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. To register: 973 482-9070 or takecontrolscanj.eventbrite.com Capacity is limited.

Summer Camps preview. Check our website for organizations with camp offerings and other useful resources

### www.sicklecellnewjersey.org

June18th -19th World Sickle Cell **Disease Day Commemoration** 18th Sickle Cellabration Saturday 8:30 a.m.—2:30 p.m.at the Jersey Explorer Children's Museum, 192 Dodd Street in East Orange. Events include Sickle Cell Awareness Blood Drive and selection of the NJ Sickle Cell Poster Child and Teen Spokesperson. RSVP:

sicklecellabration.eventbrite.com

19th Sunday Sickle Cell Sabbath Joint Worship at 11:00 a.m. You're invited to come to Shiloh Baptist Church, 99 Davenport Ave, Newark, or to worship at a place of your choosing. Please keep the sickle cell community in your thoughts and prayers.

July 1 & 3rd Thanks to the New York College Reunion School Daze Party & Cookout for committing a portion of their party proceeds to benefit our Poster Child Program. For information on this "party with a purpose" go to

www.newyorkcollegereunion.com

**SAVE THE DATES:** 

October 7-8th SCANJ 24Seven

**New Jersey City University** 

Turn for Page 2...



# Say It Loud!

Issue 6

Sickle Cell News You

Sickle Cell Association of

## A Note from the Executive Director...



Mary Bentley LaMar

"So what do you do...sit around and dream all this up?" That was the question posed to me by one of our volunteers as we were preparing for the upcoming Sickle Cellabration. I had just shared the news that we got clearance from the London, England office of Guinness World Records to attempt to set a new world record. What's even more notable is that what we proposed had never been attempted before so they opened up a whole new category to accommodate our request.



**Empowerment Day May 7th Newark Hilton** 

What in the world could we possibly be attempting that's never been attempted before? I'll give you a hint...the electric slide has a LOT to do with it (pg 2). You may wonder what does that have to do with sickle cell disease?

I suppose it could go back to my answer to the question from our volunteer. Yes. I do dream up many things ... I envision ways to involve others and bring attention to sickle cell disease. I envision funding for every legitimate need that comes

across my desk each day. I envision a cure for every person suffering from sickle cell disease.

Now for the reality check; I read a quote that said "to make your dreams come true, first you have to wake up." Well, I'm fully awake finalizing preparations for the Sickle Cellabration and planning for the SCANJ 24 Seven (pg. 2). We have accomplished many things and there is so much more to be done. I ask you to help us. Please look to the need and see where you can serve. ~ Mary

# RSVP For A Sickle Cellabration, June 18th World Sickle Cell Disease Day!



Savion invites you to the Jersey Explorer Children's Museum

Join us for a trek around the world at The Sickle Cell Association of New Jersey's 2nd Annual Sickle Cellabration in commemoration of World Sickle Cell Disease Day. When you arrive you'll receive your "Passport to The World" of fun and learning.

Festivities include workshops for adults and teens, activities for children, a baby shower for babies and parents with sickle cell disease, continental breakfast, and a luncheon where the 2011-2012 designated spokespersons for the New Jersey Sickle Cell Poster Child Program

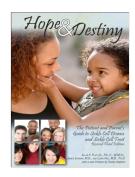
will be selected. Poster Child program. Sickle Cellabration at applications are accepted now thru 10:00 a.m. at the Sickle Cellabration.

> Among our panelists are Wondwessen Bekele, MD, Pediatric Hematologist / Oncologist and Associate Director of the Valerie Fund Children's Center at Children's Hospital of New Jersey, pediatrician, Lori Colyer-Aversa, MD and Ediomi Utuk, Sickle Cell Activist. "We are pleased to participate in an event that recognizes the strength and the bravery of patients with sickle cell anemia, and celebrates their accomplishments," says Dr. Bekele.

The Jersey Explorer Children's Museum is the perfect setting, as it is filled with exciting and unique exhibits and learning experiences, totally built and staffed by young people from NJ Youth Corps.

Families who arrive early will receive a gift bag including the recently released third edition of the bestselling sickle cell lay reference book Hope and Destiny, The Patient and Parent's Guide to Sickle Cell Disease and Sickle Cell Trait.

Please register in advance: www.sicklecellabration.eventbrite.com or by calling our office at 973 482-9070.





We depend on donations from individuals like you to provide local programs and services to fight sickle cell disease. Please give generously to SCANJ. You donations are fully tax deductible to the extent allowed by law.

## www.sicklecellnewjersey.org

You can donate online or mail your contribution payable to:

SCANJ P.O. Box 9501 Newark NJ 07104
EIN# 80-0474935 SCANJ is a 501c 3 agency
Thank You

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

e-mail: 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 Father's Day

## SCANJ gets help from New Jersey City University to Raise Funds and Awareness 24 Seven.

The Sickle Cell Association of New Jersey (SCANJ) is laying the ground work for the first ever *SCANJ 24seven Marathon*, a 24 hour event, with 7 major components including line dancing the electric slide. This event is designed to increase community awareness and funds for programs and services that help families with sickle cell disease. We're especially excited about the potential for setting a Guinness World Record.

"24seven" takes place October 7-8th at New Jersey City University (NJCU) in Jersey City. We're thrilled that NJCU has graciously agreed to be our host sponsor. Under the leadership of President Carlos Hernandez, the university is committed to community service. We hope that you too, will consider giving us your support.

To learn more, RSVP to attend one of our Community Leader's 24Seven Marathon Introductory meetings held throughout the state. The first meeting is scheduled for June 28th at 12:00 noon at New Jersey City University. You will be in the company of community, academic, health and civic leaders. Your involvement makes the difference in overcoming this inherited blood disorder.

Please email <a href="mailto:sicklecelanj@gmail.com">sicklecelanj@gmail.com</a> or call 973 482-9070 to RSVP for the Community Leader's 24 Seven Introductory Meeting, or to learn more. We welcome and need the support of the entire community to make this a success.



Coming Up Soon...

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 thru our website;
sicklecellnewjersey.org and click on "Sickle
Cellabration," call 973 482-9070 or go to
www.sicklecellabration.eventbrite.com

American Red Cross Sickle Cell Blood Drive To register for the Blood Drive go to redcrossblood.org and enter sponsor code 15167.

June 19th Joint Worship Service Sickle Cell Sabbath 11:00am Shiloh Baptist Church, 99 Davenport Ave. Newark, or worship at the place of your choosing.

### SAVE THE DATES:

October 7-8

SCANJ 24 Seven Marathon begins at 1:00 p.m. through October 8 at 1:00pm.

New Jersey City University in Jersey City. Stay posted for exciting details.

The "Say It Loud" newsletter is published monthly.

**Beverly Lucas-Editor** 

www.sicklecellnewjersey.org