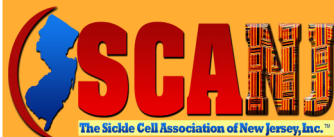


Sickle cell disease is the most common inherited blood disorder in the USA. People with sickle cell disease have red blood cells that become hard, cause anemia, pain and many serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings

NOVEMBER

10th SCANJ 10th Anniversary Celebration. Sheraton Parsippany 4:00pm



23rd Statewide SCD Symposium & Student Research Fair 10am
Liberty Science Center, Jersey City

DECEMBER

3rd Giving Tuesday. Support SCANJ in your year end giving. Donate online or by mail. You can also set up a Facebook fundraiser by selecting The Sick Cell Association of New Jersey.

3rd Connections Support Group
7pm IHOP 109 Bergen St. Newark.

SCANJ Holiday Parties with Kenta Klaus (Santa's brother)

- **12th Holiday South** 6pm
Garden State Discovery Children's Museum in Cherry Hill, NJ
- **21st Holiday North** 3pm Van Vleck House in Montclair, NJ

20th Newark Beth Israel Hospital RWJBarnabas Adult SCD Holiday Party. Contact the SCD Center for more information.

MOST SCANJ EVENTS ARE FREE REGISTER

via events (eventbrite) on
sicklecellnewjersey.org
or call 973 482-9070

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America



Volume 9
Issue 7

Say It Loud!

November/December 2019

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

We are Thankful for Your Gifts...



Mary Bentley LaMar
Founder
Executive Director

It is said that the two most important words in the English language are 'thank you.' Those two words are short and to the point. I will attempt to make my message the same.

I am thankful to you; the individuals living with sickle cell disease whose courage and tenacity continues to be the inspiration for our work. I am thankful for all the volunteers and partners who have contributed to our realizing the 10th year of operation for the SCANJ.

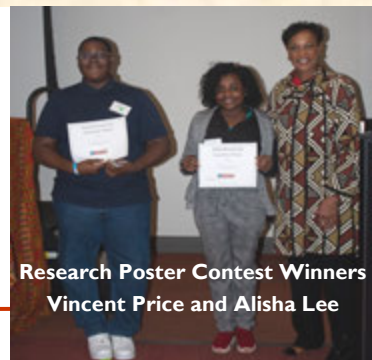
Because of you, we are on a mission towards a cure and there "ain't no stopping us now."

Do join us at the Holiday Parties as we reflect on your gifts and give thanks for the part you play in this mission. Happy Holidays!

~Merry Mary

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.



Research Poster Contest Winners
Vincent Price and Alisha Lee

New SCD Treatments Show Promise

If you attended the Statewide SCD Symposium then you know that these are exciting times in the sickle cell community. As we celebrate Thanksgiving, we can be thankful that there are new treatments, some potentially curative, that hold promise. While the SCANJ does not endorse any particular treatment, it is important that you are educated about what is available so that you can make informed decisions about your health.

Last year, we saw the release of the first new sickle cell drug in 20 years with Emmaus Medical's Endari, an L-glutamine oral powder that is indicated to reduce the acute complications of sickle cell disease in adults and children 5 years and older. This year we now have two more medications approved by the Food and Drug Administration (FDA) for the treatment of complications of sickle cell disease.

Novartis' Adakveo was released on November 15th and is now available. It is designed to prevent vaso-occlusive crises (VOCs) in patients with sickle cell disease. These VOCs are essentially blood-vessel blockages and they can be painful and sometimes fatal. Adakveo works by targeting a protein that can make misshapen red blood cells and blood vessels sticky, thereby preventing the blockages that can result in painful VOCs.

Novartis has set up Adakveo Support at PANO (Patient Assistance Now Oncology) where dedicated support specialists are available to help direct callers to services that best fit their needs. Patients or providers can call 800-282-7630 or visit Patient.NovartisOncology.com to learn more.

On November 25, 2019, Global Blood Therapeutics (GBT) received approval for Oxbryta in the treatment of sickle cell disease. It works by directly inhibiting sickle hemoglobin polymerization, the root cause of SCD. Oxbryta is a once daily tablet that works by increasing hemoglobin's affinity for oxygen. More information is available at www.Oxbryta.com or 1-833-428-4968 (1-833-GBT-4YOU).

