

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



November Calendar

1st. Connections Support Group Meeting. 7:30pm Rochester's Barbeque & Grill 130 N. Whitehorse Pike in Lawnside, NJ

2nd. SCANJ Get Connected Pop Up Event: Cirque Du Soleil- 8:00pm. Randall's Island, NY.

8th. On Tuesday Election Day Say It LOUD!

YOUR VOTE IS YOUR VOICE

11th Newark Beth Israel Hospital, The Valerie Fund and SCANJ host an American Red Cross Blood Drive and Be The Match Bone Marrow Donor Drive.
210 Lehigh Ave. H3 Conference Room 3rd Floor. Newark, NJ
1:00PM-6:00PM. 1 800 Red Cross or www.redcrossblood.org

19th 4th Annual Statewide Sickle Cell Symposium and Dr. Charles F. Whitten Awards. Liberty Science Center, 222 Jersey Ave. Jersey City. 9:30 AM-3:00 PM.

Attention South Jersey-We are providing van and transportation assistance. Departing at 8:00am sharp from the Hilton Garden Inn 111 Hancock Lane Westampton, NJ. Return by 4:00pm. RSVP online or call 862 371-7138.

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America



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Say It Loud!

November 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

So Much To Be Thankful For...\$14,000 and Counting For The 24 Seven!



Mary Bentley LaMar
Founder
Executive Director

I am doing a happy dance for all the support that we have received. Most notably, we are well on track to reach our \$15,000 goal for the 24 Seven Line Dance Marathon fundraiser held last month.

Through the help of donors, volunteers, organizations and especially the New Jersey City University-Office of Community Service, we danced, laughed, ate, played games and raised nearly \$14,000 so far towards the goal. There is still time

to get those donations in. You have until November 30th to make it count for this year's 24 Seven.

It's all inspiration to keep working to make a difference for the families we serve. And speaking of inspiration, on

October 28 and 29th, Theresa Amoloja, MPH, and I attended the Patient Centered Outcomes Research Institute's (PCORI) Tier I and II Awardee Convention in Chicago. We gained valuable insight into the "PCOR" expectations for comparative effectiveness research (CER). This is useful as we work on our PCORI Project: "We'll Take The Village: Engaging The Community To Better Health." We'll share more about our PCORI Project at the Statewide Sickle Cell Symposium (see below).

Other news to highlight this month is the launch of the Connections Support Group (pg. 2). We kicked off with a great meeting in South Jersey and we look forward to continuing that momentum.

And lastly, I ask you to Say it Loud with your VOTE on November 8th. Nuff said!

~Mary

You Definitely Don't Want To Miss This One...

"Fantastic event."

"I was inspired to do more."

"Well put together...excellent speakers, informative and fun."

The quotes above are just a few of the comments from attendees at last year's symposium. Register now for this FREE (before Nov. 17th) educational and inspiring day of networking and knowledge sharing on sickle cell disease.

New this year is a patient led panel on Living Well with Sickle Cell. In addition, the Lunch and Learn will focus on research including SCANJ's PCORI project and Hackensack University Medical Center's Sickle Transplant Alliance for Research (STAR) for Bone Marrow Transplants.

Other exciting highlights are an art exhibit featuring the works of Mycroft Laryea and a poster session in partnership with the New York Mid Atlantic Consortium for Genetic and Newborn Screening Services. And the Big Apple Playback Theatre is back by popular demand.

The day would not be complete without honoring individuals and organizations with the Dr. Charles F. Whitten Awards for outstanding service.

We are in for a great day. Be there. Register now!



Saturday, November 19, 2016

~Symposium Schedule~

9:00 AM Welcome Breakfast Meet & Greet
9:30 AM Living Well With Sickle Cell Patient Panel Discussion—*Dr. Marjorie Dejoie-Brewer*
10:00 AM Youth Research Expedition—*Georgios Kalageropoulos, Teen Spokesperson, Konstantinos Kalageropoulos, Child Ambassador and Dr. Ansley LaMar*
10:20 AM The 411 on SCD and Hydroxyurea—*Dr. Alice Cohen*
11:15 AM- Big Apple Playback Theatre
12:30 PM Lunch and Learn Spotlight on Research-SCANJ's PCORI Project—*Mariah Scott, Beverly Lucas and Edimi Utuk; Bone Marrow Transplant STAR Alliance— Dr. Stacey Rifkin-Zenberg*
2:00 PM Dr. Charles F. Whitten Awards
2:30 PM Village Town Hall & Afterword's Networking
3:00 PM Adjourn until November 18, 2017
December Holiday Party Toy Drive Kick Off. Toys accepted all day during the symposium.

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Did you know that families in our Get Connected network are eligible for special "Pop Up" outings. We've enjoyed trips to the movie Trolls, the UniverSoul Circus, Ringling Bros. Barnum and Bailey Circus, Sesame Street Live and Cirque Du Soleil.

Most importantly, you are a priority for SCANJ programs and services. Call Darlene at 862 371-7138 for more information.

Get Connected Today!

www.getconnectedscd.org

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



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.

With the launch this month of our Connections Support Group for Sickle Cell Disease, we continue to make progress in reaching individuals who need to know that they are not alone. This is yet another reason to be thankful as we see our mission in action.

Did you know that according to the Health Resources Services Administration, there are over 6000 individuals in New Jersey living with sickle cell disease? We want to connect with each and everyone affected by sickle cell disease. If you, or a loved one, have sickle cell disease, we invite you to come out to give and receive support and understanding. You may share your story and be of support for yourself and others.

Except for July and August, meetings are held on the first Tuesday of each month. The time is from 7:00pm-8:30pm unless otherwise announced.

Where?

South Jersey location in the odd numbered months i.e., January, March, May, September and November

North Jersey location in the even numbered months i.e., February, April, June, October and December

The next meeting is Tuesday December 6th from 7:00pm-8:30pm.

Location: Deborah's Jazz Café 18 Greene St. in Newark (next to City Hall). Parking available. Dinner provided.

For more information and to RSVP please call our office at 973 482-9070 or 973 568-8119. You may also contact our Community Outreach Coordinator, Darlene Young, at 862 371-7138. Stay posted for the SCANJ Connections Support Group registration page on www.eventbrite.com and/or the newsletter for the current month's location as it may vary.

1st Tuesday of the Month

The Connections Support Group Has Launched!



Coming in December...

Connections Support Group Meetings 1st Tuesday of the Month.

Chronic Disease Self Management and Diabetes Self Management 4-Day Peer Leader Certification Training. Stanford School of Medicine licensed program. Stay posted for location and date.

Holiday Parties with Kenta Klaus

- 9th Party Central 6:30pm iPlay America in Freehold
- 15th Party South 6:00pm Garden State Discovery Children's Museum in Cherry Hill
- 17th Party North 3:00pm Van Vleck House in Montclair

RSVP Please



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