

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 other serious health problems. Your involvement makes the difference in overcoming this disease.



Volume 7  
Issue 9

# Say It Loud!

October 2016

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



## October Calendar

3rd SCANJ Get Connected Pop Up Event: Sesame Street Live-Elmo Makes Music. RSVP for our



Get Connected Families. 6:30pm Show. Mayo Performing Arts Center 100 South Street, Morristown.

## 4-5th New York Mid Atlantic Consortium for Genetic and Newborn Screening Services Summit.

SCANJ presents on our PCORI Research Project. Hilton Hotel, Inner Harbor Baltimore, MD

Oct. 16th—Nov. 28th Take Control of Your Health Chronic Disease Self Management 6 week workshop. Monday's at 10am. Living Springs, 600 Parkview Dr., Delanco

21st-22nd The 24 Seven Line Dance Marathon. From 5pm-5pm New Jersey City University. Gillian Student Union Building, New Jersey City University, 2039 Kennedy Blvd, Jersey City.

**ALL EVENTS ARE FREE UNLESS OTHERWISE NOTED**

REGISTER via [eventbrite.com](http://eventbrite.com) or the events tab on [sicklecellnewjersey.org](http://sicklecellnewjersey.org)

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America

## SCDAA 44th National Convention: SCANJ Present and Accounted For!!



Mary Bentley LaMar  
Founder  
Executive Director

Our Road Scholars have just returned from the SCDAA convention in Baltimore Maryland (Sept. 28-Oct. 1) where we attended great workshops, lectures, luncheons and forums. Sickle cell advocates, researchers and clinicians shared knowledge on SCD including the latest in clinical care, pain management and research for a cure.

Our PCORI Research Project "We'll Take The Village: Engaging The Community to Better Health" was presented on Saturday and we were able to get input from the attendees on our current research ideas.

Kudos to Dominique Goodson who serves on the Young Adult Alliance Committee and was a panelist during their forum. And give a shout out to our Child Ambassador Kostantinos and Teen Spokesperson, Georgios. As first time attendees to the convention they learned a lot and represented us well. Lastly, I'm pleased to share that I was elected to the Executive Directors' Leadership Council and will be serving as secretary to this dedicated group of Executive Directors, Presidents and CEOs of SCDAA member CBOs from around the country.

### 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.

Now that we're back and inspired with a renewed sense of purpose...it's time to team up to raise funds and line dance for sickle cell disease!

*That's why we wobble baby! ~Mary*

## October 21st at 5:00PM. It's ON!



Can you hang? I'm talking about the 24 Seven Line Dance Marathon—the ONLY 24-Hour line dance marathon raising funds and awareness for sickle cell disease in the WORLD!! It's going down this month starting at 5pm on the 21st and we won't stop until 5pm on the 22nd. You can stay for all, or part of the 24 hours. And we will have lots of great activities for you too. Sickle cell awareness, comedians, line dance lessons, a movie, line dancing, a phone-a-thon, party with a purpose, games, prizes, food and more. Top fundraisers receive awards.



**Why the 24 Seven?** Since birth, individuals with sickle cell disease have this inherited potentially life-threatening blood disorder, twenty-four hours a day, seven days a week and currently there is no universal cure.

The funds raised will benefit families served by the SCANJ. We are working 24 Seven to make a difference in the quality of life for individuals living with sickle cell disease. We couldn't do this work without the help of great volunteers, organizations and companies who support our mission.

We especially appreciate the New Jersey City University-Office of Community Service. They lead the way as our primary sponsor in support of this worthy cause.

So come on out. We'll even teach you the "sickle cell stomp." Join, or form a fundraising team, or if you prefer, simply make a donation. Every step you take helps us to stomp out sickle cell disease.

