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:

December

7th Breakfast With Santa Courtesy of NY Jets' Santonio Holmes Third and Long Foundation. Saturday 8:30am-10:00am. Applebees Newark

SCANJ Holiday Parties with Kenta Klaus; Santa's Brother From Another Mother Festive games, gifts for the family, food and fun. FREE, but you must RSVP online or call our office. Three locations statewide:

(North) 8th Sunday, 3:00pm-5:00pm Van Vleck House 21 Van Vleck Street in Montclair

(South) 12th Thursday 6:00pm-8:00pm Garden State Discovery Children's Museum 2040 Springdale Ave in Cherry Hill

(Central) 14th Saturday 5:00pm-7:00pm Howell Bowling Lanes, in Howell.

11th Holiday Dinner Benefit and Toy Drive for Sickle Cell. Hosted by Looch and Rasheed S. 5pm-7pm. Kings Restaurant 327 Lyons Ave in Newark. \$25.00

12th, 13th, 16th & 17th. Chronic Disease Self Management Program (CDSMP) 4 Day Peer Leader Certification Course. Living Springs Residential Center in Delanco. Capacity is limited. Register now.

January, 2014 Take Control of Your Health Chronic Disease Self Management Workshops Series, part of the Stanford School of Medicine CDSMP program, Stay posted for details on how to attend this empowering program offered by SCANJ.

> SCANJ is the New Jersev Chapter of the



Sickle Cell Disease Association of America



Volume 4 Issue IO

Say It Loud!

December 2013

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

Season's Greetings From The Executive Director



Thanks to all who helped make our Inaugural Statewide Sickle Cell Symposium a success! I am thrilled with the results (see below).

We concluded the symposium with our annual Thanks For Giving Award Program where we honor those who have done outstanding work to improve the lives of others with sickle cell disease. Join us in congratulating this year's Dr. Charles F. Whitten Awardees; The Independent Club of Colonia-Mr. Phillip Hall, President-Community Service, Shiloh Baptist Church Newark-Malachia Brantley, Jr., M DIV Pastor- Sickle Cell Sabbath Partner.

Mr. Haywood Barnes of Barnabas Health-Health Care Professional, Ms. Hermeline Blanc-Volunteer, and Mrs. Chevalle Phillips- Advocate.

There are still a few weeks left in 2013. Let's make the most of it. Register for the Chronic Disease Self Management Peer Leader Certification 4 Day Class. And you're invited to celebrate the season by attending one of our Holiday Parties with Kenta Klaus. Be sure to **RSVP** online or call for the location nearest you.

Happy Holidays. We wish you JOY!

~Mary



Symposium Highlights!

The Liberty Science Center was the place to be for SCANJ's first statewide Sickle

Cell Symposium. We welcomed over 120 guests to a day filled with informative presentations, engaging conversations, research, museum exploration, connecting with others and connecting with oneself. With the help of the Big Apple Playback Theatre, we told the story. For those who were there, we need you to tell the story to others. Good news should travel fast!

Much appreciation to the planning committee and the sponsors: Embrace Kids Foundation and Tackle Sickle Cell. Thanks to the presenters: Dr. Wanda Whitten-Shurney,SCD 101; Dr. Fred Waldron-Emergency Room; Dr. L. Krishnamurti- Bone Marrow Transplants; Kunal Sanghavi, MBBS-Genetics; Ansley W.

LaMar, Ph.D.-Youth Connection Treasure Hunt; Darlene Young and Margaret Hadnott -Introduction to the Chronic Disease Self Management Program. **On to November 22, 2014!**

Sickle Cell 101

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nappen to have (le Cell Disease











The Sickle Cell Association of New Jersey Mailing Address

P.O. Box 9501 Newark NJ 07104

Phone: 973 482-9070 Fax: 973 485-659 I NEW! email: info@sicklecellnewjersey.org Thanks to all who supported the 24 Seven Line Dance Marathon; 24 Hours raising funds and awareness for sickle cell disease. We raised over \$8,000.00 as of this writing.

