

Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard and pointed which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings

December 11, Holiday Party-Van Vleck Mansion 21 Van Vleck St. in Montclair. RSVP by December 9th 973 482-9070. Special appearance by Kenta Klaus. Toy donations accepted in advance at 20 Northfield Ave West Orange-Law office of Connie McGhee

30 Say It Loud! Conversations on Sickle Cell Disease Dial 1 712 432-0080 Pass code 490765# at 12:30 p.m. or 6:30 p.m. EST. Topic: Sickle Cell Trait? Get it Straight!

January 8, 2011 Take Control of Your Health Workshops Series, part of the Stanford University CDSMP program, Begin January 8, 2011 and run each Saturday through February 12, 2011. Locations: **JFK Community Center** 429 JFK Parkway in Willingboro **9:00am-11:30am OR Shiloh Baptist Church**-RD Spain Center 102 Davenport Ave in Newark **2:00pm-4:30pm**. The series is free, however, enrollment is limited so call now to be part of this empowering program offered by SCANJ.

SC Advocacy Day at the Capitol Planning Committee Call Kevin Baxter, Chair, if you would like to serve on this committee. 609 477-9092

SCANJ teams up with The American Red Cross to promote a Sickle Cell Scholarship Contest for High School Students. Deadline is March 31st, 2011. Contact SCANJ for more information.

Important Dates:
December 11, 2010
January 8, 2011
March, 24, 2011



Say It Loud!

December 2010

Sickle Cell News You Can Use

Volume 1
Issue 4

The Sickle Cell Association of New Jersey

A Note from the Executive Director...



Mary Bentley LaMar

Our Mission

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.."

Please read the report below and you will see that The Sickle Cell Association of New Jersey has been diligently working to fulfill our mission. We ask for your help. No matter the amount, your contribution makes a positive difference for those affected by sickle cell disease. Please give a donation today.

End of The Year Report

As the conclusion of our first full year of operation draws near, we are pleased to report that since being established in September of 2009 we have been able to:

Create the New Jersey Sickle Cell Poster Child and Teen Spokesperson Program and secure sponsorship to cover all expenses to attend the Sickle Cell Disease Association of America (SCDAA) convention.

Offer the State of New Jersey *Take Control of Your Health* Workshop Series (part of Stanford University's Chronic Disease Self Management Program) with state certified trainers; Kevin Baxter, Mary Bentley LaMar and Darlene Young.

Create *Say It Loud! Conversations on SCD*; quarterly nationwide teleconferences on topics related to sickle cell disease.

Conduct and support blood drives in honor of the late Dr. Charles Drew, African-American medical history maker who developed the blood bank in 1940.

Educate the community through special events such as *The Meet & Greet, A Sickle Cellabration, the Thanks For Giving Concert, SCANJ 2010 Road Trip to Bethesda MD* and the *December Holiday Party*.

Present a workshop at the 2009 SCDAA Convention in Orlando Florida and a poster presentation at the 2010 SCDAA Convention in Oxen Hill Maryland.

Increase awareness through newsletters, brochures, calling posts, email, teleconferences and health fairs.

Arrange for scholarships to help promising students with sickle cell disease.

Serve on the American Red Cross Penn-Jersey Region Sickle Cell Donor Advisory Board.

Serve on the Central-Northern New Jersey Sickle Cell Medical Advisory Board for Newark's Beth Israel Hospital Adult Sickle Cell Center and provide the chair for its Public Awareness and Advocacy Committee.

Partner with, and/or support, sickle cell services in New Jersey such as Embrace Kids Foundation, UMDNJ Hospital, Robert Wood Johnson Hospital, Hackensack Tomorrows Children Institute and Newark Beth Israel Hospital.

Assist in facilitating emergency services for families affected by sickle cell disease.

Advocate on Capitol Hill Washington DC with the SCDAA for federal legislators to support efforts to increase resources for people with sickle cell disease.

Initiate a support group to provide emotional and practical support and treatment information.

Host a Road Trip for families affected by Sickle Cell Disease to attend the James B. Herrick Symposium on Sickle Cell Disease at the National Institutes of Health in Bethesda Maryland.

Honor Dr. Alice Cohen, Embrace Kids Foundation, Ediom Utuk, Kevin Baxter and Regina Cruz Burden with the Dr. Charles F. Whitten Awards for outstanding service.

Turn for Page 2...



