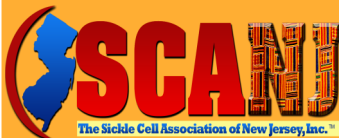


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings:

June 7 Election Day Vote!

8th Take Control of Your Health Chronic Disease Self Management (CDSMP) 6 week session workshop. Wednesday's at 6pm. through July 6th.

9th SCANJ's Research Project; "We'll Take The Village Engaging The Community To Better Health." **Town Hall Meeting 6:00pm**

Stanford School of Medicine's CDSMP & Diabetes Self Management (DSMP) Certifications

- June 16, 17, 20 & 21st. CDSMP 4 Day Peer Leader Training. 9:30 am-4:00pm
- June 27, 28, 29 & 30th. DSMP 4 Day Peer Training. 9:30 am-4:00pm

Programs listed above take place at 1016 Broad St. Newark. RSVP now.

June 18th



9:00am. Donate in support of SCANJ's "Walk the Talk Team." Liberty State Park in Jersey City

June 25th Sickle Collaboration Commemorating World SCD Day World Festival of fun and learning. 9:30am-2:00pm in Cherry Hill.

ALL 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



Volume 7
Issue 6

Say It Loud!

June 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

Commemorate World SCD Day at the Sickle Collaboration!



Mary Bentley LaMar
Founder
Executive Director

June 25th!!

June is always an exciting month in the sickle cell community. It is during this month that sickle cell advocates all over the world pause to commemorate the courage of individuals affected by sickle cell disease with (June 19th) World Sickle Cell Disease Day. At the SCANJ that calls for...

"A SICKLE COLLABORATION"

We invite you to come out and enjoy our world festival of fun and learning for the

whole family. **This year's program includes a Patient Panel on Self Management and our Patient Centered Outcomes Research Institute Project.** You will enjoy international cuisine and celebrate the 2016 Frances T. Walton Scholarship Awardees. Another highlight is the selection of the new SCANJ Teen and Child Ambassadors. All of this and more takes place when the drums sound at the Garden State Discovery Children's Museum in Cherry Hill on June 25th from 9:30am-2:00pm.

Be sure to RSVP online or by calling our office at 973 482-9070.

Here's quick shout out to the families who attended the SCANJ POP Up Event! Advocacy and Awareness at the UniverSoul Circus. Did we have a good time? I heard that yes! It was great seeing everyone having a blast! And special thanks to volunteers from the SCANJ; Alpha Kappa Alpha Sorority, Pi Mu Omega and Omicron Xi Omega Chapters; and the Oranges Maplewood NAACP. Your support allowed us to raise SCD awareness and conduct voter registration drives during the 2 weeks of the UniverSoul Circus tour in Newark.

No time to rest. This newsletter has plenty for you to consider... Workshops, A Town Hall, Walks.

It's a Sickle Collaboration!! ~Mary



Afterwords Part 4: The Cure...

Although not everyone is eligible for "the cure", there are many who are not aware of the procedure. We are speaking of the Bone Marrow Transplant (BMT).

Jennifer Krajewski, M.D., pediatric hematologist and oncologist at the Joseph M. Sanzari Children's Hospital at Hackensack University Medical Center (HackensackUMC), led the workshop and Lunch and Learn Patient Panel on BMT at SCANJ's Annual Symposium in 2015. It was eye-opening for many in attendance.

Attendees learned about pediatric Bone Marrow Transplants (BMT) from the doctor's perspective and from patients who have been cured after undergoing the procedure. Transplanted stem cells have to be provided from compatible siblings or from suitably matched unrelated donors (volunteer donors are identified through the National Marrow Donor Program or umbilical cord blood units).

Dr. Krajewski explained about the nationwide studies that led to expansion in donor eligibility. She designed a protocol to minimize the effects of treatment. These and other advances will enable parents to serve as stem cell donors. Potentially all severely affected sickle cell patients can be offered transplant therapy. **This is good news!**

Recognizing the need for better supportive care options, the team at HackensackUMC has been working with several companies to provide new bone marrow transplant drugs. Most recently, in order to provide a comprehensive option for sickle cell patients across the region, they have opened their own investigator initiated protocol for the transplantation of patients with sickle cell using unrelated donors.

HackensackUMC has the only pediatric stem cell transplant center in the state of New Jersey. They treat hematologic non-malignant diseases such as thalassemia, sickle cell, aplastic anemia, metabolic disorders, severe combined immunodeficiency and immunodeficiency syndrome. They have been performing transplants for patients with severe SCD since 1998. For more information on BMT you can contact HackensackUMC's Pediatric Blood and Marrow Transplant Program at 551 996-5600.

Afterwords; is a six-part newsletter series to shed insight on the topics covered during the most recent SCANJ Statewide Sickle Cell Symposium. The 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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or sicklecellanj@gmail.com



Register Now

www.getconnectedscd.org

SCANJ TOWN HALL MEETING

Meeting on Thursday June 9th at 6pm.

Get updated on our

Patient Centered Outcomes Research Institute Tier II Award

1016 Broad St. Newark (NBCS)

Dinner provided.

RSVP online or call 973 482-9070

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

THE SICKLE CELL ASSOCIATION OF NEW JERSEY
INVITES YOU TO COMMEMORATE

WORLD SICKLE CELL DISEASE DAY

SICKLE CELL ABRACTION 2016



SATURDAY, JUNE 25TH

Garden State Discovery Children's Museum
2040 Springdale Ave, Cherry Hill.

9:30am-2:00pm.

A World Festival of fun and learning for the whole family.
Frances T. Walton Scholarships awarded.
International Luncheon. Selection of the 2016-2017
New Jersey Sickle Cell Child and Teen Ambassadors.
Register today for this FREE event

event brite



Coming Soon...

AUGUST 21st Kente Carpet
Movies Under The Stars 7:00pm
Van Vleck Gardens in Montclair.

August 27th SCDAA Walk with
the Stars! Donate to SCANJ's
team www.sicklecellnationalwalk.org

SEPTEMBER

Sickle Cell Awareness Month
September 10th Phi Beta Sigma
Fraternity SCD Program (Science
Bldg) 3:00pm-4:00pm 185 So.
Orange. Ave. in Newark

SCANJ Road Trip September 29-
Oct 1 SCDAA National
Convention, Baltimore MD.

OCTOBER

NEW DATE FOR THE 24 SEVEN:
October 21-22nd.

THE SICKLE CELL ASSOCIATION OF NEW JERSEY
IN COOPERATION WITH HOST SPONSOR NEW JERSEY CITY UNIVERSITY

24th Annual
Seven
line dance marathon

Register for SCANJ programs via
events on sicklecellnewjersey.org ,
www.eventbrite.com or
or call 973 482-9070.

SUPPORT SCANJ's WALK THE TALK TEAM BY JOINING OUR TEAM

CANTON
WATERFRONT
PARK
BALTIMORE, MD



WWW.SICKLECELLNATIONALWALK.ORG

2016

Walk With The Stars
Benefiting Sickle Cell Disease Association of America

August 27, 2016



VAN VLECK
GARDENS
MONTCLAIR, NJ

Enjoy the Gardens prior to the Movie in support of our virtual Walk Team

AUGUST 21, 2016