We're gearing up now for the 2014 24 Seven. With your help we can greatly increase our fundraising. With increased funding we will be able to strengthen our current programs and build a foundation for increased services.

If you would like to be on the planning committee for the next 24 Seven Line Dance Marathon please contact our office. We welcome your involvement.

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

Beverly Lucas-Editor

Tax deductible donations accepted by mail and via www.sicklecellnewjersey.org



2013 End of The Year Report: Wouldn't Take Nothing For My Journey Now

This has been an amazing year! We have continued successful programs, met some challenges with fundraising and we have successfully tried new initiatives. Most importantly, we have stayed on our mission. When you look below to see some of the accomplishments this year, please see yourself. Without you, we could not do this. Thanks for your walk along the journey.

- Conducted Take Control of Your Health (CDSMP) Peer Leader Certification and 6 Week Community Workshops
- Presented at numerous Health Fairs and Programs
- Say It Loud! Outreach through monthly newsletters, www.sickle cellnewjersey.org, social media and telephone calling post announcements.
- Conducted 3rd Annual WBLS Radio/Omega Psi Phi/ SCANJ, American Red Cross Blood Drive at New Jersey City University
- Established the Frances Thompson Walton Scholarship and awarded \$1,500.00 in scholarships
- Established Thursday's in March Breakfast Mini Series Workshops on SCD. Concluding workshop on Hydroxyurea
- Presented on SCANJ's SCD outreach programs for the NJ Office Of Minority and Multi Cultural Health
- Partnered on community outreach through McDonalds Restaurant (Grand Street) in Jersey City
- Invited to the regional meeting of the New York Mid Atlantic Consortium for Genetics and Newborn Screening (NYMAC) to present on SCANJ's Say It Loud! Outreach Video; a project funded by NYMAC.
- Partnered with Embrace Kids Foundation and NFL's McCourty Twins for the Tackle Sickle Cell 5K Walk.
- Sponsored SCANJ Road Trip to the SCDAA convention.
- SCANJ presentations at the SCDAA Convention
- Advocated on Capitol Hill for Sickle Cell Funding

- Partnered with the SCDAA Philadelphia/Delaware Valley Chapter for the Sickle Cellabration and American Red Cross Blood Drive in Cherry Hill, NJ
- Partnered with Johnson and Johnson for Take Your Child to Work Day that included awareness and build a trike and bear service for children with sickle cell disease
- In cooperation with Host Sponsor New Jersey City University, hosted the 3rd Annual 24 Seven Line Dance Marathon; 24 hours with 7 major events raising funds and awareness for sickle cell disease.
- Selected Ayoola Ogunyimika as 2013-2014 Teen Spokesperson for the SCANJ. Ayoola attended the national SCDAA convention and appeared on NY Jets TV with Jet's star, Santonio Holmes.
- Worked with Santonio Holmes Third and Long Foundation's Strikes for Sickle Cell and Breakfast with Santa to involve families affected by sickle cell disease.
- Established and implemented the first Statewide Sickle Cell Symposium at the Liberty Science Center.
- Continued service on the American Red Cross board, The Central and Northern New Jersey Sickle Cell Network, NYMAC and national committees of the SCDAA.
- Hosting December Holiday Parties with Kenta Klaus in 3 locations throughout the state. Each party features a Toyland sponsored largely through donations from the National Organization of Black Law Executives; the Northern and Central New Jersey Chapters.

The children remind us that the 'Best is Yet To Come...'





Please Remember SCANJ In Your Year End Giving We are a 501c3 Organization

SCANJ's Wish List for Kenta Klaus:

- Volunteers
- Funds or in kind service for renovating the office
- Gas Cards
- Operating Funds
- Corporate Sponsorship for Sickle Cellabration, Statewide Symposium 24 Seven Line Dance Marathon Kente Karpet Movie Gala SCANJ Road Trips

A Universal Cure For Sickle Cell Disease