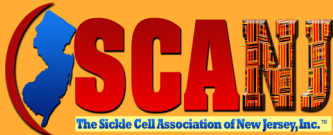


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings.

APRIL Minority Health Month

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

4th 9:00am-4:00pm Minority Health Month (MHM) Forum South sponsored by the NJ Office of Minority and Multicultural Health Atlantic City Convention Center.

18th MHM Forum North at Montclair State University

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

8th-9th SCDAA Advocacy Day Training and Capitol Hill Visits Washington DC.

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

MAY 14-17th Peer Certification Class Self-Management Resource Center Diabetes Self-Management 4 Day Peer Leader Certification in Delanco

**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 4

Say It Loud!

April 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

This month continues to be a whirlwind of activity. We began with a Meet, Greet and Eat at Kelsey's Restaurant in Atlantic City.

This was the first of several outreach efforts that we will engage in for the South Jersey area. And I do hope that some of you were able to take advantage of the FREE Mammograms provided courtesy of Alpha Kappa Alpha Sorority, North Atlantic Region as well as the NJ Office of Minority and Multicultural Health's Health Equity Forum at the Atlantic City Convention Center.

Plans are underway now to host the Sickle Cellabration commemorating World SCD Day in Atlantic City.

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.

Stay posted for details as we look to get the 6000 throughout New Jersey who are living with sickle cell disease, connected to services. We need your help to make this happen. Please "Say It Loud!" by sharing our message with others who may be helped by our programs. And it would be GREAT if you bought a Tee shirt to support SCANJ and raise awareness for World SCD Day (pg 2). **Now that's saying something!**

~Mary

April is Minority Health Month

National Minority Health Month is here, and for the observance this year, the Health and Human Services (HHS) Office of Minority Health (OMH) will join partners in raising awareness about the important role an active lifestyle plays in keeping us healthy. The theme for the 2019 observance is Active & Healthy, which allows OMH and minority health advocates throughout the nation to emphasize the health benefits of incorporating even small amounts of moderate-to-vigorous physical activity into our schedules.

Physical activity promotes health and reduces the risk of chronic diseases and other conditions that are more common or severe among racial and ethnic minority groups.

In New Jersey, the First Lady Tammy Murphy and Health Commissioner Shereef Elnahal join state and local partners this month for Health Equity forums as part of National Minority Health Month. The forums focus on ways to close racial health gaps by promoting a lifestyle of wellness and encouraging disease prevention.

Nurture NJ, a statewide awareness campaign launched by First Lady Murphy, is committed to ensuring equitable access to maternal and infant care for women and children of all races and ethnicities. "As New Jersey has one of the highest disparities for black maternal and infant health outcomes, I urge our partners across the state to use these forums as an opportunity to examine how we can better deliver care to our diverse population," she said. In keeping with Minority Health Month, your sickle cell advocates got their physical activity in as they walked the halls of Congress in Washington DC for SCDAA Advocacy Day.

April 9th SCDAA Advocacy Day in Washington DC



Pictured above is the visit to the office of Congresswoman Bonnie Watson Coleman. Other legislative offices visited were Congressman Christopher Smith, Congressman Bill Pascrell, Jr., Congressman Donald Norcross, Congressman Albio Sires and Senator Cory A. Booker.

The purpose of Advocacy Day was to advocate for: Reauthorization of the Newborn Screening Saves Lives Act; robust funding for the National Institutes of Health (NIH) and the FDA in the fiscal year 2020 Agriculture Appropriations Act to support research and help bring cures to patients through review and approval of innovative medicines and devices; request \$8-10 million in appropriations to support S. 2465 -The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018, signed into law by the President; and the development of payment and reimbursement strategies that address care transition, care coordination services and preventative care visits, telemedicine, and telehealth. **Please activate the advocacy in you! Ask your elected officials to support SCD legislation.**

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

April Topic: Atlantic City Meet Greet & Eat

May Activity: 10 Year Anniversary planning

April Meeting changed to the 3rd. The May 7 Meeting is at Newark Boys Chorus School. 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

Shine The Light On SCD-World Sickle Cell Day Campaign Underway!

June 19, 2009 marks the first commemoration of World Sickle Cell Disease Day. September 1, 2009 marks the founding date for the Sickle Cell Association of New Jersey (SCANJ). Join us in celebrating this 10 year milestone for both occasions by buying your very own "Sickle Cell Matters" Tee Shirt to support our mission.

Only available for order until May 9th. Go to www.SickleCellNewJersey2019.fundraisertee.com

and order the T-shirt during this time period. Proudly wear it on June 19th World SCD Day and at the Sickle Cellabration. The T-shirt sells for \$22.00 plus shipping and handling (slightly higher for XXL or larger).

The manufacturer will ship the T-shirt directly to you along with

a 4x6 glossy two-sided card that will "Shine the Light" with 5 important facts and myths about sickle cell disease. The other side will have information about the artist – Hertz Nazaire.



Hertz was born in Port-Au-Prince, Haiti on October 2, 1973. The source of his love of color stems from his memories of the Taptaps, which are colorful trucks and taxis painted with murals depicting Haitian life.

He studied art at the Art Institute of Fort Lauderdale and the University of Bridgeport. Hertz struggles with the pain and challenges of sickle cell disease, which has caused his vision to fail over the years. The frustration of slowly going blind, however, has encouraged him to appreciate the process of painting with a deeper purpose. A recent series of his paintings is focused on the themes and images of the earthquake in Haiti and the life that comes after such a tragic event. To learn more about Hertz Nazaire, "Naz," visit: www.nazaire.info



Coming Soon...

MAY

1st Frances Thompson Walton Scholarship Application Deadline

7th Connections Support Group

14-17th CDSMP Peer Leader Certification Training

JUNE

19th World Sickle Cell Disease Day. Wear your Sickle Cell Matters Tee Shirt

22nd SCDA National Walk With the Stars in Canton Park, Baltimore, MD

AUGUST

TBA Kente Carpet Movies Under The Stars Garden Stroll and Walk

SEPTEMBER 1st

SCANJ's 10 Year Anniversary

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

SCANJ held its first Sickle Cellabration to commemorate World SCD Day in September 2010 at the Pines Manor in Edison in partnership with Embrace Kids Foundation.

Workshops were held on SCD. An American Red Cross Blood Drive was conducted and we selected our first Teen Spokesperson Amanda and SCANJ Child Ambassador, Savion.