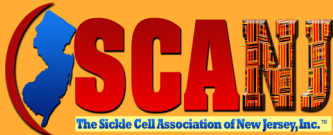


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings

FEBRUARY

1st

Frances Thompson Walton Scholarship Applications now being accepted. Visit our website and click on the events tab to apply online. Deadline May 1st, 2019

5th

Connections Support Group
7:00pm–8:30pm AMC Movie Theatre in West Orange

February 9th-March 16th

Chronic Disease Self Management 6 Week Workshop and Diabetes Self Management Workshop. 10:00am Alpha Baptist Church, 25 Rose St. in Willingboro. Enrollment is limited.

MARCH

5th

Connections Support Group
Paint and Chew JFK Center
429 JFK Parkway Willingboro, NJ
7:00pm–8:30PM

19th -22nd

4 Day Peer Leader Certification in Chronic Disease Self Management. Living Springs Residential Center. 600 Park View Dr. Delanco. 9:00am-4:00pm each day. Register online via Eventbrite.com

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 8
Issue 2

Say It Loud!

February 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

February is a month where we pause to reflect on the rich history of African Americans. Here at the SCANJ, I'd like to take this opportunity to dispel the myth that sickle cell disease only affects African Americans, or persons of color. While it is true that sickle cell disease primarily affects persons of African descent, it is also present in Portuguese, Spanish, French Corsicans, Sardinians, Sicilians, Greeks, Turks and Cypriots.

Sickle cell disease also appears in Middle Eastern Countries and Asia. In the United States it is estimated that over 100,000 people have sickle cell disease and 6000, are living with the disease in New Jersey.

Sickle cell disease is a genetic blood disorder and has most likely been in existence for thousands of years. You will find it most prevalent in areas of the world where malaria is present. Those areas are primarily populated by people of color. Published reports of sickle cell disease were found in African medical literature as early as the 1800's.

The first documented case of sickle cell disease in America was in 1904. Dental student, Walter Clement Noel was

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.

examined by Ernest E. Irons, a 27-year old intern at Chicago's Presbyterian Hospital. Irons noticed "the oddly shaped blood cells" of his patient and shared his findings with his attending physician, Dr. James B. Herrick, who published those findings in the *Archives of Internal Medicine* in 1910.

In reflecting on that history, I am reminded of one of our signature programs; the "SCANJ Road Trip." These are sponsored trips for individuals affected by sickle cell disease to attend scientific conferences. The first road trip hosted by SCANJ was in 2010 to the National Institutes of Health for the James B. Herrick 100th Anniversary of the Discovery of Sickle Cell Disease. A large delegation of Jerseyans boarded a bus to Bethesda Maryland for the event. We learned a lot, shared a lot and came back more inspired to do the work.

Still inspired...

~Mary

Reflecting on the late Dr. Charles F. Whitten

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

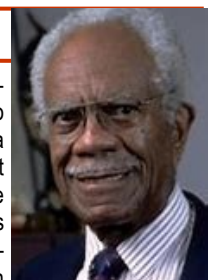
In November of 2011 we established the annual Dr. Charles F. Whitten Awards to recognize individuals and organizations that do outstanding work for the sickle cell community.

Dr. Whitten was a physician, medical pioneer, Founder and President Emeritus of the Sickle Cell Disease Association of America. Distinguished Professor and Dean Emeritus of Wayne State University School of Medicine. He graduated from the University of Pennsylvania in 1942 and Meharry Medical College in 1945. He was in general medicine practice before serving as a captain in the United States Army for two years. He then moved to Detroit, Michigan to serve under a pediatric hematology fellowship at the Children's Hospital of Michigan.

While on the faculty of Wayne State University School of Medicine he established in 1969 the first post baccalaureate

enrichment program for disadvantaged and minority students who applied but were not accepted into a medical school. His program at Wayne State University became the model by which minority students would be recruited to serve in under-represented areas, and it has been replicated at medical schools across the country.

In 1971, Dr. Whitten formed the Sickle Cell Detection and Information Center, a community program that developed educational tools for teaching children and families about sickle cell disease. He also created the National Association for Sickle Cell Disease (now known as the Sickle Cell Disease Association of America) in 1971, with over 100 chapters across America. He is credited with paving the way for routine newborn screening for sickle cell anemia in Michigan and, subsequently, in the United States. He died in 2008. The SCANJ honors his example with the annual Dr. Charles F. Whitten Awards.



WWW.SICKLECELLNEWJERSEY.ORG



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or sicklecellanj@gmail.com

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

February Topic: Volunteering

March Topic: Paint & Chew

February 5th at the AMC Movie Theatre in West Orange (Essex Green) March 5th Paint & Chat at the JFK Center in Willingboro. 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.

ON THE ROAD AGAIN...SCANJ ROAD TRIP PLANNED FOR 2019



SCANJ is preparing now for the 2019 Road Trip. We plan to send a large delegation of New Jersey "Road Scholars" to the Sickle Cell Disease Association of America, Inc. (SCDAA) Annual National Convention. It will be held October 9-12, 2019 at the Renaissance Baltimore Harbor Place Hotel, 202 E Pratt Street, Baltimore, MD 21202. SCDAA's Annual National Convention is a four-day conference designed to address the multi-factorial aspects of sickle cell disease (SCD) and sickle cell trait (SCT). In an effort to advocate for improved quality of life for individuals and families affected with SCD and its associated morbidity and mortality, the conference fosters the exchange of the latest scientific and clinical information related to the disease. This is done through the offering of innovative symposia, training seminars, interactive panel discussions, and special events.

This year's convention offers an array of exciting activities designed to educate and motivate the entire community to get involved in the fight against sickle cell disease.

The convention is intended for individuals living with sickle cell disease and sickle cell trait and their family members, physicians, researchers, nurses, social workers, psychologists and community health workers. Participants will be able to:

- Interact with medical experts as well as others living with sickle cell disease.
- Demonstrate in an effective manner procedures for addressing sickle cell pain in various settings.
- Utilize evidence-based guidelines and best practices in their daily self-care to improve overall health and quality of life.
- Understand the latest in treatment options.
- Appreciate the growing number of new medications being developed in clinical trials.
- Identify how to participate in clinical trials.
- Decrease the amount of fragmentation of care from adolescent to adult providers.
- Recognize, identify or assist in the development of social and emotional resources for patients and families.

To apply for SCANJ's Road Trip Scholarship applications visit Eventbrite.com. The deadline is August 1st for applications. Notification of awards is on, or before, September 1, 2019.

Coming Soon...

APRIL Minority Health Month Outreach

Wednesday, April 3rd 5:30pm-7:30pm. SCANJ Meet & Greet at Kelsey's Restaurant in Atlantic City. (Hosting this event is in place of the April Support Group Meeting).

Thursday April 4th 9:00am-4:00pm Minority Health Month Forum and Health Fair 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. SCANJ to participate.

Tuesday April 9th 7:00pm UniverSoul Circus Sickle Cell Awareness Night with SCANJ Weequahic Park, Newark, NJ

SAVE THE DATE

September 1, 2019 for the
SCANJ 10th Anniversary
Celebration