

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!

February 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Volume 7
Issue 2

Calendar Listings:

February

1st TD Bank Health Fair SCANJ raises Sickle cell Awareness Wednesday 8:00am-noon. TD Bank Call Center in Mt. Laurel

2nd Blue Skies & Brickwork

SCANJ attends Health Policy Summit. 8:30 am - 5:00 pm. Newseum in Washington DC.

7th Connections Support Group

Tuesday at 7:00 PM 1016 Broad St. Newark, NJ. Dinner provided.

18th Sickle Cell Awareness Luncheon

Saturday noon—4:00 pm. Marciano's Restaurant 947 N. Delsea Drive, Vineland, NJ. Hosted by the Deborah Chapter #51 Order of Eastern Star. Tickets are \$35.00. For more information call 856 692-4037 or 856 378-8729.

Feb. 18—March 25th Diabetes Self

Management Workshop. 6 weeks Saturdays at 10:00 am. Alpha Baptist Church, Willingboro. FREE. Register early. Capacity is limited.

March 7th Connections Support

Group Tuesday at 7:00 PM. JFK Center, 429 JFK Way in Willingboro.



March & April Support Group Activity:
Paint Chat and Chew

REGISTER FOR MOST EVENTS
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

Stay Woke! Bad English, But Good Advice. . .



Mary Bentley LaMar
Founder
Executive Director

Whew! February...the shortest month of the year and it feels like the most active to me. Maybe that's because I am trying to fit everything into a narrow window of time.

I ask you to fit into your schedule at least one thing...answer the Call to Action (see below). There are so many things going on that could adversely affect the sickle cell community. We need everyone to do as the youth say...Stay Woke!

What does that mean? For me it means to pay attention to what is going on in the community and make your voice heard. We named this newsletter *Say It Loud!* for a reason. We strive to share with you the tools to be vocal in your advocacy, knowledgeable in your disease state and connected to advancing the sickle cell community.

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.

And once you receive those tools, use them to speak with assurance in a voice that cannot be ignored. It is my hope that your voice will lead to better conditions for those living with sickle cell disease.

I'll just leave you with this call to action written by John Wesley in the 1700's. "Do all the good you can. By all the means you can. In all the ways you can. In all the places you can. At all the times you can. To all the people you can. As long as ever you can."

You can... ~Mary

A Call To Action on Prescription Opioid Use!

If you haven't been following the local news lately, you may have missed this important development for the sickle cell community: New Jersey Governor Chris Christie recently instructed our state Attorney General to issue regulations requiring physicians to limit an initial prescription for opioid painkillers for acute pain to a five-day supply instead of 30 days, which is currently allowed. Only after re-evaluating the patient, can the physician write a prescription for more medication.

Why? Opioids are addictive medications, and their misuse is believed to contribute to the heroin addiction epidemic that has hit many states, including New Jersey. According to the American Society of Addiction Medicine, "four out of five new heroin users started by misusing prescription painkillers."

Our concern: Although stopping opioid abuse is a laudable goal, most people with sickle cell disease are not abusers and must rely on these medications to manage severe acute and chronic pain. The ability to manage severe acute pain with an oral opioid can, in some cases, reduce the likelihood that an ED visit or hospitalization will be required for pain management. If hospitalization is necessary, it can reduce the length of the stay since patients will be able to continue managing the pain at home with the medication.

Although the goal is to stop using the opioid as soon as possible, for many people with sickle cell disease pain, five days is not a realistic time frame. Consequently, limiting an initial prescription to a five-day supply and a requirement for an additional evaluation places an unnecessary burden on people who have a legitimate need for these medications when other alternatives fail to provide relief. Such a burden will, no doubt, have an adverse impact on the patients' health, finances (due to another co-pay), and quality of life. The requirement is also burdensome to the doctor and may inadvertently discourage some primary care physicians from treating patients with sickle cell disease.

Next steps: Let Governor Christie know that patients with sickle cell disease who need an opioid prescription for acute pain should be exempt. You can contact the governor at 609 292-6000 or better yet, send a FAX to 609 292-3454. You may send your comments via email to www.state.nj.us/governor/contact/ and under "Select E-mail Topic," choose "Health."

