

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.



Volume 4  
Issue 9

# Say It Loud!

November 2013

Sickle Cell News You Can Use  
The Sickle Cell Association of New Jersey  
PO Box 9501 Newark, NJ 07104



## Calendar Listings:

### November

**2nd Health Fair** hosted by Alpha Kappa Alpha Sorority Beta Alpha Omega Chapter, 9:00am-3:00pm Metropolitan Baptist Church, 149 Springfield Ave. Newark

**5th Election Day. VOTE!!**

**21st American Red Cross Blood Drive.** 8:00m-2:00pm Willingboro HS, Willingboro. Appearance by Ayoola Ogunyimika, SCANJ Teen Spokesperson.

**23rd Statewide Sickle Cell Symposium at the**



**Saturday 8:30am-2:30pm**

222 Jersey City, Blvd. Jersey City, NJ Continental Breakfast, Keynote Address, Workshops, Lunch and Learn, Big Apple Playback Theatre and Dr. Charles F. Whitten Awards. **Pre-registration is FREE prior to Nov. 23rd.** Event day registration is \$25.00, so we highly recommend that you to register in advance.

### December

**Holiday Parties with Kenta Klaus (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) Details TBA** Howell

**RSVP Required**

SCANJ is the  
New Jersey Chapter of the



Sickle Cell Disease Association  
of America

## A Note From The Executive Director...



Mary Bentley LaMar

Thank YOU New Jersey City University!

In this season of Thanksgiving, and always, we are grateful for the wonderful support of New Jersey City

University, host sponsor for our annual 24 Seven Line Dance Marathon.-24 hours with 7 events- raising funds and awareness for sickle cell disease.

This year's marathon, held October 25-26th, raised over \$6,000. Donations are still coming in so we're pushing to get past \$10,000. Thanks to everyone who danced, educated, staffed the phone bank and donated. And thanks in advance to all who are sending in donations. It's not too late to support our mission.

Stay posted for the final report on the 24 Seven in the December newsletter.

We tend to have fun at the SCANJ. Our programs are designed to inspire, educate and bring people together. Making the work enjoyable helps keep our spirits up when dealing with such a devastating disease. But please make no mistake...we understand that sickle cell disease is no joke. That is why we work hard to make a positive difference in the lives of individuals who are living with sickle cell disease.

Part of our mission is to improve the care and treatment of individuals living with sickle cell disease. With that in mind, we are excited to invite you to our first Statewide Sickle Cell Symposium. It takes place Saturday, November 23rd at the Liberty Science Center in Jersey City (see below).

Pre-Registration for the Symposium is FREE. Space is limited so I encourage you to call or go online now to register. Registration is also open for our December Holiday Parties with Kenta Klaus (see calendar listings).

I had the honor of working with the Sickle Cell Disease Foundation of California several years ago. That experience was part of my inspiration to establish the SCANJ. Please read the article Sickle Cell Disease is No Joke - Part I. It is reprinted with permission (pg. 2). Be encouraged.

~Mary



## The Sickle Cell Symposium Is Here!

Join us at the Liberty Science Center on Saturday, November 23rd from 8:30am to 2:30pm. The Sickle Cell Association of New Jersey, with the support of Embrace Kids Foundation and the McCourty Twin's Tackle Sickle Cell, will host the first Statewide Sickle Cell Symposium.

If you, or someone you love, are dealing with sickle cell disease, or have sickle cell trait, the symposium is your opportunity to learn and get your questions answered. It is suitable for anyone affected by sickle cell disease, all health care professionals who provide care for patients with the condition from infancy to adulthood (including private practice physicians, hospitalists, ER staff, nurses, social workers, medical students) and the community at large.

We promise you a highly engaging and informative day that includes continental breakfast, lunch, museum admission (after the workshops) and a performance, exclusively for us, by New York's Big Apple Playback Theatre. We will conclude with the *Dr. Charles F. Whitten Awards* honoring outstanding service. This year's 'Whitten' Honorees are; Mr. Haywood Barnes, Ms. Hermeline Blanc, Mrs. Chevalle Phillips, Shiloh Baptist Church of Newark and The Independent Club of Colonia.

The Symposium is FREE if you're Pre-registered so register early via [www.scanjsymposium.eventbrite.com](http://www.scanjsymposium.eventbrite.com) or the events page on our website. Or call our office 973 482-9070.

