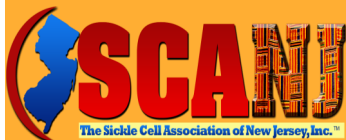


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Volume 7
Issue 1

Say It Loud!

January 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

This Could Be The Start of Something Good...



Calendar Listings:

January

3rd Connections Support Group
Tuesday at 7:00 PM Rochester's Grill, Lawnside, NJ

20th New York Mid Atlantic Consortium Webinar on Patient-centered Communications, Advocacy and Cultural Humility. Friday 12:00pm– 1:00pm. SCANJ's PCORI Project Co-Chair and Sickle Cell Advocate, Ediom Utuk, is one of the featured presenters. To request the link to register please email: nymac@health.ny.gov

23-24th Patient Centered Outcomes Research Institute (PCORI) Conference From Application To Closeout. Washington DC. SCANJ's PCORI Project Lead and Co-Chair to attend.

January 30–March 6th Diabetes Self Management Workshop. 6 week Brunch & Learn. Monday's at 10:00am. Broadway Genesis House Newark. Register early. Capacity is limited to 20 enrollees.

February 7th Connections Support Group Tuesday at 7:00 PM. 1016 Broad St. Newark, NJ. Dinner provided. Parking available.

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



Mary Bentley LaMar
Founder
Executive Director

I say "could be" because I believe we have to take action to make "something good" happen.

The motto of our agency is "SCANJ equals faith with good works for sickle cell disease." Those works don't happen without your active involvement.

Fortunately, we provide several opportunities for you to take action through your good works.

You could become a Peer Leader for our Chronic Disease and Diabetes Self Management Workshops. You could be a part of the Village for our PCORI

Project. You could volunteer for one of our many committees that support the programs and events.

These and many other programs will be strengthened through your participation. So check out the calendar listings and

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.

Get Connected to something good. As we head into a presidential inauguration on the heels of Martin Luther King's Day of Service Holiday, ask yourself how you will contribute your talents for the good of our society.

Something good? With your help, we can change that "could" to "will."

Where there's a will there's a way!

~Mary

Who's Who On SCANJ's PCORI Project?

For the past year, we've shared the news about our participation in a groundbreaking effort spearheaded by the Patient-Centered Outcomes Research Institute (PCORI) to have patients' voices heard by the scientific research community. Our project, "We'll Take the Village: Engaging the Community to Better Health" was made possible by funding from PCORI. In the next few issues, we'd like to introduce you to some of the people helping us on our journey.

"Take the word 'can't' out of your vocabulary, because anything is possible." That's inspirational advice from Mariah Scott, M.S., SCANJ's research assistant for the PCORI project. In this role, she searches the medical literature to find out what scientific studies have been published on sickle cell disease. Mariah's work sheds light on what's known and what's not known about sickle cell disease. The Village Advisory Committee then uses this information as it works with the Village to formulate a research question that truly reflects what the community wants to know.

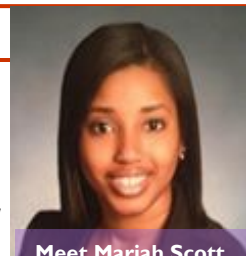
This task is a perfect fit for Mariah who has a Master of Science degree in microbiology from Seton Hall University in South Orange, NJ, and who has been a "sickle cell warrior" for 25 years. "During our Town Hall meetings with the Village, I can provide my input as a scientist and offer my perspective as a sickle cell patient. At the same time, I get to hear the opinions from other sickle cell patients."

She adds, "It is therapeutic to discuss and debate what is essentially important to us."

Mariah is thankful to SCANJ Executive Director, Mary Bentley LaMar, for the opportunity to work on the PCORI project and has found working with the New Jersey sickle cell community to be a pleasure. "I hope that this project will enlighten and empower patients as well as providers within the sickle cell community." And she hopes it will progress and have an impact on the entire field of medicine.

