

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

**Take Control of Your Health 6-Week Series Workshops**, licensed under the Stanford School of Medicine's CDSMP program are underway. Capacity is limited. We encourage you to register now at 973 482-9070, sicklecellnewjersey.org events or via eventbrite.com.

**May 2-3rd NJ Governors Conference For Women. Atlantic City Convention Center.** Look for the SCANJ booth at the Health Fair.

**May 7th Be Sickie Smart Empowerment Day with Celebrity Dr. Ian Smith. 10:00am- 4:00pm Newark Gateway Hilton Hotel.** RSVP via email at sicklecellanj@gmail.com, through eventbrite.com, or call us at 973 482-9070.

**May 10th New Jersey Head Start Statewide Conference 8:30am Hilton Hotel, Atlantic City.** SCANJ presentation on sickle cell disease.

**May 18 & 19th SCANJ 2011 Road Trip to the NYMAC Consortium Summit in Baltimore Maryland.** SCANJ presents on the 19th.

**May 29th Statewide African American Parade and Festival** Downtown Newark and Weequaic Park. See SCANJ in the parade and visit our booth at the festival.

**June 18th - 19th World Sickie Cell Disease Day Commemoration**

**Sickle Cellabration** Saturday at the Jersey Explorer Children's Museum. 192 Dodd Street in East Orange. Sickie Cell Awareness Blood Drive and selection of the NJ Sickie Cell Poster Child and Teen Spokesperson. Registration available now.

**Sunday Sickie Cell Sabbath** Joint Worship. 11:00am You're invited to come to Shiloh Baptist Church, 99 Davenport Ave in Newark, or to worship at a place of your choosing. Please keep the sickie cell community in your thoughts and prayers.

Summer preview...check our website for Summer Camp offerings and other useful resources.

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

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Volume 2  
Issue 5

# Say It Loud!

May 2011

Sickle Cell News You Can Use

The Sickie Cell Association of New Jersey

## A Note from the Executive Director...



Mary Bentley LaMar

### Mary's Month of May Mother's Day Musings

Did your Mom ever tell you "when opportunity knocks, open the door?" Several who read about our upcoming **SCANJ 2011 Road Trip** recognized the opportunity to RSVP for this free educational excursion and will now journey with us on May 18th to the **New York Mid Atlantic Consortium (NYMAC) For Genetic and Newborn Screening Services Summit** at the Radisson Lord Baltimore Plaza Hotel in Baltimore Maryland.

The theme for the Summit is "Improving Quality and Coordination of Care and Services for Children with Special Health Care Needs and Their Families." Darlene Young, SCANJ's Vice President, and I, will present SCANJ's outreach initiatives during Session 12 of the Summit with "Say It Loud! Pump Up The Volume about Sickie Cell Disease." Kudo's to those who answered the call for New Jersey to be in Lord Baltimore's house pumping up the volume.

SCANJ Road Trips help make it possible for families experiencing sickie cell disease to interact with program managers, researchers, physicians, and policy makers, during important conferences that influence services affecting the sickie cell community.

On a different note, I encourage you to register now for the next series of **Take Control of Your Health Work-**

**shops.** These peer led workshops, created and licensed by Stanford's School of Medicine, help individuals with health conditions and caregivers learn how to better manage their health.

Another opportunity to learn more and have fun in the process is the **Empowerment Day.** Once you "Be (come) Sickie Smart" keep that momentum going by commemorating World Sickie Cell Disease Day with a **Sickie Cellabration** and **Sickie Cell Sabbath** (page 2).

I hope you will agree that SCANJ welcomes your involvement. Go to our website; sicklecellnewjersey.org, or give us a call for more information. I encourage you to take advantage of every opportunity and use it for good. This is your call to action!

Listen to your mom...

~ Mary

## Be Sickie Smart Empowerment Day is Happening at the Hilton!



### May 7th Empowerment Day! Featured Speaker Dr. Ian Smith

SCANJ is rolling out it's red and yellow kente carpet for you on **Be Sickie Smart: Empowerment Day** from 10:00am to 4:00pm. This will be a day of empowering workshops, a delicious luncheon and engaging activities. It's not too late to RSVP.

Everything happens at the Gateway Hilton near Newark's Penn Station.

Sickle cell disease effects over 80,000 in the US and millions worldwide. If you, or a loved one, has sickie cell disease, come to Empowerment Day. What you learn could make the difference in dealing more effectively with the potentially devastating effects of this inherited blood disorder.

Dr. Felicia Wilson, professor and Director of Hematology and Oncology at the University of Alabama (Mobile), will lead workshops addressing sickie cell disease and related issues, including emergency room etiquette, pain management and how to deal with the risks associated with having multiple blood transfusions.

You will have an opportunity to be tested with a free blood screening for Iron Overload.