What SCANJ is doing: SCANJ has sent a letter to Governor Christie letting him know that doctors who are treating sickle cell patients who are experiencing an acute pain crisis should be exempt from this provision. We will follow up with Governor Christie, and take further action as needed. Stay posted.

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

February Topic: Employment and Sources of Income

This month's meeting is Tuesday February 7th at NBCS 1016 Broad St. in Newark. Next month's meeting is Tuesday March 7th at the JFK Center 429 JFK Way. Willingboro, NJ. 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

Ayoola's Story of Triumph Over Pain

"What's the pain on a scale from 1 to 10" is something I've been used to hearing for the majority of my life. Nurses, doctors, family members, you name it; all asking me the same question. As if my pain was only limited to the number 10. As if 100 or even infinity could describe my distress. To them my body seemed fine. Uncomfortable and in pain of course, but just fine. No bruises, no blood gushing from anywhere, no poking bones or dislocated limbs, just fine. But to me, I knew that my body was having its own battle. One that felt like it could go on forever.

I sat there with my head down, shriveled in pain, waiting for someone to notice I was drowning in my tears. "What's the pain on a scale to 1 to 10?" I probably should have said 12. The only thing I regret is not telling my teacher the room was too cold for me to bear. I was embarrassed because I knew better, I knew I could take care of myself. I knew that I should have spoken up when I had the chance; however, I didn't want to bother anyone around me. I knew I didn't want to have any unnecessary spotlight, especially as a freshman. Now I'm in the back of an ambulance, oxygen tube in my nose, trying to stay calm. Who knew a sickle cell crisis would result in an almost two-week hospital stay, the longest ever. Growing up with sickle cell already came with its trials and tribulations that continuously tested me. And somehow any struggle I faced, I was able to handle it with a smile. I was prepared with support from loved ones, for anything sickle cell would throw in my face. Although I always had this positive outlook on life and was assured I could handle myself in almost any situation, I was nowhere close to being prepared for October, freshman year.

The biggest transition back into reality was getting out of the hospital. Even though I was stuck in my own world of discomfort, life still went on. Friends still went to school; drama still occurred; homework was still due; and parents were still parents. Yet I was not there to experience it, leaving me a "misfit" of high school. I left the hospital with no pain, but weak with unexplainable vomiting that carried on for another 7 plus days. "What's the pain on a scale to 1 to 10?" I had no answer.

Becoming the Teen Spokesperson of Sickle Cell in New Jersey (2013-2016) was one of my greatest accomplishments. It was my final year in middle school, eighth grade, and I couldn't have been more excited when my caseworker called my mom to ask if I would like to apply for the position. I learned that I would be interviewed, travel to the national convention in Baltimore, attend sickle cell events hosted by the Sickle Cell Association of New Jersey (aka SCANJ), and much more, so of course I said yes. It was June 19th, 2013, Sickle Cellabration Day, and I decided to write a poem for my application. Everyone loved my poem and on that day it was then decided that I would become the new face of sickle cell in New Jersey.

Being the Teen Spokesperson of Sickle Cell in New Jersey (2103-2016) I already knew I had one job—advocate for my disease—so once I left the hospital, the motivation to shed light on sickle cell grew. I was a new face for sickle cell, and those around me could see that this disease was not getting in the way of my success. I was able to enlighten students and adults in my school about sickle cell. My numerous presentations encouraged others to donate blood, ask questions, and even teach their family members about the disease. Because my older brother and father are also significantly affected by this disease, I've always had a passion for sickle cell. At this moment, my dream is to build hospitals in areas around the world predominantly affected by sickle cell, especially in Nigeria my birthplace, as a hematologist. Regardless of what I experienced during high school, I've never let this disease define me as a person. I always remind myself that I have sickle cell and sickle cell does not have me. I've learned that no matter what the number on the scale is, I know I will always be able to bounce back with a smile.



Ayoola and her Dad
Olu Ogunyimika

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 through June 1st. Scholarships awarded during the Sickle Cellabration on June 17th.



Register Now

www.getconnectedscd.org

