

Volume 2
Issue 11

Say It Loud!

November 2011

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

Calendar Listings:

November

5th Health Fairs:

NCBW Bergen/Passaic and The Links at the Hilton in Hasbrook Hgts. 8:30am-3pm

Alpha Baptist Church Annual Wellness Day. American Red Cross Sickle Cell Blood Drive 15 Rose Street in Willingboro. 9am -3pm

7-8th Hemoglobinopathy Learning Collaborative. HRSA Sponsored. Rockville MD. SCANJ's Executive Director, Mary Bentley LaMar, to attend with Newark Barnabas Health Sickle Cell Demonstration Treatment Project.

8th Election Day. VOTE

12th Plainfield Community Health Fair at Barack Obama Charter 209 Berckman St. Hosts AKA Sorority, Theta Phi Omega & Phi Eta Omega Chapters, Alpha Phi Alpha Fraternity and the NCNW Plainfield 11am-1pm

19th Thanks for Giving Concert postponed. In the spirit of the season we encourage you to donate at an **American Red Cross Sickle Cell blood drive.** Go to redcrossblood.org.

30th Volunteers Think Tank Meeting. Catchings Community Suite adjacent to the Glenfield Middle School 25 Maple Ave (corner of Maple and Bloomfield Ave) in Montclair. Help plan SCANJ programs and services. **6:30pm**

December 10, SCANJ Holiday Party -Van Vleck Mansion 21 Van Vleck St. Montclair. RSVP by December 9th online or 973 482-9070. Free for families effected by sickle cell disease. **3pm-5pm**

Updates on sicklecellnewjersey.org and Eventbrite.com

A Note of Thanks From the Executive Director...



Mary Bentley LaMar

The 24 Seven Line Dance Marathon was a Success! On October 7-8, for 24 hours (or parts thereof) we danced, laughed, learned, and contributed to fight sickle cell disease with the first ever 24Seven Line Dance Marathon.

We're especially grateful to our Host Sponsor, New Jersey City University (NJCU). NJCU's Office of Community Service, Student Government Organizations and Greek Organizations, were instrumental in planning, providing volunteers, promoting and donating. We would not have been as successful without such great help from NJCU. Thanks for helping to raise over \$13,653.00!

And pledges are still coming in.

It's not too late to donate.

Sickle cell disease can have a devastating effect on those who suffer from this life threatening inherited blood disorder. The funds raised support our mission as we strive to strengthen our delivery of help, education and advocacy for those living with sickle cell disease.

A great way to see our mission in action is to get involved with SCANJ. We have numerous opportunities for you to participate or volunteer. For example, on Wednesday November 30 at 6:30pm you're invited to come out for a Volunteers Think Tank Meeting, Glenfield Middle School Catchings Suite 25 Maple Ave in Montclair. We value your thoughts as we plan for 2012.

Coming up December 10th is our Annual Holiday Party at the Van Vleck Mansion in Montclair.

Back by popular demand is "Kenta Klaus...Santa's brother from another mother" and Toyland. At this festive gathering we will present the Dr. Charles F. Whitten Awards to those who have done outstanding work for sickle cell disease. This is a joyous occasion for you and your family. Just remember to RSVP.

We have even more reason to be thankful. We recently were selected to receive a grant from the NYMAC Consortium on Genetic Diseases. The funds will help us to upgrade and increase our outreach, including providing Spanish language materials.

I won't ever run out of a reason to say thank you. Your support of our efforts continues to put the words in my mouth.

~Mary

The 411



Joyce Jones working the Phone A Thon

24^{1st} ever SEVEN™ line dance marathon



We may not have made a Guinness World Record, but we sure partied with a purpose while trying.

147 participants (pg 2) line danced everything from the Electric slide to the Hokey Pokey. Comedians Jeff Goff and Gina Brillon (from Comedy Central) kept us laughing. Poster Child Sanaa and Teen Spokesperson Amanda kept us inspired.

The Health Fair provided information from the SC Center at Barnabas Health, Jersey City Medical EMS, Horizon NJ Health, Dress For Success, The American Red Cross, Healthfirst and SPANNJ. We reached out to the community with the Phone A Thon. We ate great food, watched movies, learned about sickle cell disease, played games, got sleepy (3:30am), danced with Beyonce on You Tube, ate breakfast then finished strong with The Sickle Cell Stomp.

