

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.



# Say It Loud!

January 2011

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

Volume 2  
Issue 1



## Calendar Listings

**January Take Control of Your Health Workshops Series**, part of the Stanford University CDSMP program each Saturday through February 12, 2011. There is still time to enroll for the Willingboro location- **JFK Community Center** 429 JFK Parkway in Willingboro **9:00am-11:30am**.

**February 26th SCANJ Celebrates Black History Month with the WBLS Radio and American Red Cross Blood Drive at New Jersey City University in Jersey City.** Stay posted for related events including our **SCANJ Website Launch Par-tay**.

**March 24 SC Advocacy Day at the Capitol.** Call Kevin Baxter if you would like to serve on the SCANJ Advocacy Committee. 609 477-9092

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

**Reflections: Thanks to the National Organization of Black Law Executives (NOBLE) Northern New Jersey Chapter** for serving as our primary toy sponsor for the December Holiday Party. The children and families were amazed with the array of gifts. God bless your work..

### Important Dates:

February 26  
March 7-10  
March, 24

## Happy New Year 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.."*

I'm excited about all the great things this year has in store for each of us. Kudos to all who are starting the year by participating in the Take Control of Your Health Workshop series which began January 8th. As of this

writing, we have room for three more enrollees for the Willingboro location workshops. Call our office now if you want to get in on this current series. SCANJ will be coordinating more workshops as the year progresses, so I encourage you to take advantage of the opportunities. Soon and very soon, we will debut our website thanks to the good folks at Knowledgecrush. We are on our way to the dynamic web presence that we want you to log into frequently for information on sickle cell happenings in New Jersey and beyond. Stay posted for the Launch Par-tay!

2011 promises to be an impactful year as many of our successful programs from last year will be continued and expanded such as the:

- Sicklecellabration and Blood Drive on World Sickle Cell Disease Day
- Sickle Cell Poster Child Program
- SCDAA Advocacy Day Capitol Hill

- Say It Loud! Conversations on Sickle Cell Disease teleconferences
- Sickle Cell Sabbath-faith based awareness partnerships
- Thanks for Giving Concert and Dr. Charles F. Whitten Awards
- SCANJ Road Trip
- December Holiday Party

We thank you. These programs could not have been successful without your participation. With your input we will continue to raise the bar of what we can accomplish with new educational programs like "Empowerment Day" and a Baby Shower for Parents to be and babies living with sickle cell disease.

As we embrace this New Year and reflect on Martin Luther King's legacy of service, I encourage you to learn, know, and do more in your faith with good works for sickle cell disease. Now let's go make a difference!

~Mary



JOY



SCANJ's Darlene Young, Mary Bentley LaMar, Amanda Salazar, NJ Teen SC Spokesperson, and Savion Smith, NJ Sickle Cell Poster Child with Dr. Charles F. Whitten Outstanding Service honorees; Dr. Alice Cohen, Regina Cruz Burden, Ediom Utuk and Kevin Baxter. (Photo courtesy of Ediom Utuk)

Fun, Toyland and Kenta Klaus! Save the date now for the next Holiday Party- December 10, 2011. (Photos courtesy of Ashante Baxter)

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#### OUR WISH LIST:

Donated or low cost office space

Volunteers

Events Sponsorship

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 Ashante Baxter and Ediom Utuk for Pictures!

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

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.

All submissions must be received via email by the 1st of each month in order to be considered. Please note that while all submissions will be considered for publication, submission does not guarantee publication. Also note the information in this newsletter is for educational purposes only. It is not intended as a substitute for a doctor’s advice.

“Say it Loud!” is yours to shape. Let us hear from you.

—Beverly Lucas-Editor

Stay Posted for  
**SCANJ24seven**

### The Problem with Priapism

Priapism is the term used to describe the painful, unwanted erections experienced by some boys and men with sickle cell disease. The condition occurs when sickled red blood cells slow the flow of blood through the penis. Many times, multiple painful erections that occur for a brief period of time (called stuttering) are followed by a full-blown episode that lasts for several hours or days. **Priapism lasting more than 3 to 4 hours is a medical emergency.** The longer treatment is delayed, the greater the chances of permanently losing the ability to achieve an erection, a condition called impotence or erectile dysfunction.

Treatment may include drainage, hydration, supplemental oxygen, blood transfusion and medication to relieve pain and increase blood flow out of the penis. In some cases, surgery to divert blood flow from the penis may be necessary.

Experts suspect that repeated episodes of priapism, even if they do not lead to full

blown episodes, may also increase the risk of becoming impotent. Consequently, patients should be followed regularly by a urologist who has experience with sickle cell patients and is knowledgeable about current treatment recommendations.

Research suggests that sildenafil, commonly known as Viagra, may be an effective treatment and may be able to prevent full-blown episodes from occurring. Males between the ages of 14 and 45 who suffer from frequent episodes of priapism due to sickle cell disease may be interested in participating in a study of low-dose sildenafil being conducted at Johns Hopkins University School of Medicine in Baltimore, Maryland.

Dr. Arthur Burnett is the principal investigator for the sildenafil study. Dr. Burnett is a Professor in the Department of Urology, at the Johns Hopkins University School of Medicine where he is also Director of the Basic Science Laboratory in Neurourology. His key research interests are the pathophysiology of erectile dysfunction, major pelvic reconstruction, voiding dysfunction, female urology, and prostate cancer.

To participate in this important study you can contact John Hopkins at 443 297-1011 or contact Mary at SCANJ for more information. Transportation assistance is available. Your input could lead to the solution to the problem.

### Coming Up...

**Take Control of Your Health Workshops** each Saturday through February 12th. **March 7-10 Get certified to teach Take Control of Your Health. Peer leader training** is from 9:30am to 3:30pm. at Grace Baptist Church, Fords NJ.

**March 24 Sickle Cell Disease Association of America (SCDAA) Advocacy Day Capitol Hill**, Call SCANJ if you are interested in going with us.

**SCANJ is teaming up to increase SCD awareness and blood donors at the following American Red Cross blood drives:**

- **February 26th 8:00am-2:00pm WBLS Radio & Omega Psi Phi Blood Drive at New Jersey City University**
- **April 9th 8:00am-1:00pm Alpha Kappa Alpha North Atlantic Region Community Health Fair and Blood Drive. MLK School in Atlantic City, NJ** Come out to donate, learn and have fun in the process. Please sign up now.

**May 3rd New Jersey Governors Conference on Women, Atlantic City Convention Center**. Visit SCANJ at the conference' Health Fair. To register for the conference go to [www.njwomensconference.com](http://www.njwomensconference.com).

**SCANJ-973 482-9070**