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 SEPTEMBER SICKLE CELL

AWARENESS MONTH

1st Mission Day SCANJ was founded on this day in 2009.

This month visit the Cultured Expressions SCD Quilt Project on display this month at the Rahway Public Library

3rd Connections Support Group 429 JFK Parkway, Willingboro, NJ

5th-10th 4-Day Peer Certification in CDSMP Family Connections East Orange. 9:30am-4:30pm daily

13th Newark Beth Israel Sickle Cell Program Cellabration. 6pm
Costa Del Sol, Vauxhall, NJ

17th SCD Awareness RWJ Medical School Student National Medical Association 12pm Piscataway, NJ

20th Overlook Hospital Sickle Cell Symposium. Auditorium 5th
Floor. 7:30am-4:30pm Summit, NJ

21st Donna T. Darrien Memorial Foundation Walk. 8:30am. Weequahic Park Newark

25th RWJ Barnabas/ Valerie Fund /SCANJ Blood Drive. 10am-3:30pm 210 Lehigh Ave. H-3 Conference Room. Newark.

25th Roundtable Discussion on SCD 1pm-2pm Clara Maass Medical Center. Belleville, NJ

29th Living An Inspirational Life 60 and Beyond Luncheon SCD Awareness. 3pm Pinnacle. Lodi NJ tickets via eventbrite.com

MOST SCANJ EVENTS ARE FREE 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



Volume 9 Issue 6

Say It Loud!

September/October2019

Sickle Cell News You Can Use Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

September SCD Awareness Month. Whew!



Mary Bentley LaMar Founder Executive Director

As you can tell from the Calendar listings, September is an incredibly busy month. And rightfully so. It is Sickle Cell Awareness Month and all across the nation organizations dedicated to improving conditions for individuals living with sickle cell disease are working at an increased pace to Say It Loud about sickle cell disease.

With that in mind, I will be short and sweet in my message; do something

today to help our mission. As always, we have plenty of suggestions to help. And we are open to your suggestions too. One such opportunity is the Connections Support Group

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.

Meeting on October 1st. Come out and share your insight on Research Projects that we are supporting.

And get your tickets now for the Anniversary Cellabration (November 10th) and the Statewide Sickle Cell Symposium (November 23rd). It is time to celebrate 10 years of service. We're on a mission and there is no stopping now.

~Mary

A CHW's Thoughts on Attending the Convention

The SCDAA's Annual National Convention addresses various topics related to sickle cell disease. The conference provides an ideal environment for sharing knowledge, resources, and clinical information. It is also the perfect setting to network, develop partnerships or partake in discussions on many topics related to SCD. For this reason, attending the SCDAA's National Convention helps to engage members of the SCD community and develop the professional skills needed to perform my job as a Community Health Worker (CHW).

Surrounded by hundreds of researchers, physicians, nurses, social workers, CHWs and individuals living with sickle cell disease, the conference provides a veritable wealth of information and knowledge. It is always so amazing to me to see the sharing of knowledge, experiences, and success stories as individuals nationwide come together, pool resources, and share strategies. The information I have gained continues to help me to manage my sickle cell disease better than I would, or could, without it. I am now able to provide useful information and resources to the community I serve. After attending the conference, I became certain I am not in this fight alone. I can tell my clients that I have witnessed the great effort behind our search for a universal cure. I can now provide information to my clients with confidence and clarity.

SCDAA's national conferences have allowed me to connect with so many stakeholders in the SCD community. Some of the most inspirational individuals attend and speak at the conferences. As a community health worker and an individual living with sickle cell disease, making these connections has not only helped me professionally but personally as well.

During these conferences, we work toward a common goal. This collaboration is incredibly empowering and motivating, especially since our goal is to improve the quality of life for individuals, families, and communities affected by SCD.



The conferences have also allowed me to have the opportunity to create partnerships, positive work relationships, mentorships, and support systems that have filled me with hope and encouragement. This engagement has inspired me to continue to take what could cause my demise and turn it into something beautiful. It has provided me with the knowledge, inspiration, and confidence to find my voice and share my journey with sickle cell disease. I believe this allows me to connect with my clients and the SCD community more effectively and to help them truly understand that we are in the fight together.

As I approach my fourth year as a CHW, I can wholeheartedly say that my job means so much more than a paycheck. The work I do allows me to collaborate with amazing and inspiring individuals from all over the world. Through this work, I continue to learn and grow personally and professionally, as well as strive to improve the quality of life for individuals, families, and communities directly affected by sickle cell disease. Attending the national conferences provides me with the tools I need to continue to do my job to the best of my ability. There is absolutely nothing that means more to me than to do just that.



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: 973 991-0297 email: info@sicklecellnewjersey.org
or sicklecellanj@gmail.com

Connections Support Group

First Tuesdays of each month at 7:00PM



South Jersey in the odd numbered months.

North Jersey in the even numbered months.

No meetings in July and August.

September 3rd at the JFK Center 429 Kennedy Pkwy in Willingboro. Topic: 10th Anniversary Milestones

October 1st at 1016 Broad St. Newark. Topic: Research
Invitational Dinner

For more information and to RSVP you may register online via our events tab, call our office 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

It's Time to Cellabrate 10 Years of Service!





Coming Soon...

OCTOBER

1st Connections Support Group Research Invitational Dinner Meeting. NBCS 1016 Broad St, Newark 7:00pm

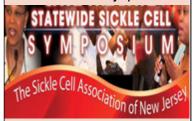
1st CDSMP Workshop. 6 weeks 9:00am. Second Baptist Church of Mt. Holly, NJ. Register via eventbrite.

10-12th SCANJ Road Trip to the SCDAA National Convention. Renaissance Hotel, Baltimore MD.

13th Bethel AME Luncheon. 1pm SCANJ Founder & SCANJ President among the honorees. Birchwood Manor Whippany NJ.

NOVEMBER 10th SCANJ 10th Anniversary Cellabration

23rd Statewide SCD Symposium



Workshops, Student Research Fair and Dr. Charles F. Whitten Awards. Liberty Science Center. Jersey City NJ