

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

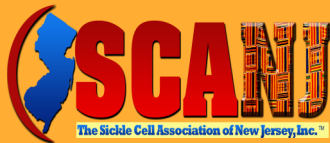


Volume 5
Issue 1

Say It Loud!

January 2014

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



Calendar Listings:

January

11th (Rescheduled snow date) SCANJ Holiday Party Central bowling, gifts for the family, food and fun. Saturday 5:00pm-7:00pm Howell Bowling Lanes, Howell. RSVP

11th Volunteer's Introductory Breakfast. Come and learn about how you can get more involved. RSVP for Saturday 9:30 am at IHOP 1129 N. Broad Street, Bloomfield.

17th Port Authority of NY & NJ 27th Annual Martin Luther King Jr. Breakfast. Keynote speaker is SCANJ's Mary Bentley LaMar. Sponsored by the Port Authority Network of Black Employees.

Chronic Disease Self Management Program (CDSMP) 4 Day Peer Leader Certification Class. Capacity is limited. We offer two opportunities:

- **23, 24, 27 & 28th** 9:30 AM to 4:00 PM Living Springs Residential Center in Delanco
- **30, 31, February 1 & 2** 9:30 AM to 4:00 PM Grace Baptist Church in Fords

Register online or call SCANJ at 973 482-9070

30th Peer Leader Refresher and Appreciation Dinner. For all certified SCANJ Peer Leaders. 7:00 PM Central New Jersey Location TBA

February 7th FDA Sickle Cell Public Meeting on Patient Focused Drug Development. FDA White Oak Campus. Silver Spring MD. RSVP by Jan 27th. patientfocusedsicklecell.eventbrite.com

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America

Happy 5th Anniversary Year SCANJ!



Mary Bentley LaMar
Founder
Executive Director

Hello 2014!

I am thrilled to see our agency enter its 5th year of existence. I am especially thrilled to report that, with your help, we have stayed true to our mission.

Thank you for supporting our work. Even reading this newsletter helps our mission because you learn about what is going on in the community to support individuals with sickle cell disease and hopefully you share that insight.

You have a standing invitation to get more involved. You can start by joining us for the Volunteers Breakfast at IHOP, or bowl in the New Year with the Holiday Party in Howell. Or perhaps you would like to get certified for the Stanford School of Medicine Chronic Disease Self Management workshops (see calendar listings). With that certification you can help yourself and others to better health. To get involved on a national level please participate in the FDA Public Meeting (pg. 2). However you choose to get involved, we welcome your participation.

This month we are introducing a six part series for the newsletter titled *Afterwords* to shed insight on the

topics covered during our first Statewide Sickle Cell Symposium.

I think its appropriate to start the *Afterwords* series from the beginning...genetics. Here's to new beginnings... **Happy New Year!**

~Mary

SCANJ Mission Statement

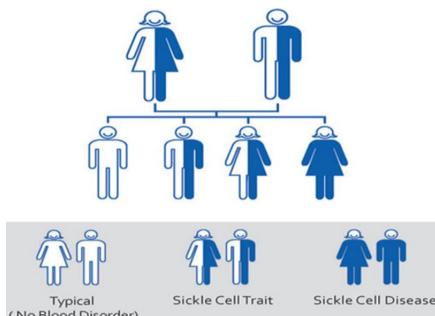
In concordance with the mission of The Sickle Cell Disease Association of America; "to advocate for and enhance our membership's ability to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease."

Afterwords: Part 1 "It's In The Genes"

SCANJ's Statewide Sickle Cell Symposium in November 2013 was the setting for six workshops designed to educate and engage. The genetics workshop was conducted by Kunal Sanghavi of The New York and Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC).

The workshop focused on the genetics of sickle cell disease including the concepts of genes and chromosomes, autosomal recessive inheritance (see Figure 1), genetic testing, newborn screening, family history, and carrier screening. The discussion continued at the Lunch & Learn.

