

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

MARCH Frances Thompson-Walton Scholarship Applications now being accepted. Visit www.sicklecellnewjersey.org events tab on to apply. Deadline May 1st.

3rd SCANJ Get Connected POP Up Event! Movie Screening of Black Panther. AMC Movie Theatre. Newport Mall. Jersey City. Thanks to the generous sponsorship of MUFG Union Bank.



6th Connections Support Group 7:00pm-8:30pm. JFK Center. 429 JFK Way in Willingboro.

April 3-6 Peer Leader CDSMP 4 Day Certification Class in Newark. Register now. Classes are limited to 20 enrollees.

SCANJ EVENTS ARE FREE UNLESS OTHERWISE NOTED

REGISTER via events on sicklecellnewjersey.org or call 973 482-9070

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America



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Say It Loud!

March 2018

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

A History Lesson: Moving Right Along...



Mary Bentley LaMar
Founder
Executive Director

How many of you have heard of the SCANJ Road Trips? These are trips hosted by SCANJ to support members of the sickle cell community to attend scientific and/or educational conferences and events.

Our very first SCANJ Road Trip was to the National Institutes of Health James B. Herrick Symposium in 2010. SCANJ sponsored a bus filled with road "warriors" to descend upon Bethesda, Maryland for the 100th Anniversary of the discovery of sickle cell disease.

Since that time we have sponsored several other road trips. I'm proud to say that our road trips to participate in the SCDAA's Advocacy Days on Capitol Hill—collectively with community-based agencies led by the SCDAA from around the country—have led to the passage of H.R. 2410, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act, which was introduced by Congressman

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.

Danny Davis (D-IL) and co-sponsored by Congressman Michael Burgess (R-TX). This bill supports the surveillance and collection of data on the prevalence of SCD and supports public health initiatives that support education and testing to identify SCD.

On the Senate side we are excited to see a bipartisan bill for SCD introduced by our own U.S. Senator Cory Booker (D-NJ) along with U.S. Senator Tim Scott (R-NC).

It's a long road, but we are getting closer to real change for the better in the sickle cell community. And it is thanks to advocates willing to go the extra mile. Can't stop now.

Keep it moving.

~Mary

SCANJ Named As a SCDAA HRSA Awardee

The Sickle Cell Disease Association of America (SCDAA) was awarded 2.9 million annually for the next four years from the Health Resources & Services Administration (HRSA) for the Sickle Cell Disease Newborn Screening Follow-up Program in June of 2017. SCDAA has identified 16 community based organizations (CBOs) in fifteen states, to receive \$2,033,080 of its HRSA grant award to support their capacity to identify, educate and link patients to care.

SCANJ is pleased to be named as one of the CBO grantees. The objectives are to work to provide care coordination, medical home assistance, education and other services to individuals living with sickle cell disease. "This fits right in with our mission as that has been the focus of the SCANJ since it's beginning in 2009," said SCANJ Founder Mary Bentley LaMar.

"The SCDAA is so grateful for the opportunity to continue to support CBO's across the country in increasing access to care while building a larger community of informed, active and motivated patients," said SCDAA President Sonja L. Banks.

Over the past 3 years the SCANJ has participated in the HRSA SCDAA Newborn Screening Program. As a result, the SCANJ has accomplished the following:

- Participated in the Get Connected Patient Powered Registry
- Increased staff to include 1 Hemoglobinopathies Health Educator and 1 Community Health Worker
- Contributed to a Shared Management System to collect and analyze patient data for HRSA and to report data outcome measures
- Increased public awareness of SCD throughout New Jersey
- Increased knowledge of SCD among individuals living with SCD
- Served as a connection to identify and provide resources helpful to the SCD community.

The funds from the grant will help the SCANJ to have consistency in outreach to the community through their Community Health Workers. The grant also allows the SCANJ to increase its capacity to provide more education and supportive services for individuals living with sickle cell disease.

HRSA, part of the U.S. Department of Health and Human Services, is the primary Federal agency responsible for improving access to health care services for people who are uninsured, isolated or medically vulnerable.

WWW.SICKLECELLNEWJERSEY.ORG



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Connections Support Group

**Meets 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: Coping Strategies for the ER

March 6th at the JFK Center in Willingboro. April 3rd at NBCS 1016 Broad St. in Newark. For more information and to RSVP you may register online via our events tab 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



Register Now

www.getconnectedscd.org

POP Up Events!



What do the Black Panther Movie, UniverSoul Circus and Disney On Ice have in common? They have all been destinations for SCANJ Get Connected Pop Up Events.

SCANJ POP Up events are FREE special events for New Jersey residents directly affected by sickle cell disease AND who are registered with

SCANJ through www.Getconnectedscd.org; the SCDA Patient Powered Registry.

The POP Up's are possible thanks to the generous sponsorship of local companies and organizations. For example, the Black Panther Movie Screening was thanks to MUFG Union Bank of Jersey City.

Pop Up Events are a great opportunity for families affected by sickle cell disease to connect through fun, stress-free programs. Sometimes these programs are announced with short notice, and limited capacity so you must RSVP right away.

Priority for SCANJ programs and services is given to those who are in our supportive network. Other advantages for you include receiving our callingpost voice mail announcements.

You will be among the first to know of programs that benefit you. We also include our Get Connected families in our email list serve for the monthly newsletter and occasional "Newsflash" announcements.

So make sure you are in www.getconnectedscd.org SCDA Patient Powered Registry and registered with the SCANJ

To get connected with the SCANJ please give us a call at 973 482-9070 or email us at info@sicklecellnewjersey.org.

Coming Soon. . .

April Minority Health Month

April 21st. Zeta Phi Beta Sorority, Inc., Omicron Omicron Zeta Chapter is honoring members of sororities for their community service. SCANJ Founder, Executive Director, and member of Alpha Kappa Alpha Sorority, Inc., Omicron Xi Omega Chapter, Mary Bentley LaMar, is an honoree. Brunch tickets are \$50.00 for adults and \$30.00 children 12 and under. Call 609 668-3107 for tickets.

June 21, 22, 25 & 26th Peer Leader Diabetes Certification in Newark .

Ongoing: SCANJ Get Connected Pop Up Events