OUR WISH LIST:

- Donated or low cost office space
- Volunteers
- Events Sponsorship
- Toys for the Holiday Party
- Gas Cards for transportation assistance
- In Kind Services
- Financial contributions

EIN# 80-0474935 We are a 501c 3 agency

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Thank You

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“SCANJ equals faith with good works for sickle cell disease.”



Pictures from the SCANJ 2010 Road Trip to the James B. Herrick Symposium at the National Institutes of Health, Bethesda, MD

The “Say It Loud” newsletter is published monthly. It is a communication tool that we hope you will use to stay informed and involved. Please read it and give us your input.

—Beverly Lucas-Editor

Ediom Utuk attended the SCANJ 2010 Road Trip to the James B. Herrick Sickle Cell Symposium at the National Institutes of Health in Bethesda Maryland. The following are her thoughts on the experience: Debrief 11.17.10

How is it that a disease that affects so many (both directly and relationally) seems so overlooked by the general population? How do we challenge our communities to raise the "bombastic bullhorn of awareness" so that our movement can be heard all over the world?

Are we as both as a collective and as an individual the common dam that stymies the flow of Sickle Cell Disease (SCD) awareness to those around us? How can we break our personal levies and allow the river of information to flood the population?

As challenging as these questions may be, they are the driving force inspiring me to work towards creating a 180 degree change of thought and behavior on how we as a community view and support SCD initiatives! I ask myself these questions daily to both prevent complacency and also to remind myself that with research, facts, and faith they can and will be answered.

Attending the James B. Herrick Symposium- "Sickle Cell Disease Care and Research: Past, Present, and Future" at the National Institute of Health on November 16th and 17th, has been pivotal for me. Both as a person living with SCD as well as a proponent to spreading awareness, the symposium allowed me to be an active participant in joining the SCD community at large in the strengthening of a groundbreaking and noteworthy movement!

Meeting and greeting the influential individuals

at the forefront of SCD research, care and funding has been (and still is) a truly inspiring experience. And although one could feel intimidated by the prowess of the academics and activists, their approach to advancing the movement was far from intimidating- but was rather inspiring and empowering! Where it was quite easy to get lost in the scientific jargon associated with the pathophysiology of SCD, many of the presenters were quite willing and able to break down the information in laymen's terms on a one-on-one basis. It felt like the perfect party: where you're able to relinquish yourself to the vibe and truly and authentically take in the beat and the energy. I "moved and shaken" with the "best of them" and felt that my uniqueness was accepted and embraced. A fact I am most grateful for.

I found that strictly as a patient of SCD, my attendance at the symposium graciously opened the door to the "hidden" knowledge behind sickle cell progress. Quite often, it is easy to get lost in the awareness side of movements- like cancer walks, and autism bumper stickers; however, we rarely know how the awareness side affects the science. The same science that promises a cure. Admittedly, maybe out of my arrogance, or possibly out of my fear, living with sickle cell disease privileged me to not pursuing the science but still deeming myself as "expert". The conference swept away the fear and complacency and opened the doors to exploring the other side of the awareness. Never before have I felt so enlightened! Going forward as a patient and advocate of awareness, I have made it my duty to learn more and more about the science- if not solely to instill that knowledge in others, than at least to more mindfully support the process from awareness to cure.

This experience will never be forgotten. I'll use it artfully to raise awareness and show, as an example, how far awareness can go. I encourage others to embrace and grow in this movement- for progress can only be obtained when we collectively decide to change things for the better!

Coming Up...

Embrace Kids Foundation Holiday Party December 4th 1:00pm-3:00pm.
Atrium of RWJ Hospital, New Brunswick.
RSVP with glassman@embracekids.org

SCANJ Holiday Party December 11th 3:00pm-5:00pm Van Vleck Mansion in Montclair RSVP by December 9th

Take Control of Your Health Do you have, or care for someone with, sickle cell disease or another health condition, such as diabetes, high blood pressure, or arthritis? Do you want to learn about ways that can help you feel more in control of your health and your life?

If your answer to these questions is yes, plan to attend our free 6-session Take Control of Your Health workshop, which will be held each Saturday from January 8 through February 12, 2011. You'll learn how to make better nutrition and exercise choices, relaxation techniques to help reduce your stress, better ways to communicate with your doctor and loved ones about your health, and more. See the calendar on page 1 for more information and locations.

Contact us at 973-482-9070 or via email at sicklecellanj@gmail.com for more information