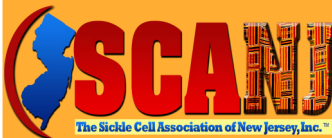


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings NOVEMBER

2nd Montclair Branch NAACP 102nd Thurgood Marshall Freedom Fund Dinner & Awards. SCANJ Founder, Mary Bentley LaMar to receive The Julian Bond Community Service Award. Hanover Manor. East Hanover, NJ

6th ELECTION DAY

YOUR VOTE IS YOUR VOICE

Connections Support Group

This month's topic: Advocacy
Tuesday 7:00pm -8:30pm JFK Center
429 JFK Parkway, Willingboro, NJ

9th The Eighth Annual Line Dance

5:00pm-Midnight. New Jersey City University, Gillian Student Center, Multi-Purpose Room 2539 Kennedy Blvd. Jersey City, NJ.

Nov. 9th

24 EVENTS
7 HOURS
LINE DANCE MARATHON
RAISING FUNDS AND AWARENESS FOR SICKLE CELL DISEASE!

15th ASAH Annual Luncheon Association of private schools serving special needs children. SCANJ Founder, Mary Bentley LaMar to receive The Humanitarian Award. Harrah's, Atlantic City, NJ

17th The Sixth Annual Statewide Sickle Cell Symposium. Liberty Science Center, Jersey City, NJ. 10:00am-3:00pm.

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America



Volume 9
Issue 10

Say It Loud!

November 2018

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

Thank You. Simple Words. Simple Meaning. We Appreciate YOU!



Mary Bentley LaMar
Founder
Executive Director

November is a month that we make a concentrated effort to reflect on what we are thankful for. I am thankful that the SCANJ is approaching its 10th year of operation having been founded on September 1, 2009.

We have accomplished a lot in that span of time and none of it would have been possible without the support of the community.

One of our accomplishments is establishing the longest running Line Dance Marathon for Sickle Cell Disease. Yes, the 24 Seven is still going strong in its 8th year of raising funds and awareness for SCD. Do you remember that the first several 24 Seven Line Dance Marathons actually were 24 hours non-stop? I do.

We've made it a little easier for you now with 24 activities in a 7- hour time period. We will have line dance lessons, line dancing, SCANJ Jeopardy, comedians, food, and fun. Please come out and join us for this fundraiser. Another accomplishment is the Annual Statewide SCD Symposium. For the 6th year, we are able to come together at the Liberty Science Center in Jersey City

SCANJ Mission Statement

To advocate for people affected by sickle cell conditions and to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

for a day of learning and networking for the betterment of the sickle cell community. We have workshops that cater to all ages. The symposium is suitable for patients, health care professionals and anyone interested in learning more about sickle cell disease.

Make sure you are involved in these events and more. Each month we publish this newsletter with calendar listings of events. We also have a Callingpost (voicemail message) phone reminder that you may elect to receive with information on activities that may be of benefit to you. So yes, I am grateful in this season of Thanksgiving. Each day, I have an opportunity to make a difference in the sickle cell community.

Count it all joy!

~Mary

Ad-vo-cate: What Does This Mean To You?

The word "advocate" is from the Latin *advocare*, to "add" a "voice." To *advocate* is to *add a voice* of support to a cause or person. At the Statewide Symposium on SCD on November 17th, you can learn more about how to add your voice to issues and concerns that affect the sickle cell community.

Historical Perspective: Since 2002 the Sickle Cell Disease Association of America (SCDAA) has worked with Congressional champions to authorize and fund a number of national SCD legislative programs. These programs provide support for patients suffering from SCD while encouraging enhanced research intended to identify next-generation treatments and a cure for SCD.

The sickle cell community celebrated with the announcement of two legislative victories in Congress. First, the U.S. House of Representatives passed H.R. 2410 on February 26, 2018, the **Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act**, which was introduced on May 11, 2017, by Rep. Danny Davis (D-IL).

On February 28, 2018, Senator Cory Booker (D-NJ) and Senator Tim Scott (R-SC) introduced the Senate companion bill to H.R. 2410 into the Senate. The bill passed the Senate on October 11, 2018.

To ultimately pass this bill into law, we are calling on the you to advocate for H.R. 2410. With your help, this bill would authorize the Secretary of Health and Human Services to track and analyze data on the prevalence of sickle cell disease (SCD). In addition, the bill would authorize the Secretary to develop public health initiatives that support community-based organizations in education activities and to support regional and state health departments in testing to identify SCD.

Check out our Facebook page for the latest updates on the symposium. This event is FREE but you must register. Call us or visit the events (Eventbrite.com) tab on sicklecellnewjersey.org. We want to see you there!

Content for a portion of this article was provided by the SCDAA. Learn more about advocacy during the Sickle Cell Symposium at the Liberty Science Center.

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

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

This month's topic: Advocacy

This month's meeting is Tuesday November 6th at the JFK Center in Willingboro. **Next month's meeting is Tuesday, December 4th 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

SAVE THE DATE
STATEWIDE SICKLE CELL
SYMPOSIUM

The Sickle Cell Association of New Jersey

Saturday, November 17, 2018
PRE-SYMPOSIUM STUDENT RESEARCH FAIR BEGINS @ 9:00 am
SYMPOSIUM Starts @ 10:00 am • Ends @ 3:00 pm

REGISTER @

liberty science center®
222 JERSEY CITY BLVD, JERSEY CITY, NJ 07305

MEET AND GREET LUNCH AND LEARN
SCANJ JEOPARDY! Game
YOUTH RESEARCH EXPEDITION

WORKSHOPS
Sickle Cell Disease-Redefined
Success In Schools; Working with IEP & 504 Plans
Teen to Transition
Emerging Treatments for SCD
Lunch & Learn Panel Discussion on Advocacy

DR. CHARLES F. WHITTEN AWARDS
RESEARCH FAIR AWARDS

HOSTED BY **SCANJ**



Coming Soon...

November

Diabetes Self-Management Program. 6 Week workshop series. Wednesday's November 14th—December 19th at First Baptist Church of Beverly, 405 Broad Street, Beverly, NJ

DECEMBER

Holiday Parties with Kenta Klaus (Santa's brother)
7th Holiday Central

IPlay America Freehold, NJ

13th Holiday South
Garden State Discovery Children's Museum in Cherry Hill, NJ

15th Holiday North Van Vleck House in Montclair, NJ

12th Newark RWJBarnabas
Adult SCD Holiday Party

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