

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 2

Say It Loud!

February 2014

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



Calendar Listings:

February:

6th
SCANJ Road Trip to the FDA Sickle Cell Public Meeting on Patient Focused Drug Development. FDA White Oak Campus. Silver Spring MD. Van departure at 4:00pm from Newark Beth Israel Hospital 201 Lyons Ave. Pick Up in South Jersey at 6:00pm. Hotel, refreshments and transportation provided.

7th
SCANJ hosted Webcast viewing and participation in the FDA Public Meeting. Refreshments provided. 10:00 am-4:00pm. Gilda's Club Lyons Ave. Newark, NJ (Across from Newark Beth Israel Hospital.)

The SCANJ Road Trip and the SCANJ webcast participation at Gilda's Club are FREE, however, you must RSVP through our office 973 482-9070 or via sicklecellnewjersey.eventbrite.com

7th
FDA Sickle Cell Public Meeting on Patient Focused Drug Development with simultaneous webcast. 10:00am-4:00pm FDA White Oak Campus. Silver Spring MD. RSVP patientfocussedicklecell.eventbrite.com

March
Chronic Disease Self Management Workshops ongoing. Check our website for a workshop in your area.

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association of America

This Is Your Year to Make History!



Mary Bentley LaMar
Founder
Executive Director

Department of Health, we offer a program called "Take Control of Your Health."

Our actions today impact our future. Take a moment to think about what you can do to effect change.

I ask that you start with yourself. Thanks to a grant from the New Jersey

It is an evidence based Chronic Disease Self Management Program (CDSMP) licensed through The Stanford School of Medicine Patent Education.

The core of the CDSMP is centered around giving you tools that will help you become a better self-manager of your health. When you're in better health you can help others to effect change too.

I encourage you to take advantage of the opportunity when we offer a workshop in your area.

And lastly, help us to celebrate 2014. It is the 5th anniversary year of our founding.

A great way to celebrate this SCANJ history is by volunteering for one of our many programs. In this way you can actively make a difference in your life and the lives of others.

There is no time like the present to effect the future. **Get started now so you can tell the story!**
~Mary

Afterwords: Part 2 "Sickle Cell 101 History"

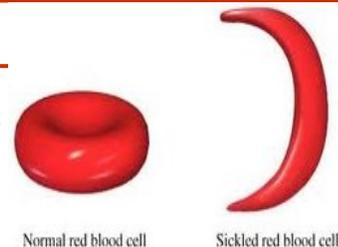
The "Discovery" of Sickle Cell Disease

Imagine heading to a foreign country aboard a ship, and during the journey you develop a sore on your ankle that won't heal. Shortly after your arrival, you fall ill again, this time with anemia and pneumonia-related breathing troubles. Worse yet, no one realizes that you have a serious medical condition that's causing these seemingly unrelated problems. That was precisely the situation facing Walter Clement Noel in 1904 as he headed to Chicago to attend dental school.

There is evidence that Noel, a 20 year-old man of African descent from a wealthy family on the island of Grenada, had experienced similar symptoms over the years before he left home. But it's likely that he, too, had no idea that a serious illness was responsible for his ongoing medical troubles. Indeed, it was not until he arrived in Chicago and went to a nearby hospital seeking help for his severe breathing difficulties that the first clues came to light. There, he was seen by a young resident, Dr. Ernest Irons. As a part of the examination, Irons viewed a sample of Noel's blood under the microscope and saw many strange looking, irregularly shaped red blood cells. Irons consulted his supervising physician, Dr. James Herrick, who, in spite of his interest in blood disorders (hematology was not yet a specialty), was also puzzled by the findings.

Over the next 2.5 years as Noel continued his education, he became ill several more times and both doctors continued to see him. Noel's direct relationship with the two doctors ended in 1907 following his graduation from dental school and return to St. George, Grenada to practice dentistry. Herrick continued to research the strangely shaped blood cells but found no other reports.

In 1910, he presented the case at a medical meeting and published an article titled "Peculiar elongated and sickle-shaped red blood corpuscles in a case of severe anemia" in the medical journal *Archives of Internal Medicine*. Soon after its publication other physicians began reporting similar findings. By the mid 1920s, enough cases had been reported that physicians began to suspect that there was a hereditary pattern to the disease and they had a better understanding of its natural course. Importantly, although Herrick's 1910 article was the first report of sickle cell disease in the Western literature, some have noted that reports can be traced back to a family in Ghana as early as 1670. And by the 1870s, there were reports of the condition in the African medical literature. Interestingly, the condition went by a variety of names, depending on the tribe. In some areas the condition was referred to as "ogbanjes" ("children who come and go") because of the very high infant mortality rate associated with the disease.



For more on the history of sickle cell disease, visit our website www.sicklecellnewjersey.org. Primary source: Herrick's 1910 Case Report of Sickle Cell Anemia: The Rest of the Story. *JAMA*, Jan 13, 1989.

Afterwords is a six part newsletter series to shed insight on the topics covered during the 2013 SCANJ Statewide Sickle Cell Symposium.



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SCANJ Is On The Move!

This time we're going to the FDA Public Meeting on Patient Focused Drugs for Sickle Cell Disease.

If you can't join us on the Road Trip, you can still participate in the webcast from the comfort of your own home, or by joining in a group viewing sponsored by the SCANJ at Gilda's Club 208 Lyons Ave. in Newark, Friday February 7th from 10:00am-4:00pm.

For more information go to
www.patientfocussedicklecell.eventbrite.com

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



Save the Date to Advocate!

April 2-3, 2014 we're going to Capitol Hill in Washington DC for the SCDAA Advocacy Day.

We're pleased to announce the newly formed Sickle Cell Disease Congressional Caucus. Visit the SCDAA website for more information and please encourage your federal legislators to be a part of this caucus. Advocacy is important!

Stay posted for registration for the SCANJ Road Trip to the SCDAA Advocacy Day via www.sicklecellnewjersey.org



Proud mom, Lesa Givens with her daughter, Keema.

SCANJ welcomes our new intern, Keema Givens. Keema is a senior at Rutgers University in New Brunswick majoring in Sports Management and Pre - Law. Before she graduates in May, she will be learning the nuts and bolts of our agency, event planning and relationship building as it relates to our affiliations with sports celebrities. Join us in welcoming Keema!



SCANJ's Mary Bentley-LaMar (4th from the left) with officers of the Port Authority of NY & NJ Network of Black Employees (NBE) at their 27th Annual Martin Luther King Jr. Breakfast on January 20, 2014. Mary gave the keynote address and was honored by the NBE for her community service. SCANJ thanks the NBE for making a donation to support our mission.