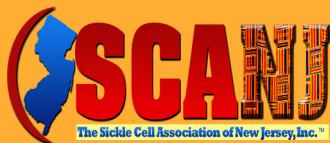


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings:

March: Today! **Donate blood or platelets.** We need your help. One donation can save up to 3 lives. You must be at least 17 years old, meet age and weight requirements and be in general good health. Schedule via redcrossblood.org or call 1 800 Red Cross.

Ongoing: Take Control of Your Health Chronic Disease Self Management Workshops & Peer Leader Training Workshops hosted by SCANJ throughout the state.

12th Women Making a Difference Program. 6:00pm SCANJ Executive Director, Mary Bentley LaMar to give the keynote address for Rho Phi Chapter of Alpha Kappa Alpha Sorority. Bloomfield College and Montclair State University.

19th Liberty Science Center Free Community evening. 5:30pm-9:00pm. SCANJ Genes Genius Game Show, IMAX Film.

29th Health Fair. Hosted by Mt. Zion AME Zion Church Wellness Ministry 11:00am-3:00pm Location Ramapo Reformed Church: Annex 100 Island Rd., Mahwah NJ

29th You're Invited to The Lincoln University and Cheney University Choirs in Concert 2:00pm at Bethany Church located: 30 Ashwood Terrace in West Orange. SCANJ has a limited number of FREE tickets available for families effected by sickle cell disease.

For updates or to register for SCANJ programs, call 973 482-9070 or go to our event link via

www.sicklecellnewjersey.org

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America



Volume 5
Issue 3

Say It Loud!

March 2014

Sickle Cell News You Can Use
Sickle Cell Association of New Jersey
PO Box 9501 Newark, NJ 07104

A Note From The Executive Director...On to Capitol Hill!



Mary Bentley LaMar
Founder
Executive Director

Some months the content for this newsletter just jumps onto the page. Other times (like this month) I hit a block and struggle to get words to paper.

So please help me through this. I'm asking you to think good thoughts,

meditate, pray, or do whatever you are comfortable with, to simply will into existence

that every need of those served by the SCANJ be fulfilled.

As we go into planning for the 24 Seven Line Dance Marathon...please think of us. As we work to help families with our programs...think of us. As we travel to raise awareness...think of us. As we do the work that is necessary to bring about a change...please think of us.

Thank You. I, and many who need that good will, appreciate it.

~Mary

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."

Afterwords: Part 3 Is There A The Cure? Bone Marrow Transplants

Is there a cure for sickle cell disease? Well, let's get some clarification here. There is no "universal" cure for sickle cell disease. There is no cure that is widely available for most persons suffering from this devastating blood disorder.

What is available for a select few is what is known as the bone marrow transplant (BMT). This curative treatment replaces the patient's blood stem cells with donor blood cells. Blood stem cells grow every kind of blood cell the body needs in the bone marrow. After a successful bone marrow transplant, the patient's bone marrow would produce non sickled, healthy cells.

The challenge is finding a genetically matched donor. Siblings who don't have sickle cell disease are the best source for seeking a match. The next source would be to use an unrelated donor's stem cells. The more closely matched the genetic background of the donor, the more likely they will be a suitable match. There are not enough minority donors so it is important that persons of color and minority groups sign up for the National Marrow Donor Program.

Another factor is that one must have enough complications from the disease to make the potential benefit of the transplant outweigh the risks which can be considerable. High costs that may not be covered by insurance also present a challenge for many who would seek this cure.

Despite the challenges, many have found success with the BMT. SCANJ's first Teen Spokesperson, Amanda Salazar, is living a healthy life and studying nursing in college. She got her transplant at Joseph M. Sanzari Children's Hospital of Hackensack UMC in Hackensack, New Jersey. Amanda sets

a wonderful example of perseverance as she underwent her BMT and emerged a leader in raising awareness about sickle cell disease.

