

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.



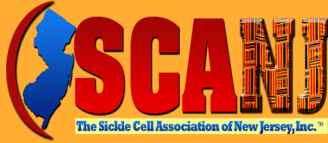
# Say It Loud!

May 2015

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Volume 6  
Issue 5

## Patient Centered Research? It's All About YOU!

### Calendar Listings:

#### May

May 7-June 11th SCANJ partners with the Friends of PD Support Group and the Willingboro Library to offer FREE CDSMP *Take Control of Your Health Six Week Community Workshops* Willingboro Public Library in Willingboro. Thursday's at 10 am.

#### 15th SCANJ hosts Research Invitational Dinner.

6:30pm.-9:00pm at The Heldrich Hotel 10 Livingston Ave. New Brunswick. You can RSVP via Eventbrite or by contacting our office by phone or email.

#### June 20th Sickle Collaboration

##### Commemorating World SCD Day

Join us for a World Festival on fun and learning for the whole family. Advocacy workshop for adults and teens. International lunch with foods from around the world. Garden State Discovery Children's Museum in Cherry Hill 10:00am-2:00pm

#### 20th McCourty Twins Tackle

Sickle Cell 5K Benefit for Embrace Kids Foundation. Liberty State Park Jersey City 9:00am

For updates or to register for SCANJ programs, call 973 482-9070 or go to our event link via

[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America



Mary Bentley LaMar  
Founder  
Executive Director

"Patient centered" is a term you may be hearing more of. The concept is that the voice of the patient should be heard first when making treatment decisions. This concept is not new to the sickle cell community. Many of you have been working to make your voices heard from the time you could make a sound. I'm pleased that the volume is up and more "movers and shakers" in the health care industry are beginning to listen.

Learn more about developments in sickle cell disease, and how you can play a role in research development. RSVP now for SCANJ's Research Invitational Dinner on May 15th at the Heldrich Hotel in New Brunswick.

Feel free to bring the children. We will provide fun activities to keep them engaged. The Research Invitational Dinner is the first of a series of topic specific meetings hosted by the SCANJ.

I look forward to the day when the sickle cell community drives research that makes a difference for individuals living with sickle cell disease. We're on our way to making that a reality with the PCORI award (see below).

Special thanks to Road Trip attendees to National SCD Advocacy Day. On April 16th, Quacian McEnough, Sireca Gregory, Darlene Young, Maria Garcia, Mery Ledesma, Wendy Adi-Darko, Theresa Amoloja and I, met with legislators in Washington DC. We advocated for funding for research and treatment for sickle cell disease (pg. 2).

Learn more during the Advocacy Report and workshop at the Sickle Collaboration on June 20th.

Be sure to read this entire newsletter. We're calling on you to be the change.

~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."

## A PCORI Award Goes To the SCANJ!

We are thrilled to have been approved for a \$15,000 award by the Patient-Centered Outcomes Research Institute (PCORI) to support our project "We'll Take The Village: Engaging the Community to Better Health." SCANJ is one of 47 awardees approved through PCORI's competitive process. Only 17% of those who applied were awarded.

"The Pipeline to Proposal Awards program is a manifestation of PCORI's commitment to the meaningful involvement of patients, caregivers, clinicians, and other stakeholders in all our research endeavors. It provides support to those who may not otherwise have an opportunity to contribute to the field of comparative effectiveness research." said Jean Slutsky, PA, MSPH, PCORI's Chief Engagement and Dissemination Officer.

SCANJ will use the funds provided through PCORI's Pipeline to Proposal Awards program to build a partnership of individuals and groups who share a desire to advance patient-centered outcomes research focused on sickle cell disease. PCORI Awards enable individuals and groups that are not typically involved in clinical research to develop the means to develop community-led funding proposals focused on patient-centered comparative effectiveness research (CER).

Guided by the voice of the "patient," we will engage our community and others from the nontraditional research community in identifying areas they consider important for comparative research that will lead to increased use of medical and nonmedical resources for individuals affected by sickle cell disease in New Jersey. We expect that this will ultimately lead to healthier outcomes and to reduced health disparities.