There is more on the horizon as Bluebird Bio has a gene therapy study in late-stage clinical trials. They have partnered here in New Jersey with the Children's Cancer Institute at the Joseph M. Sanzari Children's Hospital at Hackensack Meridian Health and the John Theurer Cancer Center and are participating in a multicenter Phase I/II clinical trial of an investigational gene therapy.

This trial is specifically for adolescents and adults with severe sickle cell disease (SCD) who cannot be effectively treated using standard therapies such as antibiotics, vitamins, blood transfusions or any pain relieving medications. The study is evaluating the safety and effectiveness of Lenti-Globin® for sickle cell disease, a gene therapy produced using the patient's own modified stem cells to treat their sickle cell disease. The John Theurer Cancer Center is one of a limited number of centers internationally, and the Joseph M. Sanzari Children's Hospital is the only pediatric site in New Jersey, where the study, which is enrolling patients age 12-50, is taking place.

SCANJ will continue to raise awareness about new treatments as we learn more. Be encouraged. Stay informed.

WWW.SICKLECELLNEWJERSEY.ORG



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EIN# 80-0474935 SCANJ is a 501c3 agency

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Phone: 973 482-9070 Fax: 973 991-0297
email: info@sicklecellnewjersey.org
or sicklecellanj@gmail.com

Connections Support Group

First Tuesdays of each month at
7:00PM

South Jersey in the odd numbered
months.

North Jersey in the even numbered months.

No meetings in July and August.

Topic: SCDA Convention Learnings

November 5th at the Pastorellos Restaurant, Moorestown.

December 3rd at IHOP 109 Bergen St. Newark.

For more information and to RSVP you may register online via our
events tab, call our office or call our Community Outreach
Coordinator, Darlene Young at 862 371-7138.



The Say It Loud Newsletter is published every two months except for July and August. Archived copies are available for download from our website.

Beverly Lucas-Editor

SCANJ
THE SICKLE CELL ASSOCIATION OF NEW JERSEY, INC.
INVITES YOU TO

Celebrate the Holidays

Come and Join us on
December 12th and December 21st

SOUTH
THURSDAY DEC. 12TH 6:00PM - 8:00PM
GARDEN STATE DISCOVERY CHILDRENS MUSEUM
2040 SPRINGDALE ROAD, CHERRY HILL, NJ 08003

NORTH
SATURDAY DEC. 21ST 3:00PM - 5:00PM
VAN VLECK HOUSE & GARDENS
21 VAN VLECK ST, MONTCLAIR, NJ 07042

FESTIVE GAMES • CAROLING • TOYLAND • GIFTS • FOOD

SPECIAL APPEARANCE BY
"Kenta Klaus"

THIS EVENT IS FREE FOR FAMILIES AFFECTED BY SICKLE CELL DISEASE
ALL OTHERS ARE MERRY MAKERS \$25 ADULTS

FOR MORE INFORMATION CALL 973-482-9070
RSVP - WWW.SICKLECELLNEWJERSEY.ORG

OR VISIT
Eventbrite



10 Year Milestones for SCANJ

- 2009** Founded on September 1st.
- 2010** Established A Sickle Cellabration, Thanks For Giving Concert, Road Scholar Trips and Holiday Party Program with Kenta Klaus
- 2011** Established the 24 Seven:1st 24 Hour Line Dance for SCD. Awarded first grant for Chronic Disease Self Management
- 2012** Became SCDA chapter
- 2013** Established the Frances T. Walton Scholarships, established the Statewide SCD Symposium
- 2014** Established Kente Carpet Movies Under the Stars SCD awareness
- 2015** Patient Centered Outcomes Research Institute Awardee
- 2016** Established the SCANJ POP Ups; fun free events for families.
- 2017** Established Student SCD Research Poster Fair Contest at the Liberty Science Center
- 2018** Advocacy contributed to the passage of the Sickle Cell Treatment Act (Bill S. 2465)
- 2019** 10th year serving the sickle cell community.