



Calendar Preview

Detailed Listings Pg. 2

September 1 Mission Day:
2 Year Anniversary of The Sickle Cell Association of New Jersey.



Volume 2
Issue 9

Say It Loud!

September 2011

Sickle Cell News You Can Use
The Sickle Cell Association of New Jersey

September

Sickle

Cell

Awareness

Month

Sign up this month to support SCANJ's

24 Seven Line Dance Marathon!

October 7-8 SCANJ 24Seven Line Dance Marathon
New Jersey City University
Host Sponsor
Friday 1pm – Saturday 1pm

Fundraiser to support services for the families affected by sickle cell disease.

A Note From the Executive Director...



Mary Bentley LaMar

There is no reason for anyone in New Jersey to remain uninformed about sickle cell disease. Why? Because YOU are armed and dangerous with the knowledge to educate and empower.

Join us in a special mission this Sickle Cell Awareness month. Use this newsletter as an arsenal to draw from, should you decide to accept this mission. *Your Marching Orders...*

- Learn more about sickle cell disease.
- Share the knowledge
- Support Sickle Cell programs
- Register now for SCANJ's 24 Seven Line Dance Marathon October 7-8th
- Support the 24 Seven by Fundraising, placing an ad, securing, or becoming a corporate sponsor (pg2)
- Volunteer for SCANJ
- Make up your own orders then ACT.

I hope you will join us on this special mission.

SCANJ Mission Statement

In concordance with the mission of The Sickle Cell Disease Association of America; "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."

Take No Prisoners!

-Mary

September is Sickle Cell Awareness Month...Educate and Empower!

What Is Sickle Cell Disease?

Sickle cell disease is an inherited blood disorder affecting the red blood cells. People with sickle cell disease have red blood cells that become hard and pointed causing blocked blood flow, anemia and pain, resulting in lung tissue damage, pain episodes, and strokes. It also causes damage to most organs, including the spleen, kidneys, and liver. Damage to the spleen makes sickle cell patients, especially children, easily overwhelmed by certain bacterial infections, resulting in hospitalization.

Who Is Affected by Sickle Cell Disease? While it primarily affects persons of African descent, it is also present in Caucasians, mostly of Mediterranean descent and Hispanics. Sickle cell disease also appears in Middle Eastern countries and Asia. It is estimated that over 80,000 people have sickle cell disease in the United States and over 4,000 people live with sickle cell disease in New Jersey.

Why Is It Called Sickle Cell? Many red

blood cells in people with sickle cell disease look like the sickle, a tool used by farmers.

How Does A Person Get Sickle Cell Disease?

The gene that causes sickle cell disease is called the S gene. If a person gets one S gene from one parent and one S gene from the other parent, they will have two S genes or SS. If they got the S gene from one parent and a gene for different abnormal hemoglobin from the other parent, they would have another form of sickle cell disease.

Is There A Cure? There is hope for a universal cure through the bone marrow transplant which has been successful with a few patients, including our teen spokesperson. Bone marrow transplants are not yet widely available.

What is Sickle Cell Trait? Sickle Cell Trait means that you carry the gene for sickle cell disease that can be passed on to your children, if your partner also has sickle cell trait or the trait from another hemoglobin disorder. A person gets

sickle cell trait the same way they inherit the color of their eyes or hair...through the genes that their mother and father pass on to them. Sickle cell trait is not an illness. People with sickle cell trait are healthy. Sickle Cell trait can never turn into Sickle Cell Disease.

What Should a Person with Sickle Cell Trait Do? In planning a family it is wise to ask your partner to be tested in order to understand what the possibilities are for your baby to have sickle cell disease. Teens and adults should be tested to see if they carry the gene for sickle cell disease.

What Can You Do To Help? Support the mission of the SCANJ.



Poster Child, Sanaa, is on her way to the national SCDAAC convention in Memphis!

Turn for Page 2...



Teen Spokesperson, Amanda Speaks about Sickle Cell Disease..

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YOU CAN BRING IT!

Support the

24 Seven Line Dance Marathon!



Registration by mail or online at

www.sicklecellnewjersey.org

To raise funds and awareness for sickle cell disease.

Say It Loud Newsletter

Beverly Lucas-Editor

September Calendar Listings:

1 Mission Day: 2 Year Anniversary of The Sickle Cell Association of New Jersey.

8 Medical Grand Rounds The Central and Northern NJ Sickle Cell Medical Advisory Board presents Stephen Pemberton PhD "The Rise and Fall of an Invisible Malady: SCD Historical Perspective and Racial Health Care Disparities." 8:30 am. Beth Israel Hospital, 201 Lyons Ave, Newark

9 Line Dance Lessons with Kenny J. Practice for 24 Seven at the Symphony Hall, Terrace Ballroom. 1030 Broad Street, Newark FREE from 5 pm- 7pm. \$10. admssion after 7 pm. Dinners, drinks and games available.

