

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 10

Say It Loud!

October 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Calendar Listings

OCTOBER

3rd Connections Support Group
Tuesday 7:00pm -8:30pm Topic Patient Centered Research. Newark

7th SCD Luncheon Hosted by NJ State Association of the Elks and NJ Daughters of the Elks IBPOEW
12PM Red Pine Inn. Clayton, NJ

11th DSMP Workshop. 6 weeks
9:00am. Living Springs Center. Delanco

12-13TH PCORI Tier III Awardee Convention. SCANJ to attend. Chicago

18th Liberty Science Center Community Evening. 6:00pm. SCANJ table on Research Fair Contest. Jersey City

19th American Red Cross Blood Drive First Baptist Church. Willingboro.

October 25-29th SCDA National Convention. SCANJ Road Trip Scholars and Young Adult Alliance members to attend. SCANJ to present on our PCORI Project. Atlanta, GA

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

November 3rd 24Seven Line Dance Marathon. 5PM-Midnight. Teams forming now to fundraise. New Jersey City University. Jersey City, NJ

7th ELECTION DAY . VOTE!

ALL SCANJ EVENTS ARE FREE UNLESS OTHERWISE NOTED

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America

On The Road Again. . . In My Kenny Rogers' Voice



Mary Bentley LaMar
Founder
Executive Director

I'm singing Kenny Rogers' song "On The Road Again" because it seems like just about every week this month, we are travelling to advance the mission of the SCANJ. At the time of this writing, I am on a flight to Chicago to attend the Patient Centered Outcomes Research Institute (PCORI) Pipeline 2 Proposal Tier II & Tier III Convention.

This is an exciting time, as our SCANJ team has been on this research development journey since 2015 with our PCORI Project "We'll Take The Village: Engaging The Community To Better Health." Towards the end of this month, we will present on our project at the Sickle Cell Disease Association of America Convention in Atlanta, Georgia and then

it's on to Crystal City Virginia to present a poster at the PCORI Annual Meeting.

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.

I'm looking forward to reporting on learnings from our journey at our upcoming events, most notably the 24Seven Line Dance Marathon and the Statewide Sickle Cell Symposium. **Get your dancing shoes on!**

~Mary

New SCANJ Initiatives Coming Up...

We're excited about the new initiatives in our upcoming programs. On November 3rd we host our Annual 24Seven Line Dance Marathon for sickle cell disease. 2017 marks the 7th year for this signature fundraiser. Can you believe it's been almost 7 years since we attempted the Guinness World Record for continuous line dancing? Yes, in 2011 we attempted to go 24 hours non-stop line dancing to raise money for sickle cell disease.

While we did not make the Guinness record, we continue to work "24Seven" to improve the quality of life for individuals living with sickle cell disease. It is still a marathon, and we are in this for the long haul. With the help of the New Jersey City University Office of Campus Life and supporters like you, we are making a difference.

For this year's 24Seven, we are changing things up. Instead of 24 hours with seven events, join us for 24 events within the 7 hour line dance marathon. We'll start at 5:00pm and go until midnight with our non-stop party with a purpose.

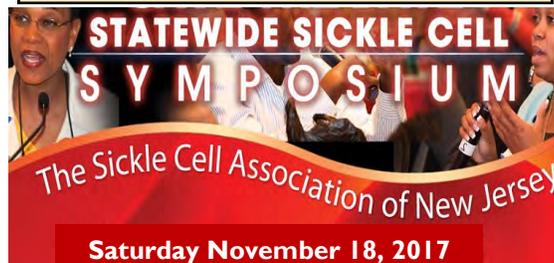
Another new initiative this year is the Pre-Symposium Student Research Fair. It will take place at 10am prior to the opening of the Statewide Sickle Cell Symposium on Saturday November 18th. Local students, grades 7-12, are invited to submit an application to display a scientific poster on comparative effectiveness research.

Only 25 poster applications will have the honor of being selected to exhibit at the Liberty Science Center and to be considered for awards. Deadline for entry November 3, 2017. The purpose of the Research Fair is to engage the community in understanding comparative effectiveness research (CER).

We're currently working on Tier III of a Patient Centered Outcomes Research Institute (PCORI) Award project titled "We'll Take The Village: Engaging the Community To Better Health." The project goal is to develop a CER question for research and implementation of the results that benefit individuals living with sickle cell disease.

SCANJ began with a P2P Tier I Award in 2015 and advanced to P2P Tier II in 2016. 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.

Learn more at the
Sickle Cell Symposium at the Liberty Science Center.



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**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

November/December Topic: Dealing With Holiday Stress

This month's meeting is Tuesday October 3rd. Next month's meeting is Tuesday November 7 at the JFK Center in Willingboro. 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

Can You Bring It? The 24Seven is Almost Here...



SCANJ THE SICKLE CELL ASSOCIATION OF NEW JERSEY
 www.sicklecellnewjersey.org
 PRESENTS

24 SEVEN HOURS

LINE DANCE MARATHON
 RAISING FUNDS AND AWARENESS FOR SICKLE CELL DISEASE!

FRIDAY, NOVEMBER 3, 2017 @ 5:00PM - 12:00AM
7 HOUR NON-STOP PARTY WITH A PURPOSE

HOST SPONSOR: NEW JERSEY CITY UNIVERSITY
 2039 JOHN F KENNEDY BLVD
 STUDENT UNION BUILDING 2ND FLOOR
 JERSEY CITY, NJ 07305

REGISTER @ **Eventbrite**

Coming Soon...

NOVEMBER 3rd
 24Seven Line Dance Marathon. Seven Hours with 24 exciting events. Line dancing, Comedians, Line Dance Lessons with Douglas Hawkins and Step 4 Step, SCD Awareness, Facebook Live moments, Prizes, Food, Fun, fundraising and more!!

Register on eventbrite and start your fundraising today! Call 973 568-8119 or 973 482-9070.

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

December Holiday Parties with Kenta Klaus
 8th iPlay America in Freehold 6:00pm
 14th Garden State Discovery Children's Museum in Cherry Hill 6PM
 16th Van Vleck House in Montclair 3:00PM

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