

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



Say It Loud!

March 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Volume 7
Issue 3

March is Women's History Month...You Have A Story To Tell

Calendar Listings:

March 4th SCANJ Get Connected Pop UP Event! Elite Team Cup Men's Gymnastics at Prudential Center Newark. FREE for our Get Connected Families. Pick up tickets at 5:30pm Sharp! You must RSVP online or call Mary at 908 247-9130.

7th Connections Support Group
Tuesday at 7:00 PM.



11th SCANJ's Research Project; Village Town Hall Meeting "We'll Take The Village: Engaging The Community To Better Health." 9:00am-1:00pm 1016 Broad St. Newark, NJ Refreshments Served.

18th Sickle Cell at Shiloh AME Zion Church 11:00am. 129 William Street, Englewood. Sickle Cell Sabbath presentation by SCANJ.

26th American Red Cross Blood Drive and Sickle Cell Awareness. Hosted by Cedarbrook Elementary School in cooperation with Delta Sigma Theta Sorority Central Jersey Chapter. 10am-3:00pm 1049 Central Ave. Plainfield

27th, 28th 29th & 31st Stanford School of Medicine Diabetes Self Management 4 Day Peer Leader Certification Class. Living Springs Residential Center. 600 Parkview Dr. Delanco, NJ. FREE. Register early.

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



Mary Bentley LaMar
Founder
Executive Director

History is made every day, but who is telling the story? This is an active time in the sickle cell community and there is a lot to tell.

We are excited to tell about our PCORI Project at the upcoming Village Town Hall (calendar listings). And each month on the first Tuesday at 7pm you have an opportunity to connect and uplift each other at the Connections Support Group.

I will make this short and sweet... raise your voice and tell your story. When you tell your story-your "history,"

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.

you help others to understand why it is important to support our mission. The men may say, but this is Women's History Month...I say, your birthday was a historical moment for your mother. You were born for a purpose...

Tell your story and SAY IT LOUD! ~Mary

Who's Who on SCANJ's PCORI Project? (Part 2)

"We'll Take The Village: Engaging the Community to Better Health" is SCANJ's groundbreaking project designed to let the scientific community hear what matters to patients with sickle cell disease (SCD). It is made possible by a Pipeline to Proposal Award from the Patient Centered Outcomes Research Institute (PCORI).

We are happy to report that Theresa Amoloja, M.P.H., is working with us on this project. Theresa is a Research Associate at Johnson & Johnson in New Brunswick, NJ. *Say It Loud!* recently caught up with Theresa to find out what motivated her to take part in the project and what she hopes it will accomplish.

Say It Loud! What is your role on the project?

Theresa: I am using my background in epidemiology to assist with the scientific aspects of the project. As the project moves forward, I will continue to use my training to help prepare the methods section of a research proposal that we will be helping to develop and the study protocol.

Say It Loud! What motivated you to participate?

Theresa: While I was a student at Rutgers University, where I earned my Master's Degree in Public Health, I worked at SCANJ as a community health intern. My experience at SCANJ, piqued my interest in conducting outcomes research. This is the reason I immediately agreed to come on board for the PCORI project.

Say It Loud! Was your SCANJ internship your first experience with SCD?

Theresa: No. I was quite familiar with sickle cell disease because I was raised in Nigeria where it is prevalent. Due to the relatively low prevalence of SCD in the

United States, this genetic blood disorder is often overlooked and research into it is underfunded. I believe continued engagement in research, advocacy, outreach etc. will shed more light on this disease and result in more government funding for specialized treatment centers and, eventually, a cure.

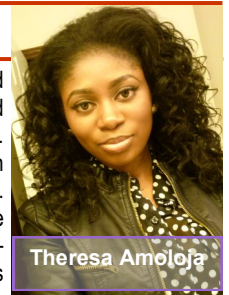
Say It Loud! What has been the most fulfilling aspect of your participation in the project so far?

Theresa: I accompanied SCANJ Executive Director, Mary Bentley LaMar, to a PCORI conference in Chicago last year and had the wonderful opportunity to speak with professionals from various disciplines, learn about their research projects, and get a better understanding of the PCORI project and the process involved.

Say It Loud! What do you hope the project accomplishes?

Theresa: I have high hopes for this project. I hope we can create a proposal and receive funding to take part in a sophisticated comparative effectiveness research (CER) project.* The results from such a project could have important clinical implications that would be beneficial not only to the people SCANJ serves, but to all people living with and affected by SCD in the community and beyond.

***Editor's note:** PCORI funds CER projects. This type of research is designed to compare the effectiveness of two or more interventions or approaches to health care, examining their risks and benefits, and identifying which best meets the needs of a given population.



Theresa Amoloja

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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

March Topic: Paint Chat and Chew

This month's meeting is Tuesday March 7th at JFK Center 429 JFK Way. Willingboro, NJ. Next Month's meeting is April 4th. Location is TBA. 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

www.sicklecellnewjersey.org



You've Got Skills! Become a Certified Peer Leader

And we want you to bring those skills of knowing about your health condition to a forum where you can help lead others to better health. That forum—the Chronic Disease Self-Management Program (CDSMP) and the Diabetes Self-Management Program (DSMP) is part of a series of workshops developed, certified and licensed by Stanford University School of Medicine's Patient Education Research Center.

These programs have 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 these and other chronic conditions (such as arthritis, heart disease, cancer, 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), peer leaders help 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, use relaxation techniques to help reduce stress, better manage pain and better communicate with their doctor and loved ones about health and more.

SCANJ has Peer Leader 4-Day certification courses coming up: March 27, 28, 29 & 31st for DSMP in Delanco and April 17, 19, 20 & 21 for CDSMP in Newark. In addition, we will offer a six-week DSMP community workshop beginning Tuesday April 11th and running through May 16th in Delanco. The program is FREE, however, you need to register as capacity is limited.

Why should you attend peer leader training? To gain the knowledge needed to lead Take Control of Your Health Workshops. Studies have shown that they produce positive results for people who complete the program. What better way to put your skills to work!

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, visit the events tab on www.sicklecellnewjersey.org. You may also call Darlene Young, SCANJ's Outreach Coordinator at 862 371-7138.

Coming Soon...

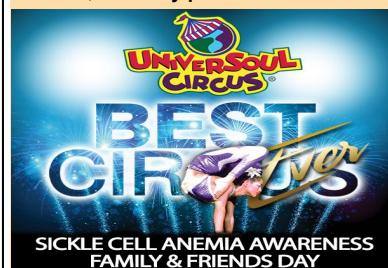
APRIL IS MINORITY HEALTH MONTH

6th Village Advisory Committee Meeting and Town Hall 6:30pm

7th Health Equity Forum 8:30am-12:30pm. Passaic County Public Safety Academy 300 Oldham Rd. Wayne, NJ

April 22nd Say it Loud! Telling Our Stories at the Underground Railroad Museum. 1-4pm. 803 Smithville Rd. Eastampton, NJ

May 10th Get Connected Pop Up Event, Newark, NJ. Stay posted...



Francis Thompson Walton Scholarship Awards. Apply online through June 1st. Scholarships awarded at the Sickle Cellabration on June 17th.



Register Now

www.getconnectedscd.org