### Symposium Schedule:

8:30am Welcome Continental Breakfast

- **Keynote Address** at 9:00am Dr. Wanda Whitten-Shurney, CEO and CMO of the SCDA-Michigan Chapter and Pediatric Hematologist at Detroit Children's Hospital. -**Sickle Cell Disease 101; Latest Developments**
- **Dr. Fred Waldron**, ER Physician, St. Barnabas Medical Center, Newark--**Emergency Room.**
- **Dr. Lakshmanan Krishnamurti**, Pediatric Hematologist, Children's Hospital of Pittsburgh, PA - **Bone Marrow Transplants**
- **Kunal Sanghavi, MBBS**, Institute of Genetic Medicine - John Hopkins University, Baltimore, MD/ Patient/ Family Project-New York Mid Atlantic Consortium on Genetic and Newborn Screening-**Genetics**
- **Ansley W. LaMar, Ph.D.**, Psychology professor at New Jersey City University, SCANJ Board Chair and Director of Superkidz Kamp- **Youth Connection**
- **Big Apple Playback Theatre**
- **Lunch and Learn** Presenters from the workshops, SCANJ, The American Red Cross and Be The Match.
- **Dr. Charles F. Whitten Awards**



**The Sickle Cell Association of New Jersey**  
**Mailing Address**

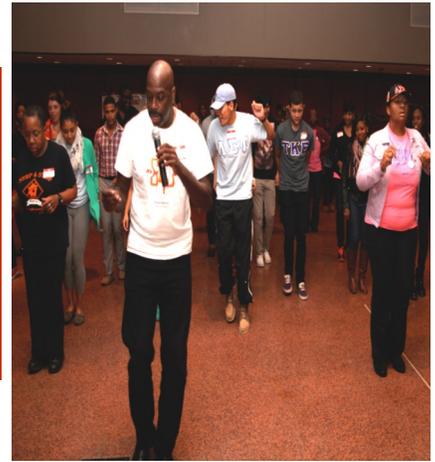
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**NEW! email: [info@sicklecellnewjersey.org](mailto:info@sicklecellnewjersey.org)**

**Shout Out of Thanks to Douglas Hawkins and the Step 4 Step Line Dancers.**

We learned a few steps as we line danced for sickle cell disease.



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

Beverly Lucas-Editor

**SCANJ is a 501c3 Organization Tax deductible donations accepted by mail and via [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)**

## Sickle Cell Disease Is No Joke- Part 1

*(The following article is reprinted with permission from the Sickle Cell Disease Foundation of California)*

Children at camp, smiling faces, wiggling bodies moving to the beat of the latest dance, that's what you see from Camp Crescent Moon, it's our way of looking on the bright side of sickle cell disease, it's our way of being in denial. But today we have to tell you what many of you already know, **"sickle cell disease is no joke, it can be a cruel, relentless, destructive disease."**

The Christmas season has begun and the Sickle Cell Disease Foundation of California is participating in its annual toy and gift card drive. I'm going to tell you about three families who will have a very difficult time this Christmas. No amount of toys or good wishes will lessen their grief for they have lost a loved one to sickle cell.

The first family lost their six-year-old son. He was to receive a bone marrow transplant from his baby brother. Luckily the young brother was a match and the parents and doctors thought that the transplant would spare their son from the ravages of the disease, the pain crises and potential strokes. During the transplant something went wrong and after 27 days of pain and fever the child died. The second family had brought their son through the difficulties of childhood and adolescence. He had begun to live on his own, but like many young adults with sickle cell, he died after the transition to adult care. Like many young adults, he thought he was invincible. He died at twenty-three.

The last family is that of our CEO Mary Brown. Her brother-in-law, Wayne Ragin has just lost his battle with sickle cell disease. Wayne was a graduate of Howard University and worked as a human resource specialist. He had three children, all college grads and worked as much as he could on the Obama 2008 campaign. Although he was able to lead a successful life, the last seven years have been crippling. Sickle cell disease can destroy every organ in the body and in Wayne's case it was his kidneys. He suffered through years of dialysis, both at home with his wife Patrice his caregiver, and at the hospital. The final assault came from a stroke and then cardiac arrest.

Other families are breathing a sigh of relief this year. The surgery to remove the spleen went well for one nine-year-old, and he is able to go longer between transfusions. Another young woman is doing well after her third hip replacement and literally months in the hospital and ER.

This is the good news but we have to ask, was there anything that could have lessened the suffering and lengthy hospital stays? Are we devoting enough time and resources to develop new treatments that can reduce the devastation of this awful disease? We ask ourselves these questions at the Sickle Cell Disease Foundation of California we want to: improve the lives of patients and families afflicted with sickle cell disease

- provide additional education and training for doctors and nurses through local and national conferences
- provide education and awareness to the general community who may be at risk to have a child with sickle cell disease
- encourage young adults to obtain regular medical care when even if they are not in pain
- advocate for better medical care, awareness and education on sickle cell disease and sickle cell trait, and lastly
- we want to provide support for families that know first hand that **"Sickle Cell Disease Is No Joke."**

~Sincerely, Nancy Rene' Vice Chair SCDFA Advocacy *First Published Nov. 29, 2012*



**Research shows that the more you know about your health conditions, the better your health outcomes.**

**Empower yourself and others with knowledge at the Statewide Sickle Cell Symposium.**

**The Symposium is made possible, in part, thanks to our Premier Sponsors**

