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.



#### **Calendar Listings:**



#### June

14 Walk/Run with the NFL McCourty Twins Tackle Sickle Cell 5K A Benefit for Embrace Kids Foundation. Register in advance www.embracekids.org Liberty State Park in Jersey City 9:00am

The Sickle Cell Association of New Jersey, Inc



21 SickleCellabration. A World Festival of Fun and Learning and a Be The Match Bone Marrow Drive. Garden State Discovery Children's Museum 2040 Springdale Ave, Cherry Hill 9:30am-2:00pm RSVP

FREE Take Control of Your Health Chronic Disease Self Management Six Week Community Workshops:

- June 23rd Monday's at 1:00pm In cooperation with Angela Cares. 463 Pacific Ave. Jersey City
- July 7th Monday's at 11:00am in cooperation with Gilda's Club 208 Lyons Ave. Newark

For the latest information and to *RSVP* visit www.sicklecellnewjersey.org Click on events or call 973 482-9070

SCANJ is the New Jersey Chapter of the Control of the SCANJ is the Description of the Sickle Cell Disease Association of America



Issue 6

# Say It Loud!

#### June 2014

### Sickle Cell News You Can Use Sickle Cell Association of New Jersey P.O. Box 9501 Newark, NJ 07104

## Walk Into June and "Cellabrate" World Sickle Cell Day!

In 2006 the United Nations declared June 19th as World Sickle Cell Disease Day.

> Each June we commemorate World Sickle Cell Disease Day by celebrating the accomplishments and courage

Executive Director of individuals in the fight against sickle cell disease. And the best part is we commemorate the event in SCANJ style. It's time for...

Mary Bentley LaMar

Founder

A SICKLECELLABRATION!!

Join us on Saturday June 21st from 9:30am to 2:00pm at the Garden State Discovery Children's Museum in Cherry Hill. The day will be filled with fun activities for the family, an educational workshop and a *Be The Match* bone marrow registration drive. And fix your palate now for the delicious international lunch.

At the SickleCellabration, we will select our next Teen Spokesperson and Poster Child, as well as award the 2014 recipients of the *Frances Thompson Walton* Scholarships. And please join us in welcoming the SCDAA Philadelphia Chapter and our Philadelphia neighbors to the festivities.

There are many opportunities to get together this month.

On June 14th walk or run with the **Tackle Sickle Cell 5K** and help Embrace Kids Foundation to raise funds that help the sickle cell community. Then let's move on to South Jersey for A Sickle Cellabration.

Looking ahead, we invite you to get involved in planning for the 24 Seven Line Dance Marathon. For 24 Hours September 19-20th it's on and poppin!

~Mary

## Afterwords Part 6: Myth Busting in the Emergency Department

Getting Prompt Emergency Department (ED) Care for an Acute Pain Crisis. A trip to the ED during an acute pain crisis can be a significant source of additional, unnecessary stress. In surveys, sickle cell patients report that ED staff are often insensitive, unsympathetic and generally inconsiderate.

Perhaps most important, the surveys reveal that pain is frequently undertreated, often because the ED staff mistakenly believe that patients with sickle cell disease who seek ED care are addicted to narcotic medications.

Dr. Fred Waldron, at Newark Beth Israel Medical Center's Department of Emergency Medicine, and a featured speaker at SCANJ's inaugural Statewide Symposium last November, reported that studies have shown that only about one in nine people with sickle cell disease suffer from opiate addiction—exactly the same prevalence that is seen in the general population. Clearly, the primary focus of treatment for an acute pain episode should be relief of pain, not withholding medication because of mistaken concerns about drug dependency.

In light of the concerns surrounding ED care and to ensure prompt treatment, some hospitals follow guidelines for ED management of sickle cell pain crisis based on principles established by the American Pain Society. For example, Newark Beth Israel's ED has instituted the 30-30-30 rule: within 30 minutes the first dose of pain medication should be administered,

- in the next 30 minutes, the patient should be re-evaluated and a second dose of pain medication should be administered if necessary.
- in the next 30 minutes the patient should be evaluated again and a determination made regarding discharge, admission or the need for further observation

Hospitals routinely conduct satisfaction surveys following discharge. If you feel that the care you or someone you're caring for has received was not satisfactory, don't hesitate to speak up. Your feedback can lead to improvement of care.

SCANJ applauds the efforts of the Emergency Department at Newark Beth Israel's Barnabas Health Medical Center and all ED departments who strive to deliver better care.

This concludes the *Afterwords* newsletter series to shed insight on the topics covered during the 2013 SCANJ Statewide Sickle Cell Symposium. If you are interested in planning this year's Statewide Sickle Cell Symposium contact us at 973 482-9070. The symposium takes place November 22nd at the Liberty Science Center.

#### WWW.SICKLECELLNEWJERSEY.ORG



The Sickle Cell Association of New Jersey Mailing Address P.O. Box 9501 Newark NJ 07104 EIN# 80-0474935 SCANJ is a 501c 3 agency

Phone: 973 482-9070 Fax: 973 485-6591 email: info@sicklecellnewjersey.org Inquiring Minds Want to Know...

Are you on our Email List Serve?

How about our Callingpost Program?

Did you know we will mail the newsletter to you on request?

Call or email us... Let us know you want to be included.

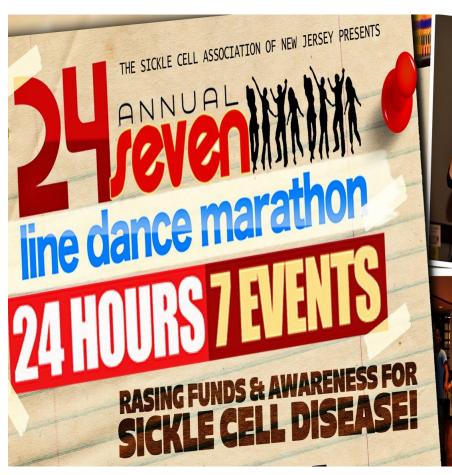
The Say It Loud Newsletter is published monthly except for July and August. Archived copies are available for download from our website. Beverly Lucas-Editor

## www.sicklecellnewjersey.org



#### GET READY FOR THE GREATEST LINE DANCE BENEFIT FOR SICKLE CELL DISEASE!

Calling all Line Dancers, school groups, community service organizations, churches, civic organizations sororities, fraternities...YOU! Join us in raising funds and awareness for sickle cell disease. September 19-20th it's ON and POPPIN!!



**Register Now!** 

## Coming Soon:

American Red Cross Community of Giving Blood Drives: July 12 Bethany Baptist Church 1115 Gibbsboro Rd. Lindenwold & July 13th Bethel AME Church 512 N. Church St. Mooresville. 1 800 RED CROSS or recrossblood.org

August 30 Kente Karpet Movie Gala. Stay posted.

September 19-20 24 Seven Line Dance Marathon at New Jersey City University Jersey City. 24 Hours 5:00pm to 5:00PM.

October 1-4 Sickle Cell Disease Association of America (SCDAA) National Convention & SCANJ Road Trip to the SCDAA National Convention Baltimore, MD