A highlight of the day will be an inspiring talk from celebrity medical expert Dr. Ian Smith. He is a highly sought after speaker, author of 8 best selling books and frequent guest on television shows, including The Oprah Show, Rachel Ray and the Dr. Oz Show. He is also well known as the medical expert for the popular VH 1 Celebrity Fit Club.

Parents are welcome to bring their children, who can enjoy electronic sickie cell awareness games and a children's art class. A healthy movement walk and an open mic segment are on the agenda too.

This event is made possible thanks to the sponsorship of Novartis. RSVP now for this free event and other programs from SCANJ (see calendar listings).

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)

Please donate online or mail your donation payable to:

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

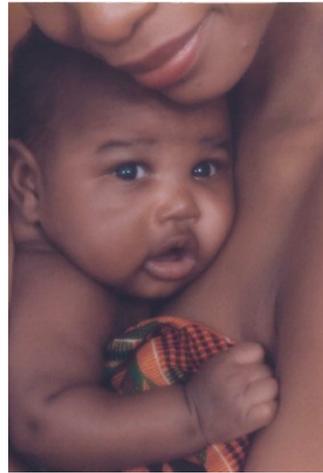
**EIN# 80-0474935 SCANJ is a 501c 3 agency**

We also encourage you to support the Sickle Cell Disease Association of America's (SCDAA) national fundraising and awareness initiative \$1 Million in 100 Days. Text the word BREAK to 52000 to donate \$10 to help "break the cycle of pain." Please note the text campaign does not go to SCANJ. To donate to SCANJ please do so by mail or through our website [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org).

**Thank You**

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

e-mail: [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com)



**To all of you who nurture, love, and dedicate yourself to worthwhile things. "I thank God upon every remembrance of thee." Philippians 1:3**

**Remember to test early for sickle cell.**

**Happy Mother's Day**

## Sickle Cellabration June 18th at the Jersey Explorer Children's Museum

The children lead the way to World Sickle Cell Disease Day with a *Sickle Cellabration* at the Jersey Explorer Children's Museum in East Orange, June 18th from 8:30am-2:30pm.

Poster child and Teen Spokesperson, Savion Smith and Amanda Salazar, respectively, are the co-chairs for this year's festival of fun and learning. They invite you to come out and receive your "Passport to The World" of festivities including workshops on sickle cell disease for adults and teens, activities for children, interactive exhibits, continental breakfast, and a luncheon where the 2011-2012 designated spokespersons for the New Jersey Sickle Cell Poster Child Program will be selected. The poster children serve as goodwill ambassadors by making appearances on behalf of SCANJ, being positive examples to other people with sickle cell disease, and educating the public about the condition. To apply for the Poster Child program, you can call our office at 973 482-9070 or email us at [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com) for an application form.

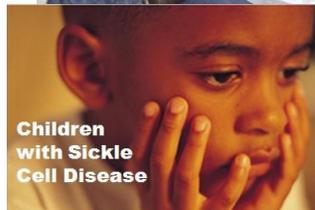
A new workshop feature this year is a "Baby Shower" for new parents living with sickle cell disease and parents of babies newly diagnosed with sickle cell disease (3 years and under). We will also host an American Red Cross, sickle cell blood drive. Please sign up now if you are eligible to donate blood.

The Sickle Cellabration is free, however, we ask that you register in advance through [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org) or by calling our office at 973 482-9070. You can also email us for a registration form.

This fun and educational *Sickle Cellabration* is made possible, in part, thanks to our gracious host, The Jersey Explorer Children's Museum, Americorps Youth, and the generous sponsorship of The Sickle Cell Disease Treatment Demonstration Program at Newark Beth Israel Medical Center.



**Inspired by the children...**



**Children  
with Sickle  
Cell Disease**

### Coming Up Soon...

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**May 29th Statewide African American Heritage Parade and Festival.** 11:00am Downtown Newark Festival in Weequaic Park. Visit SCANJ's booth.

**World Sickle Cell Disease Day Commemoration**

**June 18th Sickle Cellabration 8:30am-2:30pm**

Jersey Explorer Children's Museum, 192 Dodd Street in East Orange. RSVP by calling, thru our website; [sicklecellnewjersey.org](http://sicklecellnewjersey.org) and click on "Sickle Cellabration," or go to [eventbrite.com](http://eventbrite.com) and enter sicklecellabration. To register for the **Blood Drive** go to [redcrossblood.org](http://redcrossblood.org) and enter sponsor code **15167**.

**June 19th Joint Worship Service Sickle Cell Sabbath**

All are invited to the morning service 11:00am Shiloh Baptist Church, 99 Davenport Ave. Newark.

**SCANJ 24 Seven Marathon-Date TBA**

The "Say It Loud" newsletter is published monthly.

**Beverly Lucas-Editor**

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