Sickle cell disease is an inherited blood disorder that causes the red blood cells to become hard and pointed instead of soft and round. Sickle cells cause anemia, pain and many other health problems. We welcome your involvement. It helps to make a difference.

Say It Loud!
New Jersey September 2010
Sickle Cell News You Can Use

Calendar:

September
30 Say It Loud! Conversations on Sickle Cell Disease Join us on the quarterly 30-minute teleconference. Topic: News from the national SCDAA convention. Dial 1 712 432-0080 Pass code 490765# at 12:30 p.m. EST or 6:30 p.m. EST.

30 Support Circle for SC. 7:00pm -8:30 p.m. Join us for this kick off. Catchings/Owens Community Suite-Adjacent to the Glenfield Middle School (corner of Maple and Bloomfield Aves) Montclair.

Coming up SCANJ 2010 Road Trip Reflections...

18 Donna T. Darrien Memorial Foundation for SCD Walk. Thanks Alpha Kappa Alpha Newark Chapter and others who supported the SCANJ Team

25 Faith In Wellness Health Fair Willingboro, N.J. Thanks to Alpha Kappa Alpha-Pi Mu Omega Chapter for the sickle cell outreach.

25 NY Urban League Whitney Young Football Classic Meadowlands Giants Stadium. Thanks to Omega Psi Phi Fraternity Newark Chapter for the sickle cell outreach. Kudos to all the tailgaters for learning and agreeing to share information on sickle cell with their organizations, customers, family and friends.

26 Heel to Heal Embrace Kids Walk. Johnson Park, Piscataway. Thanks SCANJ Steppers Team.

A Note from the Executive Director...

Welcome to the inaugural edition of Say It Loud! I can’t think of a better time for this debut than September, national Sickle Cell Awareness Month. This newsletter is designed to keep you apprised of activities and resources that positively impact the lives of individuals living with sickle cell disease. We want you to be involved, and well informed.

The Sickle Cell Disease Association of New Jersey, affectionately known as “SCANJ” is poised to make a difference by implementing programs and supporting services that are meaningful to you. We welcome and value your input. Feel free to submit stories, story ideas, suggestions and pictures that may be of interest to your fellow readers.

Mary Bentley-LaMar

This issue includes information on the NCAA ruling about sickle cell trait (carrier) testing. You will also meet the New Jersey Sickle Cell Poster Child-Savion Smith and the New Jersey Teen Spokesperson–Amanda Salazar. Take note of the Calendar listings, especially the SCANJ Road Trip to the National Institutes of Health-James B. Herrick Sickle Cell Symposium in November. We want New Jersey to represent! That includes you.

We want you to be involved, and well informed. We welcome and value your input. Feel free to submit stories, story ideas, suggestions and pictures that may be of interest to your fellow readers.

Enjoy!

Poster Children Chosen at Sickle Cellabration

We are very pleased to introduce Savion Smith of Lakewood and Amanda Salazar of Haledon. They are selected as SCANJ’s 2010-2011 Poster Child and Teen Spokesperson respectively.

9-year-old Savion and 16-year-old Amanda were chosen by a panel of judges that included medical professionals and their peers at Sickle Cellabration, a free educational event and luncheon sponsored by SCANJ and Embrace Kids Foundation.

Sickle Cellabration was held on June 19 in honor of World Sickle Cell Disease Day.

Savion and Amanda will serve as goodwill ambassadors by making appearances on behalf of SCANJ, being positive examples and role models to other people with sickle cell, and educating the public about the condition. Congratulations and good luck Savion and Amanda! They represented New Jersey at the 38th Annual SCDAA convention in Oxon Hill Maryland September 21-24, thanks to the generous sponsorship of Embrace Kids Foundation. We look forward to hearing their thoughts on the convention.

We celebrate all the children who participated in Sickle Cellabration.

Mary Bentley-LaMar

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Turn for Page 2...
At the Sickle Cell Association of NJ every member is valued. With our collective participation and wisdom, I’m sure that we will have meaningful experiences that lead to action that greatly benefits individuals affected by sickle cell disease.

The “Say It Loud” newsletter will be 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 Trait Status in Student Athletes Part 1**

Do you have a child who participates in NCAA Division I athletics? If so, you may be aware of a new rule that requires athletes to be tested to determine whether they have sickle cell trait (or provide documentation of their carrier status if they were previously tested) before he or she can participate in an NCAA division I athletics. The rule applies to athletes who are in their initial year of eligibility regardless of race or ethnicity.

If testing shows that your student athlete carries the trait, it’s important to understand that this does not mean he or she has, or will develop, sickle cell disease. It means that your child has inherited one gene for sickle hemoglobin and one gene for normal hemoglobin. Sickle cell trait will not go away as your child ages. It is not contagious and generally does not cause any health complications except under extremely intense exercise. Other factors, such as excessive heat, dehydration, high altitude, and asthma, may also be associated with complications in people with sickle cell trait.

Everyone participating in sports or other physical activities should take common sense precautions, including, but not limited to, staying well hydrated at all times, taking adequate rest periods, and avoiding caffeine energy drinks or other stimulants that can lead to dehydration. If your child feels ill during training or a game, he or she should stop, and the coaching staff should seek prompt medical attention.

To find out more go to the Sickle Cell Disease Association of America website at sicklecelldisease.org or call SCANJ at 973 482-9070.

Part 2 of this story to follow in October