Established by the non-profit PCORI, the program funds three tiers of awards that help individuals or groups build community partnerships, develop research capacity, and hone a comparative effectiveness research question that could become the basis of a research funding proposal to submit to PCORI or other health research funders.

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work. To view SCANJ's project visit <http://www.pcori.org/research-results>



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**RSVP For Our First**

# Research Invitational Dinner

This first meeting is in cooperation with Mast Therapeutics, Inc.

THE HELDRICH HOTEL  
10 LIVINGSTON AVENUE  
NEW BRUNSWICK, NJ 08901

**MAY 15TH, 2015 • 6:30PM**

The Say It Loud Newsletter is published monthly. Archived copies are available for download from our website.

Beverly Lucas-Editor

[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)



## Advocacy Day Action Items...

**The Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2015 was reintroduced in the House of Representatives.** The Sickle Cell Disease Association of America, Inc., (SCDAA) along with SCANJ and other member chapters, advocates and champions received tremendous news during the Annual Sickle Cell Disease Advocacy Day. On the morning of Thursday - April 16, 2015 Representatives Danny K. Davis (D-IL) and Michael C. Burgess (R-TX) revealed the reintroduction of bipartisan legislation to renew the nation's programs for research, surveillance, prevention, and treatment of Sickle Cell Disease (SCD).

**The Priority of the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2015, H.R. 1807** is to improve quality of life, treatment, and prevention for those affected by Sickle Cell Disease. Among numerous modified benefits, the bill aims to establish full funding for twenty-five (25) Sickle Cell Treatment Centers throughout the US and provide continued support of a National Evaluation Center to collect, coordinate, monitor and distribute data, and to define best practice standards; development of treatment protocols and educational materials. Likewise, the bill requires continued authorization for community-based organization (CBO) collaborative programs to improve medical and support services delivered to affected individuals, and expanded eligibility beyond Federally Qualified Health Centers (FQHC). Furthermore, the bill seeks authorization for the Centers for Disease Control (CDC) to be the funding agency for the continuance and establishment of the Hemoglobinopathies Surveillance System program and SCD public health promotion initiatives.



### New Jersey Congressional Delegation

District	Name	Party	Phone
1 Donald	Norcross	D	202-225-6501
2 Frank	LoBiondo	R	202-225-6572
3 Tom	MacArthur	R	202-225-4765
4 Chris	Smith	R	202-225-3765
5 Scott	Garrett	R	202-225-4465
6 Frank	Pallone Jr.	D	202-225-4671
7 Leonard	Lance	R	202-225-5361
8 Albio	Sires	D	202-225-7919
9 Bill	Pascrell Jr.	D	202-225-5751
10 Donald	Payne Jr.	D	202-225-3436
11 Rodney	Frelinghuysen	R	202-225-5034
12 Bonnie	Watson Coleman	D	202-225-5801

### Coming Soon:

**August 29th SCDAA National Walk With The Stars. Join SCANJ's "Walk The Talk Team" You can be a virtual walker or come to Baltimore MD.**

**July 31 Kente Karpel Movies Under The Stars**  
Details TBA

**September SCANJ's 24 Seven Fundraiser.**  
Details TBA

**September 22-26th SCANJ Road Trip to the SCDAA National Convention Baltimore, MD**

**WE NEED YOU TO ACT! Reach out now** to your congressional leaders and request they sign and support this bill. **Ask your congressman or woman to become a co-signer on H.R. 1807.** Come to the Sickle Cellabration June 20th and receive your training and toolkit of useful information to help you advocate for sickle cell disease.

### Congratulations to the Newark Boys Chorus School (NBCS) for Raising Sickle Cell Awareness!

Science Teacher, Kyrstina McGee and Academic Dean, Ulysses R. Morris assisted the students with an Art Auction. The students plan to make sickle cell awareness tee shirts. They have been learning about sickle cell disease in their science class. **Great Work NBCS!!**