To learn more call us at (973) 482-9070 or visit [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org) or [eventbrite.com](http://eventbrite.com)

[WWW.SICKLECELLNEWJERSEY.ORG](http://WWW.SICKLECELLNEWJERSEY.ORG)



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**SAVE THE DATE**  
**STATEWIDE SICKLE CELL SYMPOSIUM**

The Sickle Cell Association of New Jersey  
**Saturday, November 19, 2016**  
9:30 am to 3:00pm

REGISTER @ [Eventbrite](#)

**liberty science center®**  
222 JERSEY CITY BLVD, JERSEY CITY, NJ 07305

BREAKFAST MEET AND GREET  
LUNCH AND LEARN  
BIG APPLE PLAYBACK THEATER  
WORKSHOPS  
DR. CHARLES F. WHITTEN AWARDS  
PATIENT CENTERED OUTCOMES RESEARCH TOWN HALL

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

## Did You Watch the 1st Presidential Debate?



**We did!** SCANJ hosted an Open House and Presidential Debate Watch Party on September 26. Although health care wasn't discussed in the first debate, it's a key issue, particularly Obamacare. As a result of this law, health insurers can no longer charge more or deny coverage to you or your child because of a pre-existing health condition like sickle cell disease. They cannot limit benefits for that condition. Once you have insurance, the insurer can't refuse to cover treatment for you or your child's pre-existing condition. It's possible the candidates in the first debate will discuss their views on this topic in a future debate. In the meantime, here's a quick look at where they stand based on information from their websites.

**Obamacare.** Mrs. Clinton supports it. She has pledged to defend the law against efforts to repeal it and to expand coverage to many who still lack insurance. Mr. Trump says that if elected, he will ask Congress to immediately repeal Obamacare on day one of his Administration.

**Health care costs.** A few of Mr. Trump's ideas are to allow health insurance to be sold across state lines to generate more competition among health insurers and to eliminate the requirement that healthy individuals buy insurance. Among other things, Mrs. Clinton wants to limit excessive out-of-pocket costs like co-pays for families. She would require health insurance plans to provide three sick visits without counting toward deductibles every year and wants lower costs for out-of-network emergency care.

**Paid family leave.** Family caregivers who work full or part time while caregiving often face financial difficulties or risk losing their jobs if they must take time off to care for family members.

Mrs. Clinton is in favor of giving eligible employees up to 12 weeks of paid family and medical leave at two thirds their pay to care for a seriously ill family member or a new child or to recover from a serious illness or injury of their own. Mr. Trump has proposed making 6 weeks of paid leave available for new mothers through unemployment insurance.

References...

- <https://www.hillaryclinton.com/issues/health-care>.
- <https://www.donaldjtrump.com/positions/healthcare-reform>.
- <https://www.hillaryclinton.com/briefing/factsheets/2015/09/23/clinton-plan-to-lower-out-of-pocket-health-care-costs/>
- <https://www.hillaryclinton.com/briefing/factsheets/2015/09/21/hillary-clinton-plan-for-lowering-prescription-drug-costs/>
- <https://www.donaldjtrump.com/positions/child-care-reforms-that-will-make-america-great-again>

This report was based on the candidates in the first presidential debate. There are actually 6 candidates that we are aware of who are running for president. We encourage you to be an informed advocate by learning more about the candidates and their positions. **And most importantly we ask that you vote on November 8th.** When you raise your voice by voting it's potentially good for the health of the sickle cell community. **Rock the Vote!**



Register Now

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

### Coming Soon...

- **November 1st** Last Day to Apply for a Mail Ballot By Mail for the General Election
- **November 7th** Deadline for in person Mail-In Ballot Applications
- **November 8th General Election Polls Open 6:00am-8:00pm**

**November 11th** Newark Beth Israel Hospital Valerie Fund SCD Awareness Blood Drive.

**November 19th** 5th Annual Statewide Sickle Cell Symposium. Liberty Science Center, Jersey City.

**December Holiday Parties** with Kenta Klaus (3 locations throughout the state)

Register for SCANJ programs via events on [sicklecellnewjersey.org](http://sicklecellnewjersey.org), [www.eventbrite.com](http://www.eventbrite.com) or

**THE SICKLE CELL ASSOCIATION OF NEW JERSEY**  
IN COOPERATION WITH HOST SPONSOR NEW JERSEY CITY UNIVERSITY  
Oct. 21-22

**24<sup>th</sup> Annual Line Dance Marathon**