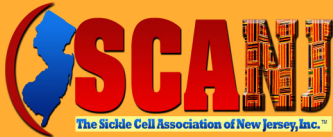


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings

MARCH

5th Connections Support Group

Paint and Chew Paint With a Twist
Mt. Laurel, NJ 7:00pm—8:30PM

10th & 11th SCANJ serves as host for the first Listening Tour for the SCDAA. 1016 Broad. St. Newark, NJ.

February 9th-March 16th

Diabetes Self Management Workshop. 10:00am Alpha Baptist Church, 25 Rose St. in Willingboro.

APRIL Minority Health Month

3rd 5:30pm-7:30pm. SCANJ Meet Greet and Eat Kelsey's Restaurant in Atlantic City. (This event replaces the April Connections Support Group Meeting).

4th 9:00am-4:00pm Minority Health Month Forum sponsored by the NJ Office of Minority and Multicultural Health in cooperation with Alpha Kappa Alpha Sorority, Inc., North Atlantic Region. Atlantic City Convention Center.

8th-9th SCDAA Advocacy Day Training and Capitol Hill Visits Washington DC. Register via sicklecelldisease.org

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



Volume 9
Issue 3

Say It Loud!

March 2019

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

A Message From the Executive Director. . .



Mary Bentley LaMar
Founder
Executive Director

Are we now in a "Women's Movement?" With Women's History Month well underway, we are making history. The question is, what will the story say? This month alone we can write that SCANJ is the first of the SCDAA-affiliated Community Based Organizations to host the SCDAA listening tour. Executive Directors from Virginia to New York converged on Newark, New Jersey to have a conversation about how to improve conditions for individuals living with sickle cell disease.

This is encouraging given the renewed interest in promising curative therapies. Many of you viewed the 60 Minutes television broadcast on the gene therapy clinical trial. That story highlighted one of several potential cures. Our aim is to make sure that the sickle cell community is at the forefront of being fully informed about choices when it comes to your health.

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.

To that point, we have are hosting a *Meet Greet & Eat* at Kelsey's Restaurant in Atlantic City on April 3rd. For those of you in South Jersey, we want to see you there! We also invite women to get a FREE mammogram on April 6th courtesy of Alpha Kappa Alpha Sorority, Inc., North Atlantic Region. You must register in advance (see pg. 2). And please put the NJ Office of Minority and Multicultural Health Forum on your calendar. These are just some of the programs in place to help you live to tell your story.

History is Herstory

~Mary

A Time of Hope for Sickle Cell Patients

This is a time of hope and great promise for children and adults with sickle cell disease—the most common inherited blood disorder in the United States. Two drugs to treat sickle cell disease—hydroxyurea and L-glutamine—have been approved by the Food and Drug Administration (FDA), and a number of potential medications are being studied by researchers. In addition, several different types of bone marrow transplants offer the promise of a cure for many affected by the disease.

Centers across the country are testing gene replacement therapies, which also offer the possibility of a cure. Very encouraging preliminary results have been reported, but longer studies in more patients are needed to confirm the findings.

Researchers in New Jersey are in the forefront of these efforts. Studies involving bone marrow transplants, gene replacement therapy, and new medications are all underway here. HackensackUMC has an ongoing bone marrow transplant program and is a member of the STAR (Sickle Cell Transplant Advocacy and Research Alliance). This group of centers in North America conducts research on the use of transplant as a cure for sickle cell. HackensackUMC will also be the statewide site for a novel gene replacement therapy clinical trial. New medications are under investigation as well.

As many of you know, "SCANJ is here to help, educate, and advocate in the fight against sickle cell disease." To that end, on November 23, SCANJ will be hosting a workshop on these studies at our annual

Statewide Sickle Cell Disease Symposium at the Liberty Science Center in Jersey City. We encourage you to save the date. And throughout the year, we'll share more information about research and opportunities to participate in clinical trials. In the meantime, don't hesitate to talk with your healthcare provider about treatment with hydroxyurea and L-glutamine as well as curative therapy.



Art by Hertz Nazaire

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

The first SCANJ Statewide SCD Symposium was held on November 23, 2013. It is held annually on the Saturday before Thanksgiving at The Liberty Science Center in Jersey City.

Guest presenters included Dr. Wanda Whitten Shurney of SCDAA Michigan and Detroit Children's Hospital, Dr. Fred Waldron-Newark Beth Israel Hospital, and Dr. Krish-nurmati-Children's Hospital of Pittsburgh.

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

March Topic: Paint & Chew

April Topic: Atlantic City Meet Greet & Eat

March 5th Paint & Chat at the Paint With a Twist in Marlton. April
Meeting changed to the 3rd. 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

Atlantic City Here We Come!



**FREE
EVENT**

SICKLE CELL AWARENESS

Invites you to

meet greet & eat

Come out and learn about sickle cell disease and programs that support
individuals and families effected by sickle cell disease.

Find out how you can get involved in making a difference for yourself
and/or others who are living with this inherited blood disorder.

Reserve at:

Eventbrite

This event is FREE but
you must RSVP in advance
Dinner provided

Kelsey's Restaurant
1545 Pacific Avenue
Atlantic City, NJ 08401
Wednesday April 3rd
5:30pm-7:30pm

www.sicklecellnewjersey.org

Coming Soon...

**APRIL Minority Health
Month**

FREE Mammograms Saturday April 6th
from 8:00am-5:00pm Alpha Kappa Al-
pha Sorority, Incorporated, Mammogram
Bus. RSVP via assuredimaging.com/AKA
or call 888 233-6121. **FREE** if uninsured or
underinsured. Atlantic City Convention
Center.



**9th SCANJ Sickle Cell Awareness Pop
Up Event 7:00pm UniverSol Circus**
Weequahic Park, Newark



**8th & 9th SCDA Training & Advocacy
Day in Washington DC** for more infor-
mation visit sicklecelldisease.org