In the not too distant future, Mariah plans to be a part of that field. Her goals are to obtain her medical degree, conduct research, and find a cure for sickle cell disease. "I've gone from feeling vulnerable as a patient at hospital visits and experiencing distressing chronic pain to becoming a successful scientist and having the ambition to go forward and pursue becoming a physician."

In that regard, working on SCANJ's PCORI project offers an additional benefit: "I'm able to put my background in research toward a subject that I have a passion for and plan to use the experience as a stepping-stone into the medical field." Clearly the word "can't" is not in Mariah's vocabulary. The SCANJ community is fortunate to have her working with us on our journey.



Meet Mariah Scott

WWW.SICKLECELLNEWJERSEY.ORG



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Connections Support Group



Meetings on the first

Tuesday of each month at 7:00PM. South Jersey location in the odd numbered months i.e., January, March, May, September and November. **North Jersey** location in the even numbered months i.e., February, April, June, October and December

Topic: Employment and Sources of Income

This month's meeting is Tuesday January 3rd at Rochester's in Lawnside. Next month's meeting is Tuesday February 7th at NBCS 1016 Broad St. in Newark. For more information and to RSVP you may register online via our events tab, call our office at 973 482-9070, or call our Community Outreach Coordinator, Darlene Young at 862 371-7138.

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



We're All In For Advocacy in 2017

Advances in programs and research for sickle cell disease would not have been possible without effective advocacy. That advocacy includes being an informed voter. As our country enters into a new administrative era, it is important to know where your elected officials stand on the issues that matter to you and your family. And more importantly, to let your elected officials know where you want them to stand on those issues and how their policies affect you. **Tell your story. Ask your questions. Insist on accountability.**

SCANJ supports the Patient Protection and Affordable Care Act (ACA). 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, asthma, high blood pressure or cancer. They cannot limit benefits for that condition either. Once you have insurance, the insurer can't refuse to cover treatment for you or your child's pre-existing condition.

Did you know that 3 million Americans in 19 states do not have health insurance because their states have refused to expand Medicaid eligibility to cover their poorest residents? For now, as a result of Medicaid expansion many more low income residents in New Jersey are eligible for health insurance under the ACA. Gov. Christie vetoed legislation that would make the expansion permanent. Millions of Americans have lost their health insurance, often due to job loss. Buying insurance through the ACA is one option.

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.

Currently: The federal Family Medical Leave Act (FMLA) provides eligible employees **up to 12 weeks of unpaid leave** during a 12-month period to care for a newborn or adopted or foster child, or to care for a seriously ill family member, or to attend to the employee's own serious medical health condition. The law applies to private employers with 50 or more employees. The FMLA also allows states to set standards that are more generous than the federal law and many states have chosen to do so. In New Jersey, for example, in addition to unpaid leave guaranteed by the FMLA, workers who qualify can receive **up to six weeks of leave at two-thirds their regular pay** to care for a sick family member or bond with a new child.

President Elect Donald Trump has asked Congress to repeal The Affordable Care Act on day one of his Administration. Should that happen without a suitable replacement the results could be devastating. We must hold our policymakers accountable if they dismantle the ACA. The sickle cell community and others with pre-existing conditions have endured enough pain.

Tell your story. Ask your questions. Insist on accountability.

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Register Now

www.getconnectedscd.org

Coming Soon...

Francis Thompson Walton Scholarship. For New Jersey residents living with sickle cell disease who are attending accredited institutions of higher learning. Apply online online through June 1st. Scholarships awarded during the Sickle Cellabration on June 17th.

Dates TBA

Take Control of Your Health

- Certification in Stanford School of Medicine's 4 Day Diabetes Peer Leader (DSMP) Training.
- Chronic Disease Self Management (CDSMP) 4 Day Peer Leader Training.
- 6 Week DSMP Community Workshops February 18-March Alpha Baptist Church. Willingboro, NJ

