

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!

April 2013

Sickle Cell News You Can Use

Volume 4 The Sickle Cell Association of New Jersey
Issue 4 P.O. Box 9501 Newark, NJ 07104



Calendar Listings:

April

2 SCANJ Presentation, Drew University. 11:00am

15th SCANJ presents for the New Jersey Office of Minority Health - Health Equity Summit-Rutgers Center for State Health Policy. 112 Paterson St. in New Brunswick. 8:30am-12:00pm Free registration 609 292-6962

19th Irvington HS Health Fair 9:00am

21 SCDAA /Philadelphia- Dancing with The Philadelphia Stars. Crystal Tea Room Wanamaker Building. Philadelphia 5:00pm-10:00pm.

24th Liberty Science Center Free Community evening. SCANJ hosts the "Genes Genius" Game Show. Jersey City 6:00pm

25th Take Your Child To Work Day; Sickle Cell Awareness Ortho Clinical Diagnostics a Johnson and Johnson Company.

30th Power of Partnership Summit. Sponsored by Novartis, Parsippany.

SCANJ partners to offer FREE CDSMP Take Control of Your Health Six Week Community Workshops:

- **April 23** Monmouth Medical in Long Branch Tuesdays at 12pm
- **25 St. Barnabas Hospital** in Newark. Thursdays at 4pm
- **27 Alpha Baptist Church** in Willingboro. Saturdays at 9am.
- **May 7**, Orange Housing Authority in Orange. Wednesday's at 5:30pm

More workshops and programs are being scheduled. For updates or to register for programs by phone 973 482-9070. Online via sicklecellnewjersey.org calendar or scanj.eventbrite.com

SCANJ is the
New Jersey Chapter of the



A Note From The Executive Director...



Mary Bentley LaMar

You've heard the saying "you can't just talk the talk, you have to walk the walk."

At SCANJ we strive to do what we say by putting meaningful programs and services into action for the benefit of the community.

Consider our work since being founded in September of 2009. I hope that you will agree that we "walk the talk."

Walk with us. Come to our programs,

volunteer or donate. You will see our mission in action, learn valuable information and contribute to making a difference.

This newsletter has plenty of ways for you to step up. For example you could join our Walk the Talk Team for the Tackle Sickle Cell Walk on June 9th at Liberty State Park in Jersey City (pg. 2). Walk funds from our supporters will be used for joint programs for sickle cell disease in partnership with Embrace Kids Foundation.

Time is short so I will be short on words.

Let the actions speak louder. We're on a mission. ~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."

The 411 on Hydroxyurea...

The Van Vleck House in Montclair was the setting for learning. Attendees were treated to breakfast and food for thought during the Month of March for a series of Mini Workshops each Thursday.

The final workshop in the series featured Dr. Jill Menell, Chief of Pediatric Hematology/Oncology at St. Joseph's Children's Hospital in Paterson.

Dr. Menell informed the audience about the treatment for sickle cell disease that—although it's not a cure—has been shown to help reduce the frequency of pain and acute chest syndrome episodes. That treatment is a pill known as hydroxyurea.

Here are some of the facts Dr. Menell shared:

- Treatment with hydroxyurea helps the red blood cells stay round and flexible. It does this by boosting the amount of fetal hemoglobin (hemoglobin F, or HbF) our bodies produce. Doctors have observed that people with sickle cell disease who maintain higher levels of Hb F usually have fewer complications.
- Some people have been treated with hydroxyurea for over 15 years. Doctors are continuing to study the long-term effects of treatment. To date, however, no increased risk of cancer has been reported.



Dr. Jill Menell

- Studies have shown no evidence that hydroxyurea use reduces sperm count in men or increases the risk of birth defects in babies born to women taking the drug. As a precaution, however, pregnant women or women planning to become pregnant are advised to stop using hydroxyurea.
- Hydroxyurea can lower white blood cell (infection-fighting cells) and platelet (cells that help blood clot) counts, so regular monitoring is an important part of this treatment.
- The FDA has approved hydroxyurea for use in adults with sickle cell disease, but it can also be prescribed to children. Findings from a study launched in 2003 showed that it also reduced symptoms in infants and toddlers.

To learn more about the benefits and risks of this medication, speak to a hematologist other doctor with knowledge about hydroxyurea for sickle cell disease.



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April is Minority Health Month and also Poetry Month.

Roses are red, violets are blue,



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www.sicklecellnewjersey.org

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

Beverly Lucas-Editor

Highlights from the March 28th Breakfast Mini Workshop...



Shante Palmer, Projects Specialist for US Senator Frank Lautenberg, issues a proclamation from the senator, acknowledging the late Frances Thompson-Walton's role in New Jersey's sickle cell history as part of Women's History Month. 1971 Mrs. Walton founded Action for Sickle Cell Anemia, Inc., of Hudson County. SCANJ has established The Francis Thompson Walton Scholarship. The first scholarship will be awarded during SCANJ's Sickle Cellabration on June 22nd at the Garden State Discovery Museum in Cherry Hill. Scholarship guidelines and applications will be available online.



Coming

Soon:

May 22 Liberty Science Center 6:00pm SCANJ presents the Genes Genius Game Show

June 9th. Tackle Sickle Cell Walk with SCANJ's "Walk the Talk" Team. Liberty State Park in Jersey City

22nd. Sickle Cellabration and American Red Cross Blood Drive at the Garden State Discovery Children's Museum in Cherry Hill. 9:30am-2:00pm

26th SCDA Advocacy Day Washington DC. (change from April 11)

September 24-27th. SCDA National Convention, Baltimore, MD. SCANJ Road Trip

October TBA 24 Seven Line Dance Marathon, Jersey City

Join SCANJ's "Walk the Talk" Team for Tackle Sickle Cell 5K Walk

Darlene Young, VP of the Board of Directors says "Get your sneakers on." You are needed on SCANJ's "Walk the Talk" team for the Tackle Sickle Cell Walk at 10:00am on Sunday June 9th at Liberty State Park in Jersey City. We'll have fun, get some exercise and raise funds to support collaborative efforts that tackle sickle cell disease.

This walk is hosted by NFL Players and twin brothers Jason and Devon McCourty, in cooperation with Embrace Kids Foundation (EK). At SCANJ we know first hand that EK truly does what they say in support of families with blood disorders including sickle cell disease. We have partnered with EK on many SCANJ programs including the Sickle Cellabration, the Holiday Party South and the Poster Child Program.



With your support we will be able to provide more programs and services for the sickle cell community.

To join SCANJ's Team go to www.tacklesicklecell.org and when prompted specify "SCANJ Walk the Talk" team. Early registration at \$15.00 ends May 31st.

If you prefer to simply donate you can do that too. Any contribution will help! All donations are 100% tax-deductible.

Feel free to call us at 973 482-9070 for more information. We also have a sign up for our team via sicklecellnewjersey.org.