Kudos to our Event Awardees

Highest Fundraising Teams

(up to event) **"Team Back Up" \$689.00**
(post event) **Minority Association of Pre Health Students of Princeton University \$2,529.15**

All Knight Long Award

For the student who exemplifies the spirit of the 24 Seven by actively serving and fundraising for the longest time during the event. **NJCU Student, Sharde Lloyd**

The Endurance Awards

For the team(s) that actively participated for the longest times during the event.

NJCU All Knight Long Student Government Organization Team (24 Hrs)
The Masters School Team (20 Hrs)

The Record Setter Award

For the individual who exemplifies the spirit of the 24 Seven by actively participating and fundraising. **Joyce Jones of the D-10 For Passion Team**

Thanks to Corporate Sponsor Chair, Darlene Young and Co-Chair Olga Barnwell. & Robert Quinones NJCU's, Dir. Community Service.

Thanks to our Corporate Donors: Cabaret For Life
Embrace Kids Foundation
Kaplan Test Prep
Mother's Kitchen of Burlington
Trader Joe's

Special Thanks to Teams:

All Knight Long-NJCU
AKA Sorority, Rho Phi Chapter
Amanda's Dancers for Awareness
D-10 Fighting With Passion
Delta Sigma Theta Sorority, DZ Chapter
Jersey City Nupes & Kappa League
Lambda Theta Phi Latin Fraternity
Lambda Tau Omega Sorority
Step Cutters For Cause
Team Back Up
The Master's School Team

24 Seven Total to Date \$13,653.00!

SCANJ

P.O. Box 9501 Newark NJ 07104

EIN# 80-0474935 SCANJ is a 501c 3 agency

Donations are tax deductible.

Phone: 973 482-9070 Fax: 973 485-6591

email: sicklecellanj@gmail.com

Thank You Ewing Councilman, Kevin Baxter...

For consistently being a staunch advocate for the community. Your service as Chair of our Advocacy Committee and as a Master Trainer for our Take Control of Your Health Community Workshops is greatly appreciated. We applaud your commitment to bettering the lives of your fellow citizens.



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

www.sicklecellnewjersey.org

Beverly Lucas-Editor



Scenes from the First Event

24 Seven Line Dance

Marathon



Enhancing Jersey City Medical Center Emergency Medical Services



Say It Loud! About Sickle Cell Disease



Single Ladies?

October 7-8, 2011

New Jersey City University



Laugh a Thon



Let the Games Begin!



Phone A Thon

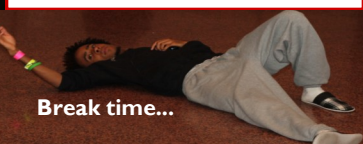
Thank You Researchers. Your Work Brings Hope.

If you are living with sickle cell disease, consider these opportunities to participate in research studies for sickle cell disease.

The Phase III Trial for L-glutamine is a clinical trial for persons ages 5+ with sickle cell anemia or sickle beta zero thalassemia. L-glutamine is an amino acid that may be found in the foods we eat. It is being tested to see if it can lessen the painful effects of SCD. For information, please call the Sickle Cell Disease Foundation of California at (310) 693-0247 or email info@scdfc.org.

UC San Francisco is conducting research on chronic pain in adults (18+) with SCD. This is a survey/questionnaire and each participant will receive a \$20 gift card upon completion. For more information please contact Lou Ella (Kitty) Taylor, RN, CNS, PhD(c) at (510) 909-5972, call (415) 476-9407 or email at louella.taylor@ucsf.edu.

Sejal Patel, MA, doctoral candidate, is conducting research on Factors related to the Sexual Behaviors of Adolescents with Sickle Cell Disease. The purpose is to find out more about how the sexual activity of adolescents with sickle cell disease compares to those without. Participants ages 13-21 with and without sickle cell disease are eligible for this study. Participants will help the researchers understand how to improve teens chances of making safe sexual choices. For more information contact Dahra Williams, PhD. Department of Psychology, LaSalle University, fingerhut@lasalle.edu. or call 215 951-1284,



Break time...