

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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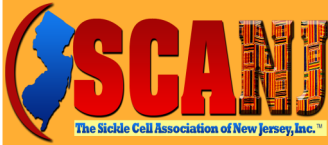
Say It Loud!

September 2015

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Calendar Listings: September is Sickle Cell Awareness Month

1st Mission Day 6th Anniversary of The Sickle Cell Association of New Jersey

3rd SCD Therapeutics Conference 8:30am-4pm NYC.

10-11th SCANJ's Research Project; "We'll Take The Village Engaging The Community To Better Health" represented at the PCORI Tier 1 Convention in Minneapolis, MN.

12th Take Control of Your Health Workshop. In cooperation with the Building Bridges Group. 6 week session begins. Plainfield. 2pm. RSVP

19th Children's Hospital of Philadelphia Town Hall on SCD Gene Therapy. 1pm. Call the Valerie Fund 973 926-6959 for details and transportation.

19th Donna T. Darrien Memorial SCD Walk. Visit dtdsicklecell.org 10am Weequahic Park Newark.

23-26th SCDAA Convention Baltimore, MD (SCANJ Road Trip) Presentation Saturday highlighting SCANJ's NJ Statewide SCD Symposium

26th Pemberton Area Block Association Block Party/Health Fair. SCD Awareness in Plainfield.

27th. Embrace Kids Heel to Heal Walk/Jog/Bike. Donate to Jimmy, our former child Ambassador's Jimmy Express Team via embracekids.org. 9am Johnson Park in Piscataway.

30th First Hopewell Baptist Church Health Fair SCD Awareness. 8am-2pm. 525 Orange St. Newark.

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America

Sickle Cell Awareness Month is Fully Underway...



Mary Bentley LaMar
Founder
Executive Director

I don't know about you, but it feels like September snuck up on me. All of a sudden, I am in the midst of great activity surrounding sickle cell disease. The calendar listings tell the story. On September 3rd, I along with researchers, pharmaceutical companies, analysts, investors and patients interested in hearing about promising treatments and drugs for sickle cell disease, attended the SCD Therapeutics Conference in New York City. The conference was organized by Mast Therapeutics. Materials from that meeting will be available at the next Research Invitational Dinner and at the Statewide SCD Symposium.

Another exciting happening this month is the Sickle Cell Disease Association of America (SCDAA) Annual Convention. I'm proud that our agency has been selected to present on Saturday, September 26. Our topic is on the NJ Statewide SCD Symposium. We will share the impact that it has had for New Jersey residents living with sickle cell disease. If you have a story to share on how our annual symposium (or any SCANJ service) has made a difference for you, please call 973 482-9070 or email me at sicklecellanj@gmail.com.

Again, we are supporting attendance to the SCDAA convention with Road Trip Scholarships. Applications are on our website via our events tab. Before we head to Baltimore, Ediomi Utuk and I are going to Minneapolis, MN for the national convention for PCORI Tier 1 Awardees. Ediomi and Beverly

Lucas are Co-Chairs for SCANJ's PCORI Project. Look for a report at the Research Invitational Dinner on October 2nd.

Thanks to all who supported our SCANJ "Walk The Talk" Team or led their own teams in support of the national SCDAA Walk With The Stars on August 29th. Keep the donations coming. We'll report next month on the amount raised.

Lastly, hold the date—October 23rd for the **24 Seven Kick Off Party!** We're doing something new this year in cooperation with New Jersey City University. So come out and be a part of efforts to bring about a change. One step at a time we fulfil our mission.

~Mary

...Now Run and Tell That!

On a warm and comfortable July 31st as we sat under the stars watching *The Princess and The Frog*, the community came together to enjoy a fun movie and learn about sickle cell disease. Some even participated in making SCANJ's new Public Service Announcement which is posted on our FB page and on YouTube.

Most importantly, enthusiastic supporters took over 200# SCANJ Research Flyers, 300# SCD Posters and 2000# SCD brochures to distribute throughout the community. They heard from our Teen spokesperson, Ayoola and others with sickle cell disease on how to get more involved. One way to get more involved is to tell what you know.

Information and resources are available on
www.sicklecellnewjersey.org

Some key points to share about sickle cell disease:

- SCD affects all ethnic groups
- Over 100,000 are affected by the disease in the US and tens of millions worldwide
- SCD is the most common inherited blood disorder in the United States
- Hydroxyurea is the only FDA approved drug for the treatment of SCD
- There are more therapies and medications being studied for sickle cell disease than ever before

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.

