

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 9
Issue 5

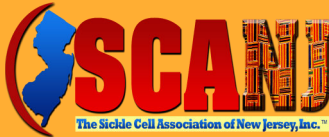
Say It Loud!

May/June 2019

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Calendar Listings

MAY

5th Connections Support Group

JFK Center 429 JFK Parkway
Willingboro 7:00pm—8:30PM

14-17th 4-Day Peer Leader Certification in Diabetes Self Management.

600 Park View Dr. Delanco.

JUNE

4th Connections Support Group

NBCS 1016 Broad St, Newark
7:00pm-8:30pm

20th, 21st, 24th & 25th 4-Day Peer Leader Certification in Diabetes Self Management.

NBCS 1016 Broad St., Newark. 9:30am-4:00pm daily.

19th Shine The Light on Sickle Cell Disease for World Sickle Cell Disease Day

1016 Broad St. in Newark 7:00pm with sundown walk to City Hall.

22nd Annual Sickle Cellabration



NJ Adventure Aquarium
1 Riverside Drive in Camden
9:30am-2:00pm

SCANJ EVENTS ARE FREE
UNLESS
OTHERWISE NOTED

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

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America

Message From the Executive Director. . .



Mary Bentley LaMar
Founder
Executive Director

We have cause to celebrate! The year 2019 marks the 10th anniversary of the Sickle Cell Association of New Jersey. It also marks the 10th anniversary of World Sickle Cell Disease Day. We have several activities coming up that provide a setting for you to honor these anniversaries by learning more about sickle cell disease and supporting individuals living with sickle cell disease.

Two such activities are the 9th Annual *Sickle Cellabration* and the *Shine The Light on Sickle Cell Disease Day Reception* followed by a sun-down walk to City Hall. All activities are in the Calendar listings. You can also visit our website and our Facebook page for the latest updates.

I encourage you to come out to our events and take advantage of workshops and certification opportunities. Don't worry, if you can't make them all. Participate as you are able. Even if you just share the information, you are helping our cause. You also have the opportunity to help yourself. For example, those who have been certified as Peer Leaders in the Chronic Disease Self-Management and the Diabetes Self-Management Program have used the tools learned to

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.

improve their own health outcomes. Our Peer Leaders have also helped others to learn to improve their health through these workshops offered free to the community.

I trust all mothers have had a wonderful Mother's Day and here's wishing all Fathers a grand Father's Day. For those of you in those categories who are living with sickle cell disease, or caring for a loved one with sickle cell disease, I salute you even more. No one knows the countless times you have had to draw upon your inner strength to overcome challenges. Please know that there is a whole community of people out here working to make your conditions better.

I look forward to seeing you at one or more of our upcoming events. Please help us to spread the word and invite others to come out as well. To reflect on one of my favorite Proverbs...

"He who refreshes others is himself refreshed."
~Mary

World Sickle Cell Disease Day Activities Near You

June 19th is World Sickle Cell Disease Day. On this day we ask you to help us to "*Shine The Light on Sickle Cell Disease*" SCANJ is hosting a reception at 7:00pm at Newark Boys Chorus School 1016 Broad St. We will have a sundown candlelight vigil to City Hall to enlighten others about sickle cell disease. And we will recognize and thank the Cultured Expressions Sewing and Quilting Studio of Rahway for conducting the SCD Quilt Project dedicated to sickle cell disease awareness.

June 22nd Sickle Cell Disease Association of America, Inc. (SCDAA) hosts the 6th Annual National Walk with the Stars a 1K, 2K and 5K walk/run, starting at 9am at the Canton Waterfront Park, 3001 Boston Street, Baltimore, MD 21224. Support SCANJ's virtual *Walk The Talk* Team through the SCDAA's largest fundraiser. Every dollar that you raise goes toward preventing the complications of sickle cell disease through awareness, education, advocacy and research! Please support SCANJ's virtual team by donating via our website or by donating to the Sickle Cell Association of New Jersey via Facebook.