10 AKA Educational Advancement Foundation Breakfast. SCANJ Founder & Executive Director, Mary Bentley LaMar is an honoree. 10:30am Sheraton Hotel, Edison. \$50.00

NBIMC Health Fair 11am-3:00pm 201 Lyons Ave, Newark booths, give-aways, screenings, food, family activities. FREE

16 Friday Night at the Movies and Sickle Cell Awareness Discussion. SCANJ in cooperation with Jersey Medical Center Emergency Medical Services presents the Feature Film: "A Warm December" The first major film to include a lead character with sickle cell disease. Jersey Medical Center EMS Headquarters 6:30pm 415 Montgomery Street Jersey City, NJ 07302. Warm up with a short line dance lesson. FREE

17 Impacting Your World Christian Center -Darlen Lyles Sickle Cell Awareness Red Cross Blood Drive and Health Fair. SCANJ workshop on sickle cell disease and the importance of minority blood donations. 8:00am-3:00pm. For appointment go to redcrossblood.org and enter sponsor code 15324 or call 1 800 26-BLOOD. 2901 Chapel Ave in Cherry Hill FREE

Donna T. Darien Memorial Foundation "Let's Walk About It" Weequahic Park, Newark 10 am. Go to dtdsicklecell.org for info.

Burlington County Faith in Wellness Health Fair. Booths, kids activities and workshops. 429 JFK Parkway in Willingboro 12 noon -4 pm FREE

Central Northern NJ SCD Network Bowling Party. Brunswick Zone 629 Washington Belleville 5pm FREE Please RSVP sicklecellanj@gmail.com or call 973 482-9070.

22 New Jersey City University (NJCU) Campus Kick Off for 24Seven Marathon as part of Club Day Host Sponsor, NJCU, 2039 Kennedy Blvd, Jersey City

23 American Red Cross-Penn/Jersey Region Sickle Cell Donor Recognition Breakfast. Keynote speaker, SCANJ Founder & Executive Director Mary Bentley LaMar . ARC Headquarters, Philadelphia, PA 9:00am

24, Central Northern NJ SCD Network Skating Party Branch Brook Park Roller Skating Rink. 11am Newark RSVP

25 Embrace Kids Foundation Heel to Heal Walk Johnson Park, Piscataway 9:00am Go to embracekids.org to register.

26 State of New Jersey Health and Senior Services' Chronic Disease Self Management Master Trainer's Meeting. SCANJ's Founder, Executive Director and CDSMP Master Trainer, Mary Bentley LaMar is invited panelist. SCANJ recognized for best practices. Princeton

September 27-October 1, National SCDA Convention . Poster Child, Sanaa Johnson and Teen Spokesperson Amanda Salazar will attend as Goodwill Ambassadors for SCANJ at the convention. SCANJ will be presenting on Chronic Disease Self Management at the convention. Memphis, Tennessee

October 7-8

SCANJ 24 Seven Marathon!

24 Hours of Fun, 7 Events

Join us as we attempt to set a Guinness World Record, line dancing for sickle cell disease!!

New Jersey City University. Student Union Building 2nd Floor. 2039 Kennedy Blvd. Jersey City. Call or email us for a registration form, or go to our website. This event is made possible in part thanks to the generous support of our host sponsor New Jersey City University.

14 Minority Association of Pre Health Students at Princeton University "Dance Vs. Disease" to Benefit the Sickle Cell Association of New Jersey. 6:30pm Princeton

24 Seven Schedule

Friday October 7th

12 noon Check In/ Registration

1pm Line Dancing

(24 Hrs)

Donations Collected

(24 Hrs)

Community Service Fair
(24 Hrs)

Live & Learn Health Fair
(24 Hrs)

Phone A Thon (24 Hrs)

3pm-5pm SCD Workshops

6 pm Dinner Par-tay

7pm Movies

Silent Auction

10 pm Laugh A Thon

Midnight Band Jam

Saturday October 8

Cards, Wii, Dominoes, Games

2 am Pizza and Wings Fling

6am Stretch and Exercise

7 am Breakfast

11am Awards Recognition and Acknowledgements

1pm Celebration Closing

Schedule is subject to change.