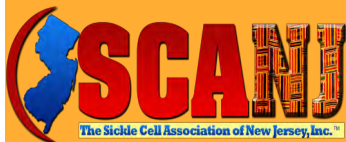


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings:

JUNE 7th Connections Support Group Tuesday 7:00pm -8:30pm
Paint Chat and Chew.

4th Morningside Christian Center Health Fair, Linden, NJ

10th McCourty Twins Tackle Sickle Cell Walk, Jersey City, NJ . To walk or donate visit www.embracekids.org

17th A Sickle Celebration! Sickle Celebration Commemorating World SCD Day World Festival of fun and learning. 9:30am-2:00pm in Cherry Hill. Frances Thompson Walton Scholarship Ceremony. Special guest Storyteller Queen Nur.

19-22nd Stanford School of Medicine's Diabetes Self Management 4 Day Peer Leader Certification Class. 9:30am-4:00pm. Grace Baptist Church Fords, NJ RSVP please.

27,28, 29 & 30th Stanford School of Medicine's Chronic Disease Self Management 4-Day Peer Leader Certification Class. 9:30am-4:00pm. 1016 Broad St. in Newark. Free parking provided. RSVP please.

Coming on August 4th Sickle Cell Walk Stroll and Kente Carpet Movies Under The Stars. Join SCANJ's Walk The Talk Team for the SCDA National Walk With The Stars. And afterwards enjoy our Movies Under The Stars. Donations and registration online. 6:00pm Van Vleck Gardens, Montclair.

REGISTER

via the events tab on sicklecellnewjersey.org

SCANJ is the New Jersey Chapter of the

or call 9070



Sickle Cell Disease Association of America



Volume 7
Issue 6

Say It Loud!

June 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

It's Time For A Sickle Collaboration!



Mary Bentley LaMar
Founder
Executive Director

The month is well underway with many positive happenings. One such happening is our Annual Sickle Collaboration." When you hear the drums sound you know it's time. **Join us on Saturday June 17th** as we commemorate the courage of individuals affected by sickle cell disease with (June 19th) World Sickle Cell Disease Day.

Come out and enjoy our world festival of fun and learning for the whole family. This year's event will feature Storyteller Queen Nur and we will celebrate the 2017 Frances T. Walton Scholarship Awardee. Another highlight is the selection of the new SCANJ Teen and Child Ambassadors and our popular international cuisine luncheon. It's all happening at the Garden State Discovery Children's Museum in Cherry Hill.

We're excited too about offering another **Peer Leader Training**

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.

Certification opportunity in the Chronic Disease Self Management and Diabetes Self Management Programs (calendar listings). These programs were originated at the Stanford School of Medicine Patient Education Department and are recognized internationally as the "gold standard" for self management programs. SCANJ Peer Leaders work throughout the state providing workshops that help individuals learn how to actively take control of their health.

Don't let the month pass without you making a difference for the sickle cell community.

~Mary

HRSA Award; More Support For the Sickle Cell Community! Yes!!

The SCDA has been awarded an \$11.6 Million Continuation Grant from the Health Resources & Services Administration (HRSA) for the Sickle Cell Disease Newborn Screening Follow-up Program. With these funds, SCDA will continue its efforts to establish the national infrastructure to ensure that individuals diagnosed with sickle cell disease (SCD) receive appropriate follow-up services including counseling, education materials and access to a medical home.

As a current grantee and the lead organization for HRSA's Sickle Cell Disease Newborn Screening Program, SCDA has served as the National Backbone Organization for HRSA, working with community-based organizations (CBOs) across the country, including SCANJ, to implement a strengthened approach to access quality care, quality care improvement and strategic activities within the sickle cell community.

Over the past 2 years, as the lead organization for HRSA's Sickle Cell Disease Newborn Screening Program, SCDA has accomplished the following:

- Enhanced the capacity of 25 member and non-member CBOs, covering 19 states by providing administrative and infrastructure support.
- Launched its National SCD Community Health Workers Training Program and trained more than 85 CHWs that have reached more than 13,000 patients and assessed over 8,000 individuals in need of either a medical home or Hydroxyurea education.
- Developed and launched a Shared Management System to collect and analyze patient data for HRSA and to report data outcome measures.
- As a result...**
- SCANJ has been able to increase it's staff to include Community Health Workers (CHW) and administrative support.
- SCANJ has been able to increase outreach to rural areas of the state.
- SCANJ has 2 certified CHW's and partnerships with Barnabas Medical in the CHW program.
- SCANJ, through the Get Connected Patient Registry, has been able to connect more individuals with sickle cell disease to supportive services.



Register Now

www.getconnectedscd.org

WWW.SICKLECELLNEWJERSEY.ORG



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 Mailing Address P.O. Box 9501 Newark NJ
 07104

Phone: 973 482-9070 Fax: 973 485-6591
 email: info@sicklecellnewjersey.org
 or sicklecellanj@gmail.com

Connections Support Group...

is on break for July and August.

Meetings resume in September on the first Tuesday of each month.



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

The Garden State Discovery Museum 2040 Springdale Ave. in Cherry Hill For

WORLD SICKLE CELL DISEASE DAY
SICKLE CELL ABRAATION
SATURDAY, JUNE 17, 2017
9:30 AM TO 2:00 PM

A WORLD FESTIVAL OF FUN & LEARNING, INTERNATIONAL CUISINE, AWARDING OF THE FRANCES THOMPSON WALTON SCHOLARSHIPS | **SPECIAL GUEST STORYTELLER QUEEN NUR**

SELECTION OF THE 2017-2018 NEW JERSEY SICKLE CELL CHILD AMBASSADOR AND TEEN SPOKESPERSON



SCANJ's Teen Spokesperson, Georgios Kalogeropoulos and Child Ambassador Konstas Kalogeropoulos with their Dad at SCD Awareness Night at the UniverSoul Circus.

Interested in Summer Camp?
 Consider...

Dragonfly Forest is an overnight summer camp for children ages 7-14 with Sickle Cell Disease and other medical diagnoses. **The hematology session for 2017 takes place July 23-28th** at YMCA Camp Speers 143 Nichecronk Rd, Dingmans Ferry, PA in the Poconos). Tiered Tuition starts at \$200 with additional camper scholarships available. 24/7 medical staff on site. Activities include ropes course, zip line, archery, tie dye, horses, basketball, canoeing, fishing and more! Transportation options available.

Register online at dragonflyforest.org or call 610-298-1820 with any questions.

We encourage you to go to camp.

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

CANTON WATERFRONT PARK BALTIMORE, MD



WWW.SICKLECELLNATIONALWALK.ORG

Walk With The Stars

Benefiting Sickle Cell Disease Association of America

August 26, 2017



VAN VLECK GARDENS MONTCLAIR, NJ

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

August 4, 2017

