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: December

4th Connections Support Group Tuesday at 7:00 PM 1016 Broad St. Newark. Topic: Advocacy

Holiday Parties- RSVP Now...



- 7th Holiday Party Central Friday 6:00 PM Freehold
- 13th Holiday Party South Thursday at 6:00PM Cherry Hill
- 15th Holiday Party North
 Saturday 3:00 PM Montclair
 Special thanks to the National Organization of Black Law Executives (NJ Chapters) for their toy drive support.

Special thanks to **Novartis Pharmaceuticals** for supporting our Winter Outreach Program

12th Newark Beth Israel Hospital Adult Sickle Cell Center Holiday Party. 5:00pm at the Rev. Dr. Ronald B. Christian Wellness Center, 208 Lyons Ave. in Newark.

January 15-18

4 Day Peer Leader Training for Take Control of Your Health Chronic Disease Self Management . Location TBA

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

Say It Loud!

December 2018

Sickle Cell News You Can Use Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

Volume 8 Issue II

Kenta Klaus Says Yo Yo Yo!



Mary Bentley LaMar Founder Executive Director

Do you know who Kenta Klaus is? He is Santa's brother from another mother. He is making his way throughout New Jersey spreading holiday cheer to all the families effected by sickle cell disease. Kenta Klaus has already been to iPlay America in Freehold. He has 2 more stops to go so you still have time to join in the festivities. RSVP today for one of the December Holiday Parties with Kenta Klaus. Join us in a festive celebration of all things that lift up the sickle cell community.

This newsletter highlights where your active engagement has made a differ-

ence in sickle cell disease. A case in point is the recent passage in the US House of Representatives and the US Senate of the Sickle Cell Treatment Act (Bill S.2465). We are closer now to it's passage into law because of your advocacy. Don't let up now. Stay posted for next steps in advocating for sickle cell disease programs.

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.

Please help us to congratulate all who collaborated in advocating for the SCD Treatment Act. Thank you Congressional Sickle Cell Caucus, Sick Cells, Sickle Cell 101, the SickleCellForum, #BoldLipsforSickleCell, the EveryLife Foundation, and the Sickle Cell Disease Association of America, Inc. (SCDAA) and it's member chapters including the SCANJ.

We have cause to celebrate. Let the festivities begin!

Here's wishing you Healthy and Happy Holidays!

~Merry Mary

Finishing 2018 With Engagement for All!





Thank you Pfizer for the generous support of the Advocacy Lunch and Learn Panel Discussion held during the symposium.

Save the Date:

November 23rd, 2019 for the 7th Annual Statewide Sickle Cell Symposium. Same place, same time, new experience at the Liberty Science Center, Jersey City, New Jersey Join us in recognizing the 2018 Dr. Charles F. Whitten Honorees

Makouani Diabate

Outstanding Volunteer

Latrice Peterson Advocate of the Year

Karen Macey- Stewart, MSN, APN-C, AGPC, RN-BC

Overlook Medical Center

Outstanding Health Care Professional

They were recognized at the Statewide Sickle Cell Symposium

We appreciate the support of The SCANJ Board Officers

Ansley LaMar, Ph. D., President Vallerie Cleveland, Treasurer Beverly Lucas, Secretary Joy Elaine Daley, Member At Large Deborah M. Wilson, Member At Large

WWW.SICKLECELLNEWJERSEY.ORG



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EIN# 80-0474935 SCANJ is a 501c 3 agency

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or sicklecellanj@gmail.com

Connections Support Group



Meetings on the first

Tuesday of each month at 7:00PM. 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

This month's topic: Advocacy

This month's meeting is Tuesday December 4th in Newark. Next month's meeting is Tuesday, January 8th in Willingboro, NJ. For more information and to RSVP you may register online via our events tab, call our office at 973 482-9070, or call our Community Outreach Coordinator, Darlene Young at 862 371-7138.

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

Eventbrite

RSVP via www.sicklecellnewjersey.org

event brite F B



RSVP - WWW.SICKLECELLNEWJERSEY.ORG

2018 Milestones for SCANJ

- Marked our 9th Year in operation
- Advocacy contributed to the passage of the Sickle Cell Treatment Act (Bill S. 2465)
- •Conducted the 6th Annual Statewide Sickle Cell Disease Symposium.
- Completed Tier III Award from the Patient Centered Outcomes Research Institute
- •Increased POP Up events providing free fun outings for families
- Added new partners for our mission
- Awarded new grants from the NJ Dept. of Minority and Multicultural Health for the Chronic Disease Self Management and Diabetes Self Management Programs
- Continued signature programs such as the Sickle Cellabration, December Holiday Parties, Family Support, Scholarships, Kente Carpet Movies, Statewide SCD Symposium, Road Trip to the SCDAA Convention, Advocacy training. voter registration and Connections Support Groups.



Thank You Buffalo Soldiers Motorcycle Club of Northern New Jersey for your generous donation.