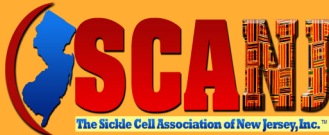


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Volume 8  
Issue 1

# Say It Loud!

January 2019

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

## A New Year's Message From the Executive Director. . .



**Mary Bentley LaMar**  
Founder  
Executive Director

I am elated to announce that 2019 is our 10th Anniversary Year! I can hardly believe that the time has passed so quickly. It is especially meaningful to me to be engaged in the work needed to improve conditions for individuals living with sickle cell disease.

SCANJ was founded on September 1, 2009. On our founding Board of Directors were Dr. Ansley LaMar, Mrs. Beverly Lucas, Ms. Darlene Young, Mrs. Deborah Wilson and Ms. Vallerie Cleveland. I have a boundless debt of gratitude to this group of people as they supported my vision and allowed me to establish this organization. I'm encouraged. I hope you are encouraged, too.

We have accomplished a lot since our infancy. And you know there is still much more to be done. I start this New Year with a thank you to everyone who has been with the SCANJ along this journey.

### 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 may be a volunteer for us. Perhaps you serve as a peer leader or an ambassador. Perhaps you are a donor or you simply pass along our information to someone else who is in need of our services. Whatever level of support you have given, we appreciate it.

There are over 6,000 individuals living with sickle cell disease in the state of New Jersey. Our goal is to reach out to all of them and to get them connected to our supportive network. We are able to do that with your help.

You have been there for the SCANJ.

**Continue to Stay on the Mission! ~Mary**

## Calendar Listings JANUARY

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

8th

**Connections Support Group**  
7:00pm - 8:30pm AMC Movie Theatre Cherry Hill

8th-Feb 12th

**Chronic Disease Self Management 6 Week Workshop** 2nd Baptist Church in Mt. Holly

February

5th

**Connections Support Group**  
7:00pm - 8:30pm AMC Movie Theatre Essex Green in West Orange

9th-March 9th

**Chronic Disease Self Management 6 Week Workshop & Diabetes Self Management Workshop**  
Alpha Baptist Church 25 Rose St. in Willingboro. Enrollment is limited.

**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

## This Is The Beginning of Our 10th Anniversary Year!

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

It was a crisp autumn day on Tuesday September 1, 2009. The Sickle Cell Association of New Jersey (SCANJ) had received its incorporation papers earlier that day and we all were excited to begin putting the mission in action.

It just so happened that on that same day there was a rally organized by grassroots groups in Bloomfield, New Jersey to fight to pass The Affordable Care Act. Well say no more...the first sentence in our mission statement begins with "To advocate for..." SCANJ Founder, Mary Bentley LaMar joined with other health care advocates that evening in a small village square in Bloomfield to advocate for the Affordable Care Act.

This was a fitting way to mark the beginning of the SCANJ, especially being that this event fell on the first day of September in Sickle Cell Awareness Month. In addition to that, many in the sickle cell community were in dire need of the Affordable Care Act.

The remainder of 2009 was spent building the infrastructure of the agency. This meant setting up the website, establishing a volunteers circle, doing outreach with industry stakeholders and most importantly, informing the community that we were established and ready to advocate, educate and support individuals living with sickle cell disease.

In 2009 we established:

- our colors as "kente" red and yellow representing a heritage of hope for the blood.
- our motto "SCANJ equals faith with good works for sickle cell disease."
- our mantra "Say It Loud!" as we want to amplify the message of the sickle cell community.



**Kenta Klaus**  
(Santa's Brother)

**Save the Date-September 1, 2019 for a  
Special 10th Anniversary Celebration**

**WWW.SICKLECELLNEWJERSEY.ORG**



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**or [sicklecellanj@gmail.com](mailto: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

**January and February Activity: Movie Outings**

January 8th at the AMC Movie Theatre in Cherry Hill. February 5th at the AMC Movie Theatre in West Orange (Essex Green) 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

## A Primer on Sick Cell Trait

**Having Sick Cell Trait (SCT)** simply means that a person carries a single gene for sickle cell disease (SCD) and can pass this gene along to their children. People with SCT usually do not have any of the symptoms of SCD and live a normal life. Hemoglobin is found in red blood cells and it gives blood its color. It carries oxygen to all parts of the body. Hemoglobin is made from two similar proteins, one called alpha-globin and one called beta-globin, that "stick together." Both proteins must be present and function normally for the hemoglobin to carry out its job in the body. People with SCT have red blood cells that have normal hemoglobin and abnormal hemoglobin. Genes are the instructions that control how red blood cells make alpha- and beta-globin proteins. All people have two genes for making beta-globin. They get one beta-globin gene from each parent. SCT occurs when a person inherits a gene for sickle betaglobin from one parent and a gene for normal beta-globin from the other parent.

**What Is Sick Cell Disease?** SCD is a genetic condition that is present at birth. In SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle." The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious problems. It is inherited when a child receives two sickle beta-globin genes— one from each parent. Therefore, a child can only have SCD when both of his/her parents have at least one abnormal beta-globin gene.

**Who Is Affected By SCT?** SCT is more common among people whose ancestors come from Africa, the Mediterranean region, Middle East, and South Asia, but anyone can have SCT. 1 in 12 Blacks or African Americans in the United States has SCT.

If both parents have SCT, each child that they have together has a • 1 in 2 (50%) chance of having SCT. Children with SCT will not have symptoms of SCD, but they can pass SCT on to their children. If only one parent has SCT, each of their children has a • 1 in 2 (50%) chance of having SCT and a 1 in 2 (50%) chance that they will not have SCT. If both parents have SCT, each child that they have together has a • 1 in 4 (25%) chance of having SCD.

**What Health Problems Might Occur in People with Sick Cell Trait?** Most people with SCT do not have any health problems caused by sickle cell trait. However, there are a few, rare health problems that may potentially be related to SCT. For example, if people with SCT have pain when traveling to or exercising at high altitudes, they should tell their healthcare provider. To find out more about SCT and to get specific answers to your questions, call your healthcare provider.



### Get Connected to SCANJ to take advantage of...

- *Get Connected Pop Up Events*
- *CDSMP and DSMP Peer Leader Certification*
- *Support Groups*
- *Scholarships*
- *Road Trips*

**Call SCANJ Today**  
**973 482-9070**

This article is provided by the Centers For Disease Control. Go to [www.cdc.gov](http://www.cdc.gov) for more information.



Register Now

[www.getconnectedscd.org](http://www.getconnectedscd.org)