

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.



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Say It Loud!

February 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



A Note From The Executive Director... "Herstory" on SCANJ History



Mary Bentley LaMar
Founder
Executive Director

As the founder of the Sickle Cell Association of New Jersey, I am often asked what inspired me to begin the agency. Do I have sickle cell disease? No. Do I have a family member with sickle cell disease? Yes, however, I was ignorant of what my cousin was going through. My journey to begin the SCANJ was born out of learning too much information.

Several years ago, I was blessed to work as a consultant on a national sickle cell awareness campaign on iron overload. Iron overload can occur when a person has had multiple blood transfusions that result in a build up of iron. Some individuals with sickle cell disease must have blood transfusions so it was important that they know of treatment options should they develop iron overload.

As I traveled around the country working on this campaign I got schooled by some remarkable people living with sickle cell disease. They shared stories of having incredible pain made worse by seemingly insensitive and uncaring health care professionals. And I learned there was very little funding for supportive services, education, research and drug development.

I also met remarkable health care professionals, advocates and Community Based Organizations (CBOs) through the

Sickle Cell Disease Association of America (SCDAA). The CBOs and health care professionals were passionate about making a change. They work everyday with relatively little resources to improve the quality of life for individuals living with sickle cell disease and ultimately to find a universal cure.

Through the SCDAA and its member organizations, I learned too much to "sit" on what was impressed upon me. New Jersey had to have more community based programs for sickle cell disease. Movers and shakers in the SCDAA showed by example, that it could be done.

So armed with a whole lot of knowledge, no start up funding, but the dedication and commitment of a great founding Board of Directors; Darlene Young, Deborah Wilson, Ansley LaMar, Vallerie Cleveland and Beverly Lucas, the Sickle Cell Association of New Jersey (SCANJ) was born on September 1, 2009. And the rest is history.

Say It Loud! ~Mary

"Our lives begin to end the day we become silent about things that matter." Martin Luther King Jr.

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.

Calendar Listings:

February

February 20th - March 26th
Take Control of Your Health
Stanford School of Medicine's
Diabetes Self Management Program (DSMP) 6 Week Community Workshop 10:00am-12:30pm
Alpha Baptist Church 15 Rose Street. in Willingboro. Registration required. Enrollment is limited.

23rd Support Group Exploratory Meeting. 6:00pm-8:00pm 1016 Broad St. In Newark. Dinner provided. RSVP

Frances Thompson Walton Scholarship Applications Accepted through June 1st. Apply online.

March 6th American Red Cross Sickle Cell Awareness Blood Drive 10:00am-3:00pm Cedar Brook Elementary School 1049 Central Ave. Plainfield, NJ 07060

To schedule in advance visit www.redcrossblood.org

REGISTER FOR
SCANJ PROGRAMS

via the events tab (Eventbrite) on sicklecellnewjersey.org or call 973 482-9070

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America



Register Now

www.getconnectedscd.org

Afterwords: Part 2. Youth Research Expedition

The Liberty Science Center is a child's dream come true for exploration and discovery. This holds true each year during the Statewide Sickle Cell Symposium, when the youth are sent on a Research Expedition throughout the exhibit halls.

While the adults are in workshops on clinical topics related to sickle cell disease, the children are on a mission.

After instructions from Dr. Ansley LaMar, President of SCANJ, the young researchers are led by SCANJ Teen Spokesperson, Ayoola Ogunyinka to find out more about sickle cell disease. Each child receives a Research Kit that includes clues with codes to crack, a map of the exhibit halls and a question and answer sheet. This fun expedition is a hit with young symposium attendees. They find it exciting, engaging and educational.

After a successful expedition, Each young researcher is

awarded with a "Scientist For The Day" Certificate and the "Hope and Destiny Jr." Book.



Afterwords is a six part newsletter series to shed insight on the topics covered during the SCANJ Statewide Sickle Cell Symposium. The Statewide Sickle Cell Symposium is held annually on the Saturday before Thanksgiving at the Liberty Science Center in Jersey City, NJ.

WWW.SICKLECELLNEWJERSEY.ORG



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Get Connected to the SCANJ. Are you interested in a support group? What should it include? Join the conversation to share your thoughts as we begin a supportive network of individuals and families living with sickle cell disease.

Tuesday February 23rd at 6:00PM
1016 Broad St. Newark (NBCS next to Symphony Hall)
 RSVP via Eventbrite or call our office. Dinner will be provided

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

www.sicklecellnewjersey.org



Winter Survival Skills Reviewed *Bonnye Johnson MS, RN*

This article is shared with permission from Bonnye Johnson MS, RN, The Patient Council of The University of Illinois Sickle Cell Center

It's that time of year again and "Old Man Winter" is upon us! So let's brush up on our winter survival skills. The focus is prevention. For example, have you had your annual flu vaccine? Is your pneumococcal/pneumovax vaccine current? Are you seeing your physician regularly? Hopefully your answers to all the above were yes. If not call your Health Care Provider for an appointment.



Even though a sickle cell crisis can be spontaneous, that is not induced by a trigger, there are known triggers that can begin a crisis. Dehydration, stress, illness, infection, alcohol use and exposure to smoke are just a few. Certain weather conditions, for example, high winds, temperature extremes, such as, cold, and heat can be triggers as well.

Speaking of cold temperatures, when one gets cold a protective function of the body is to shunt blood from your extremities to your important body organs. This is done by blood vessels in the extremities constricting. However, these narrowed blood vessels increase the risk of sickled red blood cells getting stuck and obstructing blood flow.

Besides staying indoors and hibernating for the season or becoming a "snow bird" and moving to a warmer climate for the season, there are many things you can do to stay warm and hopefully minimize the effects of the cold weather. It just requires planning and preparation. Remember dress in layers using light fabrics so when you come indoors to get warm you can easily remove them. You do not want to overheat and begin to sweat, get chilled and/or dehydrated. Start with thermal underwear then follow with shirt, sweater, and pants. Socks, wool if possible and tuck your long johns into them. Are your legs and knees susceptible to the cold? Try leg warmers and pull them up over your knees. Use a scarf around your neck and face when necessary. Finally, your coat, and don't forget your gloves and hat, when your head, face, hands and feet are warm, you don't feel the cold so easily.

Zika Virus Health Alert...

Zika? It is a viral infection that is spread by the bite of an infected mosquito. Outbreaks typically occur in tropical Africa and southeast Asia. In May 2015, Brazil reported the first outbreak of Zika in the Americas. Zika is now present in many tropical areas. The Center for Disease Control (CDC) issued a travel alert for Zika because the Zika virus can be spread from a pregnant woman to her unborn baby. There have been reports of a serious birth defect of the brain called microcephaly and other poor pregnancy outcomes in babies of mothers who were infected with Zika virus while pregnant.

Where can I learn more?

The CDC website is: <http://www.cdc.gov/zika/index.html>

The web address for CDC travel notices is: <http://wwwnc.cdc.gov/travel/notices>

For NJ information, go to: <http://www.nj.gov/health/cd/izdp/vbi.shtml>

Stay posted for updates.

Coming Soon...

Certification in Stanford School of Medicine's **Diabetes Peer Leader (DSMP)** and **Chronic Disease Self Management (CDSMP) 4 Day Peer Leader Trainings.**

