

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



## Calendar Listings

**April Begins Take Control of Your Health 6 Week Series Workshops**, part of the Stanford University CDSMP program. Call SCANJ or go to [sickle-cellnewjersey.org](http://sickle-cellnewjersey.org) events page. Registration information will be posted as classes are scheduled.

**April 9, 8am-1pm Alpha Kappa Alpha North Atlantic Region Community Health Fair and Blood Drive.** MLK School in Atlantic City, NJ

**April 12th Ramapo College Health Fair. 9:00am**

**May 2-3rd NJ Governors Conference For Women. Atlantic City Convention Center.** Reception Monday evening and powerful workshops and Health Fair on Tuesday. SCANJ's Mary Bentley LaMar serves on the steering committee and chairs Monday's Welcome Reception. SCANJ will have a booth at the Health Fair. Register today online at [www.njwomensconference.com](http://www.njwomensconference.com).

**May 7th Be Sickle Smart Empowerment Day with Celebrity Dr. Ian Smith.** Join SCANJ and other sickle cell advocates in this day of empowering workshops, a luncheon and motivational activities to educate about sickle cell disease and iron overload. All activities are FREE including parking. RSVP 973 482-9070 or email [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com). You can also register through [eventbrite.com](http://eventbrite.com)

**June 18th Sickle Cellabration** is coming to the Jersey Explorer Children's Museum. 192 Dodd Street in East Orange. We will have a Sickle Cell Awareness Blood Drive and select the NJ Sickle Cell Poster Child and Teen Spokesperson. Registration will be available soon.



Volume 2  
Issue 4

# Say It Loud!

April 2011

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

## A Note from the Executive Director...



Mary Bentley LaMar

I see...

*help, education, and advocacy in the fight against sickle cell disease*

This issue is hot off the press from SCDA Advocacy Day in Washington DC. The SCANJ delegation joined affiliates from throughout the country advocating for funding for sickle cell disease research and programs this past week (March 31-April 1). On Friday morning we were inspired with a briefing from SCDA leaders, Congress members and White House staffers. We then fanned out across

Capitol Hill to meet with our elected officials.

We are expecting, and no less than accepting, support from Senators Lautenberg and Menendez. We expect the same from Congressmen Sires, Runyan, Pascrell and others. I urge everyone reading this to make your voices heard with your elected officials on the local, state and federal levels. One thing is loud and clear...if you don't speak up for yourself, don't expect a change.

I expect a change and I'm willing to shout about it! We will post more details on our website under the "Current Programs" section for Advocacy Day. So be sure to check in and download the Talk points, so you can speak up for funding.

In other news ...I'm excited to announce the **SCANJ 2011 Road Trip**. This time, we're going to Baltimore Maryland for the New York Mid At-

lantic Consortium For Genetic and Newborn Screening Services Summit, Wednesday and Thursday, May 18th and 19th at the Radisson Lord Baltimore Plaza Hotel. The focus of this Summit is "Improving Quality and Coordination of Care and Services for Children with Special Health Care Needs and Their Families."

I am honored that our abstract was accepted for presentation at the Summit. We will be presenting "Say It Loud! Pump Up The Volume about Sickle Cell Disease."

Due to limited capacity, our SCANJ 2011 Road Trip must first accommodate individuals living with sickle cell disease and/or their caregivers. Scholarships are available. Give us a call if you would like to travel with SCANJ. We want to see New Jersey in 'Lord Baltimore's house' making noise.

~ Mary

## Be Sickle Smart...at the Hilton Hotel May 7th!

SCANJ is teaming up with *Be Sickle Smart*, a national program dedicated to educating and inspiring people living with Sickle Cell Disease.

Become a "Power Broker" by attending *Be Sickle Smart: Empowerment Day*. On May 7th, beginning at 10:00am and going strong until 4:30pm, the Gateway Hilton across from Newark Penn Station will be abuzz with empowering workshops and activities.

Dr. Felicia Wilson, an accomplished Professor and Director of Hematology and Oncology at the University of Alabama (Mobile) will lead workshops on sickle cell disease and

related issues, including emergency room etiquette, pain management and the risks associated with having multiple blood transfusions. There will also be an opportunity for questions.

*Be Sickle Smart* is providing free blood screenings for Iron Overload.

And we're excited to welcome celebrity medical expert Dr. Ian Smith who will talk about the challenges facing the sickle cell community and how to embrace a successful life despite hardships.

We'll show Dr. Smith how 'Jersey walks' by having healthy movement led by Praise Dancers from

**Dr. Ian Smith is coming to Newark. Smart move. Smart man.**



Sickle Cell Sabbath partnering churches. Statewide sickle cell programs will be showcased along with an Open Mic segment which will allow attendees to "express themselves." Parents are welcome to bring their children to enjoy activities including educational Sickle Cell Wii games and a children's art class.

