

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.



Volume 7
Issue 1

Say It Loud!

January 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Calendar Listings:

January

21st SCANJ's Patient Centered Outcomes Research Institute (PCORI) Project; "We'll Take The Village Engaging The Community To Better Health." Town Hall Meeting 6:30pm. Final Wrap Up Meeting for Tier 1 of our PCORI Project. 1016 Broad St. In Newark. Dinner provided. RSVP via Eventbrite.com or call the office 973 482-9070.

26th SCANJ Adopt A Blood Drive. 12:30pm - 7:00pm.

209 Fairfield Rd. Fair Lawn, NJ



American Red Cross
Together, we can save a life
Blood Drive

30th Frances Thompson Walton Scholarship Applications Accepted. Apply online.

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

Halfway Through January and "Ain't No Stopping Us Now..."



Mary Bentley LaMar
Founder
Executive Director

Are you connected yet? Well what are you waiting for? We have many programs and a great way to help is to be part of our supportive network. This network is made up of individuals with sickle cell disease and their loved ones and medical professionals who are interested in making a change for the better for sickle cell disease.

You can make a difference uplifting others by simply networking at our events. Make a difference participating in our PCORI project; it holds hope for research

leading to better clinical treatments. Make a difference in education by becoming a certified Peer Leader in our Chronic Disease Self Management Program.

2016 has just begun and we're moving at a fast pace. Move with us by registering for "Get Connected" the SCDA's national patient powered registry. Your input through "Get Connected" will help us to identify critical needs. But more importantly, your voice can inform and support vital research and lead to the development of much needed care improvement guidelines.

www.getconnectedscd.org. ...We're On the Move! ~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.

Afterwords: Part 1. The Village Role in SCANJ's PCORI Project

On November 21st the Annual Statewide Sickle Cell Symposium began with a presentation on the SCANJ Patient Centered Outcomes Research Institute (PCORI) Project; "We'll Take The Village: Engaging The Community To Better Health." Ediom Utuk, Co-Chair of The Village Advisory Committee and Mariah Scott, Advisory Committee Member, provided a project overview.

They shared the vision for this research development project and our excitement that the sickle cell community is the driving force in shaping the research questions we explore.

The symposium concluded with a Village Town Hall Meeting. The "Village" consists of individuals with sickle cell disease, medical professionals and research partners interested in patient centered research. Participants shared concerns regarding health complications they have experienced from sickle cell disease and the treatments they have tried to address those complications. They were invited to share thoughts and feelings about each of those concerns which resulted in a lively discussion.

Several trends were identified with concerns around pain management, acute chest syndrome and the lack of adult providers, being most prominent.

The Village was engaged in a thoughtful conversation and a very important component of our PCORI Project—the patient perspective.

You can still join in the discussion by attending the next Town Hall Meeting on Thursday January 21st at 6:30pm (see calendar listing). Thanks to funding from PCORI, individuals with sickle cell disease, who attend the meeting, are eligible to receive a stipend. Dinner will be provided. Please RSVP.

To see highlights from the symposium visit YouTube. Please set your calendar now for this year's symposium on November 19th.

Afterwords is a six part newsletter series to shed insight on the topics covered during the SCANJ Statewide Sickle Cell Symposium. The Statewide Sickle Cell Symposium is held annually on the Saturday before Thanksgiving at the Liberty Science Center in Jersey City, NJ.

WWW.SICKLECELLNEWJERSEY.ORG



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CALL 973.482.9070
 GET READY IN 2016 TO
Get 
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 Register Now
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The Say It Loud Newsletter is published monthly except for July and August. Archived copies are available for download from our website.

www.sicklecellnewjersey.org



THANK YOU RESEARCH COMMUNITY!
Your Work Brings Hope.

Periodically we will post opportunities to participate in research studies (like below) for sickle cell disease.

Coming Soon...

SCANJ Holiday Party Program
 video on Facebook and YouTube

February

Take Control of Your Health

- Certification in Stanford School of Medicine's 4 Day Diabetes Peer Leader (DSMP) Training.
- And Chronic Disease Self Management (CDSMP) 4 Day Peer Leader Training.

March

Take Control of Your Health

6 week Community Workshops in CDSMP and DSMP

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

Dates TBA.

STUDY OF PARENTAL BELIEFS ABOUT RESEARCH AND ADVOCACY

Does your child (aged 0-17) have a diagnosis of sickle cell disease?



If so, we are asking you to participate in a study of parents' involvement in and beliefs about research and advocacy for their child's condition.

You have a unique perspective — we would like to learn from your experience.

Participation is completely voluntary.

Participation involves a short online questionnaire and possibly one 45-60 minute interview.

Parents who are interested may find more information here, along with the online questionnaire: <http://goo.gl/forms/9jT0CJ2YIs>

For more information, please contact:

Leila Jamal, ScM, CGC

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This research study was approved by the Johns Hopkins School of Public Health IRB, protocol # IRB00006316. The Principal Investigator for this study, Nancy Kass, ScD can be reached at nkass@jhu.edu.

SICKLE CELL SERVICES APP
 PUTTING RESEARCH TREATMENT & SUPPORT RESOURCES IN THE PALM OF YOUR HAND
 Available on the 