June 22nd is our annual Sickle Cellabration.
9:30am-2:00pm
Adventure Aquarium in Camden.

This is SCANJ's commemoration of World Sickle Cell Disease Day. You are invited to enjoy our version of a world festival of fun and learning.

We will award the Frances Thompson Walton Scholarships and select our Teen and Child Ambassadors for 2019-2020. We have gifts for the children including beautifully crafted tables created by employees at Novartis. Lunch is provided as well as parking vouchers for registered guests. We're at a new location this year so come out and expand your knowledge and your network.



WWW.SICKLECELLNEWJERSEY.ORG



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EIN# 80-0474935 SCANJ is a 501c3 agency

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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, North Jersey location in the even numbered months i.e., February. There are no meetings in July and August.

May Topic: 10th Anniversary Milestones
June Topic: World SCD Day

This month's meeting is Tuesday May 5th at the JFK Center 429 Kennedy Pkwy in Willingboro. The June meeting is June 4th. Location: 1016 Broad St. 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 every two months except for July and August. Archived copies are available for download from our website.

Beverly Lucas-Editor

Disease Self-Management Skills Can Be Yours

If you are living with sickle cell disease, you have learned some things that have helped you cope along the way. We want you to bring those skills of knowing about your health condition to a forum where you can lead yourself and others to better health. I am speaking specifically of the Chronic Disease Self-Management Program (CDSMP) and the Diabetes Self-Management Program (DSMP). They are part of a series of workshops developed by the Stanford University School of Medicine's Patient Education and certified and licensed through the Self-Management Resource Center.

This program has been held at locations throughout the country and around the world. The sessions are led by trained volunteer peer leaders, some with health conditions themselves such as sickle cell disease and diabetes. The workshops are designed to give people with chronic conditions (such as sickle cell disease, arthritis, heart disease, cancer, diabetes, etc.) and/or their caregivers the knowledge and skills needed to take a more active role in their health care.

Thanks to a grant from the New Jersey Office of Minority and Multicultural Health; SCANJ is a host agency for Take Control of Your Health, the New Jersey program for CDSMP and DSMP. In a small group setting (15-20 enrollees) participants learn healthier ways to live, gain confidence and motivation to manage their health and feel more positive about life. The Community workshops are 2 - 2 ½ hours, once a week for 6 weeks. Setting weekly goals, making an action plan, giving feedback and sharing, is 25-35% of each workshop session. Participants learn how to make better nutrition and exercise choices, relaxation techniques to help reduce stress, better pain management, better ways to communicate with their doctor and loved ones about health and more.

SCANJ has a Peer Leader 4-Day Diabetes Certification course coming up; June 20, 21, 24 & 25th for DSMP in Newark. The program is FREE, however, you need to register as capacity is limited. We are pleased to offer stipends to our certified Peer Leaders when they teach in the community workshops.

Why should you attend: It works! Studies have shown that the Take Control of Your Health Workshop produces positive results for people who complete the program.

For more information about the CDSMP and DSMP workshops as well as other programs and services offered by the Sickle Cell Association of New Jersey, call Darlene Young, SCANJ's Outreach Coordinator at 862-371-7138.



Coming Soon...

SAVE THE DATES
SEPTEMBER IS
SICKLE CELL AWARENESS
MONTH

September 1, 2019
SCANJ 10th Anniversary
Celebration

October 9-12
SCDAA Annual Convention
Baltimore Maryland

November 23, 2019
Statewide Sickle Cell
Disease Symposium
Jersey City, NJ

Throughout this 10th Anniversary Year, we will reflect on key moments in our organization's history to keep us connected with our mission.

Key Moment: The CDSMP Program was our first grant. Although we were a budding agency at the time, the New Jersey Department of Health gave us a chance. We have proudly implemented this program since 2011 and have often been cited for best practices for its implementation by the NJ Office of Minority and Multicultural Health.