All of this, including a luncheon and parking are FREE. RSVP required. (See calendar listings.)

Turn for Page 2...

**Donate  
Now**

Donations to SCANJ are fully tax deductible and fund local programs and services to fight sickle cell disease.

**[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)**

You can donate online or mail your donation payable to:

**SCANJ P.O. Box 9501 Newark NJ 07104**

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

We also encourage you to support the Sickle Cell Disease Association of America's (SCDAA) new national fundraising and awareness initiative \$1 Million in 100 Days. Text the word BREAK to 52000 to donate \$10 to fund social service programs, treatment, and advocacy for increased research. Help "break the cycle of pain" locally and nationally.

**Thank You**

Phone: 973 482-9070

Fax: 973 485-6591



**New Jersey sickle cell advocates seeking funding for sickle cell research and programs on Capitol Hill  
2011 SCDAA Advocacy Day in Washington DC on April 1st**

## SCANJ 2011 Road Trip to Baltimore Maryland

**Come with us! We've made it easy for you to go...**to the New York-Mid Atlantic Consortium For Genetic and Newborn

Screening Services Summit at the Radisson Plaza Lord Baltimore Hotel 20 W. Baltimore Street, Baltimore Maryland 21201 May 18-19, 2011

To register for the *SCANJ 2011 Road Trip*, you MUST turn in a complete NYMAC Summit Registration Form through SCANJ and indicate on the form "SCANJ Road Trip" (in the Organization field) and the Travel Agreement and Waiver of Liability Form, no later than April 16<sup>th</sup>. Our FAX # is 973 485-6591.

Due to space limitations, we must first accommodate individuals with sickle cell disease and/or their caregivers on this educational excursion. All Road Trip passengers must complete the Travel agreement and Waiver of Liability along with their NYMAC registration form to be confirmed.

**The SCANJ 2011 Road Trip includes:**

RT Van Transportation from points in north and south New Jersey, overnight accommodations (Dbl Occ), Continental Breakfast, Lunch, Reception and Wednesday Dinner.

### Wednesday May 18

VAN Departs- Newark 5:30am SHARP (Location TBA)

Van Pick Up- Willingboro 7:00am (Location TBA)

Van Arrives-Baltimore MD at approximately 9:30am

### Thursday May 19

Van Departs-Baltimore MD at 4:30pm

Van Drop Off-Willingboro at approximately 6:45pm

Van Arrives- Newark at approximately 8:30pm

The NYMAC Summit is a FREE program of the New York-Mid Atlantic Consortium for Genetic and Newborn Screening Services. If you would like to attend the summit on your own, just complete the NYMAC registration form and register directly with NYMAC before April 30th.

The Sickle Cell Association of New Jersey IS NOT an organizer of the NYMAC Summit. We are arranging this SCANJ 2011 Road Trip as a service to help you attend. SCANJ reserves the right to cancel the Road Trip if sufficient Road Trip registrations are not confirmed.

Feel free to call SCANJ at 973 482-9070 or email us at [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com) to request the registration forms and Summit Agenda. Information will be posted soon on our website; [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org).

## Coming Up Soon...

**April 9, 8am-1pm Alpha Kappa Alpha North Atlantic Region Community Health Fair and Blood Drive.** MLK School Corner of 1700 Marmora Ave and MLK Blvd. in Atlantic City, NJ. **To sign up go to [RedCrossblood.org](http://RedCrossblood.org)** and enter sponsor code **9853** for the **AKA Drive** or call **1 800 26-BLOOD**.

**May 2-3rd NJ Governors Conference For Women. Atlantic City Convention Center.** Visit the SCANJ table at the Health Fair. There is still time to register.

### May 7th Be Sickle Smart Empowerment Day

Register through [www.eventbrite.com](http://www.eventbrite.com) or email us at [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com).

**May 18-19th SCANJ 2011 Road Trip to the Baltimore MD for the New York Mid Atlantic Consortium (NYMAC) Summit.** Registration information will be posted on [sicklecellnewjersey.org](http://sicklecellnewjersey.org) and [eventbrite.com](http://eventbrite.com).

**June 18th Sickle Cellabration** to commemorate World Sickle Cell Disease Day. Jersey Explorer Children's Museum in 192 Dodd Street in East Orange NJ. Workshops, children's activities and Sickle Cell Awareness American Red Cross Blood Drive. The 2011-2012 Sickle Cell Poster Child and Teen Spokesperson will be selected at this event. Call our office if you are interested in coming and/or applying for the Poster Child program. Details will be posted on our website.

**The "Say It Loud" newsletter is published monthly.**  
**Beverly Lucas-Editor**

[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)