- Bone marrow transplants are the only known cure and they are not widely available mainly due to difficulty in finding suitable donors
- New Jersey residents can play a role in research through SCANJ's PCORI Project "We'll Take The Village; Engaging The Community to Better Health"
- You can make a difference now!



Kente Carpet Movies Under The Stars

WWW.SICKLECELLNEWJERSEY.ORG



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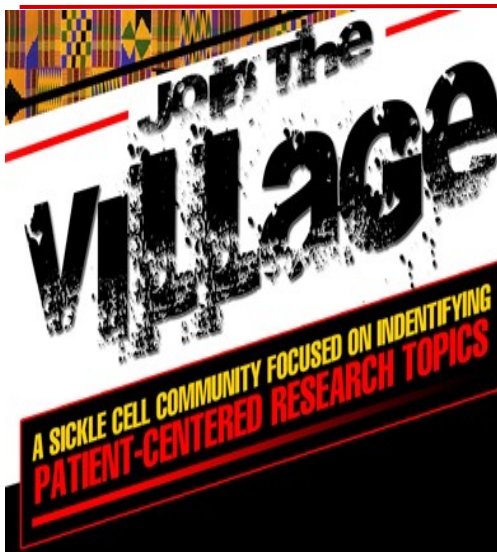
RSVP for the Research Invitational Dinner II
6:30pm October 2, 2015 at 21 Van Vleck St. in Montclair

BECOME A PART OF SOMETHING HUGE!
JOIN THE VILLAGE!



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



WHY: Since 1972, more than \$1 billion has been spent on sickle cell disease research. Now for the first time, people in New Jersey with sickle cell disease and their caregivers have an opportunity to be a leading voice in the development of a research topic relevant to people living with the condition.

HOW: SCANJ received a financial award from the Patient-Centered Outcomes Research Institute. This funding gives us the opportunity to form a community that will help drive research that makes a real difference for individuals living with sickle cell disease.

Join us in this excellent opportunity to make major strides in the field of sickle cell research. Are you ready for your voice to be heard? Learn more about our project-

**We'll Take The Village:
Engaging the Community to Better Health**

Coming Soon...

October 2nd

Research Invitational Dinner II
6:30pm. **RSVP Please.** Please note the venue change to the Van Vleck House 21 Van Vleck St. in Montclair
Agenda:

- I. SCANJ's Patient Centered Outcomes Research Institute (PCORI) Project
- II. Presentation by Prolong Pharmaceuticals.
- III. Q & A
- IV. Call To Action

SCANJ's project is on <http://www.pcori.org/research-results>

23rd Hold The Date For...

24 Seven Kick Off Party!

6:30pm-10:00pm.

This is the beginning of fundraising for the **2016 24Seven Line Dance Marathon**. Teams, organizations and individuals...let's get this party started!! Stay posted for details.

November 21st.

4th Annual Statewide Sickle Cell Disease Conference. 9:00am-3:00pm. Liberty Science Center in Jersey City

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

The Story Behind the Kente Carpet: The first Kente Carpet Movie Night was held in February 2012 at the AMC Dine In Movie Theatre in West Orange, NJ. New Jersey native Dexter Darden, who plays Walter in the movie "Joyful Noise" shared inspiring conversations with approximately 100 attendees. Dexter shared his struggle with sickle cell while successfully pursuing his dreams; he described sickle cell as both a curse and a blessing. With Dexter in their midst, the audience laughed, clapped and dined during the private viewing of "A Joyful Noise" which was followed by a Q&A session with Dexter.

In 2014, the Kente Carpet Movie Night was moved outside to the beautiful sculptured gardens of the Van Vleck House in Montclair, NJ. This allowed us to accommodate more from the community and we added what we call the "SCANJ TV Studio." Attendees were invited to make their own PSA's for sickle cell disease before the feature film and during intermission. They enjoyed a showing of the movie "Frozen." This year attendees enjoyed the feature film "The Princess and The Frog." True to the past, audience members were enthusiastic about taking the awareness packets and sharing the information. Our audience has grown too, so many more are "Saying it Loud" in the community.

Some may wonder why we call it "Kente" Carpet. The colors for the SCANJ are kente patterned red and yellow representing a heritage of hope for the blood. At the Kente Carpet Movies Under The Stars, everyone is welcome to come and learn about sickle cell disease, enjoy a family friendly event and help us to spread the word about sickle cell disease. Visit the YouTube channel to see the PSA filmed at this year's Kente Carpet Movies Under the Stars.



Stephanie Carter, Ediom Utuk (Event Chair) & Dexter Darden at the first Kente Carpet Movie Night