Hackensack UMC is currently the only hospital in New Jersey to offer a Pediatric Blood and Marrow Transplant Program. They were established more than 20 years ago and are a national leader in the field of stem cell transplants. Under the leadership of Alfred Gillio, M.D., they are planning a Fall Symposium on Stem Cell Transplantation. For more information about bone marrow transplants or the Stem Cell Symposium please contact The Pediatric Bone Marrow Transplant Program at Hackensack UMC 551 996-5600 or visit www.hackensackumc.org

And mark your calendar now for SCANJ's upcoming **Thursday's in May Mini Workshop Breakfast Series** at the Van Vleck House and Gardens in Montclair. Bone Marrow Transplants will be the topic during the Breakfast on May 8th at 9:00am. We're pleased to announce that Jennifer Krajewski M.D. will be our presenter. She specializes in sickle cell disease and was awarded the best transplantational research prize amongst pediatric fellows for her research on NOTCH signaling neuroblastoma. Details on this and other Breakfast Mini Series workshop topics will be listed on the events section of www.sicklecellnewjersey.org. where you can register.

Afterwords is a six part newsletter series to shed insight on the topics covered during the 2013 SCANJ Statewide Sickle Cell Symposium. This year's Statewide Sickle Cell Symposium will be November 22nd.

WWW.SICKLECELLNEWJERSEY.ORG



The Sickle Cell Association of New Jersey
Mailing Address

P.O. Box 9501 Newark NJ 07104
EIN# 80-0474935 SCANJ is a 501c 3 agency

Phone: 973 482-9070 Fax: 973 485-6591

NEW! email: info@sicklecellnewjersey.org

SCANJ Is On The Move...Again!
National Sickle Cell Advocacy Day
Washington DC

This time we're going to Capitol Hill to advocate for the Sickle Cell Demonstration Treatment Act. ALL SCANJ Advocates are asked to join in a conference call on March 26th at noon. Dial in information will be sent by email to SCANJ registrants.

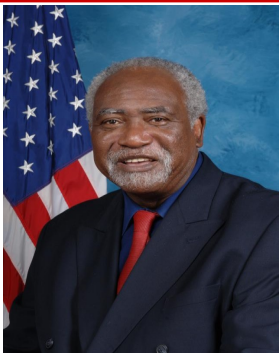
The Say It Loud Newsletter is published monthly. Archived copies are available for download from our website.

Beverly Lucas-Editor

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



Presenting the Sickle Cell Congressional Caucus



The Sickle Cell Disease Association of America, Inc. (SCDAA) announced the formation of the Sickle Cell Disease (SCD) Congressional Caucus. This legislative milestone is designed to focus on increasing support for the largely under-funded disease. Led by the Representatives pictured above, Danny Davis (D-IL), Senator Tim Scott (R-SC) and Charles Rangel (D-NY), the Caucus will work toward bringing public and congressional awareness to the unique needs of the Sickle Cell Disease community – patients, physicians, scientists and industry, and to develop opportunities to address barriers in access to and development of crucial treatments.

The 2014 year has started out strong for the SCD community, with several announcements regarding research and treatment advances across the country.

On **April 2-3, 2014** the SCANJ delegation of advocates will be on Capitol Hill in Washington DC for the SCDAA Advocacy Day. Applications for travel support for New Jersey residents to attend the National SCD Advocacy Day are now available via the events link on www.sicklecellnewjersey.org. SCANJ is the state chapter of the SCDAA.

"Agitate...agitate...agitate" ~Frederick Douglass

Coming Soon:

April 2-3 SCDAA
Advocacy Day Washington
DC.

June 14th. NFL McCourty
Twins Tackle Sickle Cell
Walk with SCANJ's "Walk
the Talk" Team. 9:00am
Liberty State Park in Jersey
City.

June 21st SCANJ
Commemorates World
Sickle Cell Disease Day
with the 5th Annual *Sickle
Cellabration* and Red
Cross Blood Drive

September TBD SCANJ's
24 Seven Line Dance
Marathon.

October 1-4 SCANJ Road
Trip to the SCDAA National
Convention Baltimore, MD