How does a person inherit sickle cell disease?



Autosomal recessive inheritance (Figure 1): <http://www.cdc.gov/ncbddd/sicklecell/traits.html>

Each individual carries two copies of a gene, one from each parent. Change or mutation in both copies of the HBB gene results in Sickle Cell Disease (SCD). If there is a change or mutation in a single copy of the HBB gene, the individual has

sickle cell trait (SCT) and is a carrier of the gene change or mutation. If both parents are carriers (have SCT), there is:

25% (or 1 in 4) chance that each child of this parent will NOT have SCD or SCT

25% (or 1 in 4) chance that each child of this parent will have SCD (inherits a copy of the gene with a change or mutation from each parent). In most cases, the parents of a child with SCD are healthy carriers of a single copy of the gene with a change or mutation.

50% (or 1 in 2) chance that each child of this parent will have SCT

Another example: Imagine a bag with one yellow, one red, and two blue candies. The yellow candy represents a healthy child with no SCD or SCT, the red candy represents SCD, and the blue candies represent SCT. If you were to take the red candy, there would be 25% (or 1 in 4) chance of taking the red candy from the bag in every attempt.

NYMAC is a federally defined multi-state and district collaborative that strives to ensure the health of all newborns and persons who have conditions with a genetic component. The region includes: DC, DE, MD, NJ, NY, PA, VA, and WV. To learn more about NYMAC and get involved, please contact SCANJ or visit the NYMAC website: <http://www.wadsworth.org/newborn/nymac/> or email ksangha1@jhmi.edu.

SCANJ is pleased to work with NYMAC and thanks Kunal Sanghavi for providing the background for this article.



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NEW! email: info@sicklecellnewjersey.org

Although we were snowed out on December 14th, we won't let the snow keep us from having a **Central Holiday Party with Kenta Klaus!** There is still time to register for this festive event. Bowling, food, fun and gifts for the family. Come out and celebrate. We can bring in the New Year too!

Saturday

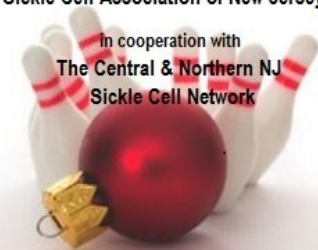
The Sickle Cell Association of New Jersey

January 11, 2014

5:00 p.m. to 7:00 p.m.

Howell Bowling Lanes

Howell, NJ



The Say It Loud Newsletter is published monthly. Archived copies are available for download from our website.

Beverly Lucas-Editor

Tax deductible donations accepted by mail and via
www.sicklecellnewjersey.org



Hear Ye! Hear Ye! FDA Public Meeting on Sickle Cell Disease and You're Invited!

Attention individuals living with sickle cell disease! (Caretakers and advocates too)

The U.S. Food and Drug Administration (FDA) wants to hear from you about your experiences with sickle cell disease and your treatments. You can attend the upcoming public meeting on sickle cell disease as part of the FDA patient focused drug development initiative.

The purpose is to hear patient perspectives on the health effects of sickle cell disease and on treating sickle cell disease.

This is an important opportunity for your voice to be heard so it is essential that you are there. You can attend in person or watch the live webcast.

Friday February 7, 2014
10:00 a.m. to 4:00 p.m.

At the
FDA White Oak Campus
10903 New Hampshire Ave.
Building 31, Great Room
Silver Spring, MD 20993

For more information and to register
<http://www.patientfocusedsicklecell.eventbrite.com>
Or call 301 796-5003

Registration closes on January 27, 2014



You feel better when you know more.
Just ask our symposium attendees...



Spread the Word and Say It Loud!

SCANJ is working on providing travel support to New Jersey patients and caregivers interested in attending the FDA Public Meeting in Silver Spring Maryland.

If you are planning to attend in person and would like to be considered for travel support please contact our office at 973 482-9070 or sicklecellanj@gmail.com.

Thanks Ediom Utuk; Photo credits