learn more about SCANJ's PCORI Project at the Sickle Cell Symposium at the Liberty Science Center.



Saturday November 18, 2017

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
or sicklecellanj@gmail.com

Connections Support Group



Meetings on the first

Tuesday of each month at 7:00PM. South Jersey location in the odd numbered months i.e., January, March, May, September and November. **North Jersey** location in the even numbered months i.e., February, April, June, October and December

Topic: Patient Centered Research

This month's meeting is Tuesday September 5th at the JFK Center in Willingboro. Next month's meeting is Tuesday October 3rd at NBCS 1016 Broad St. in Newark, For more information and to RSVP you may register online via our events tab, call our office at 973 482-9070, or call our Community Outreach Coordinator, Darlene Young at 862 371-7138.

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

We're Trying Something New...





Awareness Month Twitter Party

sicklecelldisease.org

Join us in celebration of National Sickle Cell Disease Awareness Month



We invite you to join in the fun with the SCDAA. Every Thursday this month from 12:30pm-1:30pm, join in the Twitter Parties, by using the hashtag **#SCDVICTORIES** to share tweets and your comments. Register and get your networks to join to be eligible to win prizes! The Twitter Party schedule:

- September 7, 2017: "Standing as One Voice in Advocacy & Awareness"
- September 14, 2017: "Access to Care and Treatment at its Best"
- September 21, 2017: "Pharma Initiatives on the Horizon"
- September 28, 2017: "Advances in Finding a Cure"

Stay Posted for details on the 24 Seven Line Dance Marathon and related events.



SCANJ's Child Ambassador hosting at the Kente Carpet Movies Under The Stars



Coming Soon...

OCTOBER

SCDAA National Convention
October 25-29th
Atlanta, GA go to
www.sicklecelldisease.org
to register. SCANJ selected to present on our PCORI Project

PCORI Annual Meeting

October 31-November 2nd
Crystal City, VA. SCANJ selected to present a poster.

November 24/SEVEN Line Dance Marathon. (Date TBA) New Jersey City University, Jersey City, NJ We are trying something new this year by building 24 hour events to include the Phone A Thon, A Twitter Party, A Social Media Blast and 7 continuous hours of line dancing. Teams forming now to fundraise.

November 18th 6th Annual Statewide Sickle Cell Symposium. Liberty Science Center, Jersey City, NJ. 11:00am-4:00pm.

Register for SCANJ programs via events on sicklecellnewjersey.org, www.eventbrite.com or call 973 482-9070.