

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

**October 16 Top Ladies of Distinction Yard Sale Fundraiser for SCANJ.**  
707 Parkway Ave in Ewing 10am-2pm  
(Rain date Sunday Oct. 17th)

**23 Valerie Fund Sickle Cell Blood Drive**  
10:00am-4:00pm -UMDNJ Newark

**21 & 28 SCANJ Road Trip informational teleconferences** are at 12:30pm or 6:30pm dial into 1 712 432-0080  
Participant Code 490765#

**November 4 SC Advocacy Day at the Capitol Planning Committee introductory conference call 7:30pm**  
Call Kevin Baxter, Chair in advance, if you would like to serve on this committee.  
609 477-9092

**16-17 SCANJ 2010 Road Trip** to James B. Herrick Sickle Cell Symposium at NIH, Bethesda MD. Registrations must be RECEIVED by October 30th. Details in this newsletter

**20 "Thanks for Giving Concert". Sickle Cell Sabbath 3:00pm Shiloh Baptist Church, 99 Davenport Avenue, Newark.** All who participate in Sickle Cell Sabbath outreach, health care professionals, families affected by sickle cell and the public are invited to come together in thanks for the programs and services in New Jersey that support them. Glorious voices will honor those who have done outstanding work for sickle cell disease.

**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!

**Reflections Thanks to:** Zeta Phi Beta Sorority, Camden Chapter and Alpha Kappa Alpha Sorority, Montclair Chapter for hosting presentations on sickle cell disease at their September chapter meetings and support of SCANJ outreach.



# Say It Loud!

October 2010

VOLUME 1 ISSUE 2 SICKLE CELL NEWS YOU CAN USE

## A Note from the Executive Director...

There is a lot going on, so you are in the right place to be up on the positive programs that impact the lives of individuals living with sickle cell disease. We need your help to keep us informed. Your stories, pictures and suggestions are welcome here.

Did you get a phone call from a 405 area code and not answer thinking..Who in the world is that? That call might have been from our callingpost "SCANJ Update." The calling post is an automated voice message directly from us, to you. It's designed to keep you informed of important news from



Mary Bentley-LaMar

the Sickle Cell Association of New Jersey (SCANJ).

If you would like to receive our callingpost voice messages and email blasts, please shoot us an email with your preferred contact information or give us a call.

Here's a tip-register early for the SCANJ 2010 Road Trip to the James B. Herrick Symposium. Space is limited and fees are nominal. We're working hard to make it easy for you to come. We'll learn a lot, share a lot and have fun in the process.

Check out the details in the article below and request a registration form for the Road Trip. The SCANJ deadline is October 30th. First registered, first served. Don't be the only one to miss the bus!

~Mary



Tailgaters at W. Young Football Classic read SCANJ news.

## We're Getting Our Act Together and Taking It On The Road!

You're invited to come with us on the **SCANJ 2010 ROAD TRIP** to the **James B. Herrick Symposium on Sickle Cell Disease at NIH November 16th & 17th.**

National and international experts in sickle cell care and research, members of the sickle cell community and the public are invited to participate in this commemorative symposium.

The Road Trip includes: symposium registration, round trip coach bus transportation from north and south Jersey, overnight hotel ac-

commodations, continental breakfast, welcome bags and fun.

Bus Departs- Newark 4:45am **11/16**

And Departs- Bellmawr 6:30am (Just off NJTP Exit 3)

Bus Arrives in Bethesda MD at approximately 9:30am

Bus Departs Bethesda 6:00pm **11/17**

**Come with us! SCANJ has made it easy for you to go...**

Registration forms available via email sicklecellanj@gmail.com or call our office at 973 482-9070. Your Health care provider may have registration forms too.

Feel free to call us or dial into one of the informational teleconferences with questions you may have (see calendar listings).

Road Trip Registration and payment must be RECEIVED by October 30th.

The SCANJ 2010 Road Trip is made possible, in part, thanks to the generous sponsorship of The Sickle Cell Disease Treatment Demonstration Program at Newark Beth Israel Medical Center and supporters like you.

**Turn for Page 2...**



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

We need and welcome your contributions. They are fully tax deductible and help us fulfill our mission through programs and services to fight sickle cell disease. Make checks or money orders payable to:

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

Thank You!

Phone: 973 482-9070

Fax: 973 485-6591

E-mail: sicklecellanj@gmail.com

**"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



## Know the Score: Sickle Cell Carrier Status

### in Student Athletes Part 2

The recent ruling by the National Collegiate Athletic Association (NCAA) and the National Athletic Trainers Association (NATA), requiring that student athletes get tested for sickle cell trait has sparked a great deal of discussion.

One positive aspect of this ruling is that athletes of child bearing age will be informed of their trait status. If proper counseling is included, knowing their trait status will allow for family planning that is informed by knowing the risks and challenges of having a child born with sickle cell disease. The negative aspect of this ruling is that it could lead to stigmatization and discrimination against athletes with the sickle cell trait.

According to the Sickle Cell Disease Association of America's Medical and Research Advisory Committee "...the commonsense precautions recommended by NATA —building up exercise intensities gradually, responding to athletes reporting symptoms of physical distress, and avoiding overheating and dehydra-

tion—if applied universally, would make athletic training safer for all and would obviate the need to identify carriers of the sickle cell gene in the athletic setting."

The Sickle Cell Association of New Jersey encourages early testing for sickle cell trait and sickle cell disease using laboratory methods (like hemoglobin electrophoresis) that identify specific hemoglobins and that athletes with a positive test finding receive genetic counseling. We also advocate that special care be made to protect the athlete's health record and to establish commonsense exercise precautions that would benefit all athletes, regardless of their sickle cell trait status.

For more information, visit the SCDA website at [sicklecelldisease.org](http://sicklecelldisease.org) or contact SCANJ at 973 482-9070.

Sickle Cell Trait is the topic of discussion on the next "Say It Loud! Conversations on Sickle Cell Disease" teleconference. All interested can dial in. Details in Calendar listings on the first page.

### Coming Up...

#### **"Thanks for Giving"**

Fundraising Campaign begins November 1st.

#### **SCANJ 2010 Road Trip**

To James B. Herrick Symposium in Bethesda Maryland November 16 & 17th

#### **Thanks For Giving Concert**

November 20th at 3:00pm

Shiloh Baptist Church

Malachia Brantley Jr. M. Div.

99 Davenport Ave in Newark

#### **SCANJ Holiday Open House**

December 11th 3:00pm-5:30pm

Van Vleck Mansion in Montclair

RSVP to SCANJ by December 9

#### **SCANJ Awarded Grant**

to conduct Chronic Disease Self Management Program workshops.

Contact SCANJ at 973-482-9070 or email us at [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com) for more information on any of our programs.