

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 5
Issues 11

Say It Loud!

November 2014

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Calendar Listings:
November 4th Election Day



6, 7, 10 & 11th. **Chronic Disease Self Management (CDSMP) Peer Leader Certification Course.**
9:30am- 4:00pm Shiloh Baptist Church Spain Center 103-7 Davenport Ave. Newark.

22nd Statewide Sickle Cell Symposium and Dr. Charles F. Whitten Awards. 8:30am-2:00pm Liberty Science Center Jersey City.



December Holiday Parties with Kenta Klaus Special Thanks to NOBLE our Toyland Sponsors

11th Holiday Party South 6:00pm-8:00pm at the Garden State Discovery Children's Museum 2040 Springdale Rd. Cherry Hill

12th Holiday Party Central in cooperation with Newark's Barnabas Health Adult SCD Center 6:30pm-9:00pm at the Bradley Beach Bowling Center 1217 Main St. Bradley Beach

13th Holiday Party North 3:00pm-5:00pm at the Van Vleck House & Gardens 21 Van Vleck St. Montclair
FREE However RSVP's required

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association of America

A Note From The Executive Director...



Mary Bentley LaMar
Founder
Executive Director

I'm so excited...this month we are hosting one of our most dynamic programs -The Statewide Sickle Cell Symposium.

Join in this unique gathering of experts, individuals living with sickle cell disease and others who are interested in learning more about this inherited blood disorder. We will also say thanks

to those who have done outstanding work to fight sickle cell disease. Don't let this opportunity go by. And be sure to arrive early. We have pleasant surprises for all who arrive for the Breakfast Meet and Greet.

I believe everyone has benefited from the generosity and care of someone else. Please take a moment to say thanks. Go on... tell someone how much you appreciate them.

Use this season of thanks for inspiration. We appreciate you!
~Mary

SCANJ Mission Statement

In concordance with the mission of The Sickle Cell Disease Association of America: "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."

Help Us To Congratulate The Dr. Charles F. Whitten Honorees!

Saturday, November 22, 2014 will be a day of inspiration, enlightenment and engagement at the Liberty Science Center during SCANJ's 2nd Annual Statewide Sickle Cell Symposium.

We encourage you to come and learn more. Our goal is to raise awareness and improve knowledge and treatment for sickle cell disease.

In addition to informative workshops, panel discussions, The Big Apple Playback Theatre and the Lunch and Learn; we will conclude with the Dr. Charles F. Whitten Awards Program.

Dr. Whitten was a professor and pediatrician who, during the early 1970s, realized that services for people with sickle cell disease and their families were sorely lacking.

Out of Dr. Whitten's pioneering efforts to advocate for the needs of people with sickle cell disease, the Sickle Cell Disease Association of America (SCDAA) was born. By naming the awards after Dr. Whitten, we expect that more will appreciate the history behind the advocacy to increase the knowledge and understanding of sickle cell disease in the medical community and among individuals living with the disease.

This year's "Whitten" honorees are:

- **Kay Robinson** of Irvington, Advocate of The Year
- **Keema Givens** of Williamstown, Volunteer of The Year.
- **Rev. Shelia Hobson** of Grace Baptist Church in Fords, Outstanding Community Service
- **Dr. Jill Menell** of St. Joseph's Hospital in Paterson, Outstanding Health Care Professional
- **Morning Star Christian Community Center** of Linden, Outstanding Sickle Cell Sabbath Partner

The 2nd Annual Statewide Symposium is made possible, in part, with the support of the Novartis Corporation and the Embrace Kids Foundation in cooperation with the NFL McCourty Twin's Tackle Sickle Cell.

Registration is FREE to all who register early. You can register via our events page www.sicklecellnewjersey.org or give us a call at 973 482-9070.



Make a Difference!
DONATE

The Sickle Cell Association of New Jersey

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**SCANJ Delegates at the SCDA A
Convention in Baltimore October 1-4**

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

www.sicklecellnewjersey.org



New Treatments for Sickle Cell Disease: Making Our Voices Heard!

This is an exciting time in research and drug development for sickle cell disease. It was reported at the national SCDA A convention, that over 17 pharmaceutical companies are currently working on new treatments. On February 7th of this year, the U. S. Food and Drug Administration asked patients with sickle cell disease, their caregivers and advocates to share their thoughts about improving treatment options at a patient-focused drug development meeting. SCANJ heeded the call by sponsoring a road trip to attend the meeting in Silver Spring, Maryland and by hosting a local viewing site where those who couldn't make the trip could gather and participate in a live webcast. Following are just a few highlights from the meeting:

Initial discussions focused on patients' and caregivers' experiences with the symptoms and complications of sickle cell and the resulting impacts these health effects exert on their daily lives. Acute pain crises, chronic pain and fatigue were among the most concerning issues, both physically and emotionally, for children and adults. Another discussion focused on current treatments and their positive and negative effects, including use of hydroxyurea, blood transfusions, bone marrow transplants, drugs for iron overload, and pain relievers. Participants were also asked for their perspectives on an ideal treatment. Among the priorities were the development of treatments that better target the underlying disease and that can help prevent long-term complications. The FDA also sought input on patients' and caretakers' thoughts about participating in clinical trials of potential new treatments. A number of broader issues, such as quality of care and difficulties transitioning from pediatric to adult healthcare providers, were also discussed.

SCANJ is pleased to have been able to offer this opportunity to share our community's thoughts with other stakeholders who attended the meeting, including governmental and pharmaceutical industry representatives and healthcare professionals. Stay posted for more information about additional public meetings being planned. The FDA believes such input from the sickle cell disease community will help its efforts to facilitate the research and development of safe and effective new treatments. We certainly agree! The webcast recordings and summary report are posted online <http://www.fda.gov/ForIndustry/UserFees/PrescriptionDrugUserFee/ucm370867.htm>

Special thanks to everyone who signed the SCDA A petition to the Whitehouse asking for reauthorization of the Sickle Cell Treatment Act – Bill H.R. 5124. This bill seeks to expand the national newborn screening program, develop a comprehensive adult transition program, continue public surveillance, expand research efforts and establish up to 25 sickle cell treatment centers throughout the US all in an effort to support the creation of a sustainable comprehensive model of care for individuals affected by SCD. **We had over 123,325 signatures. Well over the 100,000 goal. YOU DID IT! THANKS!**

Be There!

**Saturday, November 22, 2014
Statewide SCD
Symposium Schedule:**

8:30 Breakfast Meet & Greet

9:00 AM-10:15 AM –Keynote

Speaker and Panel Discussion

10:20 AM Workshops

- **Bone Marrow Transplants-
Dr. Alfred Gillio**
 - **Introduction to Clinical
Research and Trials –
Dr. Alice Cohen**
 - **Caring for Your Child With
Sickle Cell Disease-
Dr. Jill Menell**
 - **Stanford Chronic Disease
Self Management Program -
Kay Robinson and Keema
Givens**
 - **Youth Research Expedition–
Ayoola Ogunyimika, Teen
Spokesperson & Ansley
LaMar Ph.D.**
 - **Kente Carpet Morning at the
Movies (PSA's on SCD)**
- 11:30 AM – Big Apple Playback
Theatre Performance**
- 12:30 PM – Meet the Experts
Lunch & Learn**
- 1:30 PM – Presentation of the
Dr. Charles F. Whitten Awards**
- 2:00 PM Symposium Adjourns**