

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

March 31-April 1st Sickle Cell Disease Association of America (SCDAA) National Advocacy Day on Capitol Hill. Call Kevin Baxter, SCANJ's Advocacy Chair, if you would like to help plan the New Jersey Advocacy Day at the Capitol. 609 477-9092.

American Red Cross Scholarship Deadline March 30th. For more information go to redcrossblood.org. More scholarships and information can be found on our website.

April 2 NAACP Montclair Chapter American Red Cross Blood Drive 63 Park Place Montclair.

April Begins Take Control of Your Health 6 Week Series Workshops, part of the Stanford University CDSMP program. Call SCANJ or go to sickle-cellnewjersey.org events page for registration information.

May 2-3rd NJ Governors Conference For Women. Atlantic City Convention Center. Reception Monday evening and powerful workshops and Health Fair on Tuesday. SCANJ's Mary Bentley LaMar serves on the steering committee and chairs Monday's Welcome Reception. SCANJ will have a booth at the Health Fair. Sponsorships and ads are still available. Register today online at www.njwomensconference.com.

May 7th Be Sickle Smart Empowerment Day with Celebrity Dr. Ian Smith. Join SCANJ and other community based sickle cell advocates in this day of empowering workshops, a luncheon and motivational activities to educate about sickle cell disease and iron overload. Robert Treat Hotel in Newark. This event is FREE, however please RSVP. Call 973 482-9070 for more information or www.sicklecellnewjersey.org

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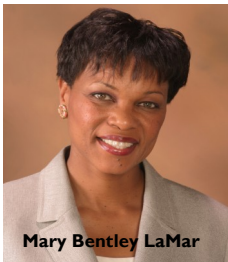
Say It Loud!

March 2011

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

A Note from the Executive Director...



Mary Bentley LaMar

I see...

Help, education, and advocacy in the fight against sickle cell disease

I want to thank the wonderful staff at New Jersey City University for their gracious hospitality during the recent American Red Cross 107.5 WBL/Omega Psi Phi Blood Drive. This Dr. Charles Drew Sickle Cell Blood Drive, co-sponsored by SCANJ, saw the community come out in force.

We were thrilled with celebrity radio host Steve Harvey for lending his voice to get the community to come out. Help me give a "shout out" to the WBL/Street team especially Mitch The People Pleezer and radio personality Jeff Fox who wowed the audience with his bass guitar licks. Special thanks too to radio host Gary Byrd who interviewed our poster child, Savion Smith, his Mom, Nicole Allmond and yours truly on his show.

The Omega's led by 2nd District Social Action Chair, Kendal Smalls, showed up and showed out. They led the drive to success. And "Buddy Blood Drop" entertained everyone. Thanks to all who played a part in saving lives by donating blood on February 26th at NJCU.

The day of the Blood Drive was also the launch day for our new website.

Looking for information about sickle cell disease? Upcoming sickle cell events in New Jersey? Reputable resources? Back issues of this newsletter? Want an easy way to donate for sickle cell? You can find it all and more at

www.sicklecellnewjersey.org.

Check it out, bookmark it, come back regularly for updates—and let us know what you think.

I'll let you in on a little secret...VH 1's Celebrity Fit, Dr. Ian Smith is partnering with SCANJ and coming to Newark on May 7th just for you...check out our website for the latest updates as they unfold.

~ Mary

Meet Kevin Baxter: Outstanding Citizen

Helping spearhead SCANJ's advocacy effort this year is the newest Ewing, NJ-council member Kevin Baxter. Kevin, who is a retired corrections officer, works tirelessly on behalf of the community and SCANJ—most recently as a certified Master Trainer for our Take Control of Your Health workshops.

Kevin also has been a strong advocate for the youth in his community. He has served as a program director for the Ewing Neighborhood Center in Hollowbrook where he mentored students.

He belongs to Kingdom Church and has been involved with several church programs, including the First Tee program for young golfers and mentoring at-risk youth.

Kevin and his wife Ashanti, are active with SOUL + Mates (Sickle Cell Overcome's United for Life + their mates), a support group through the SCDAA – Philadelphia/Delaware Valley Chapter that connects, mentors, and inspires those that are married, engaged, or dating persons affected by sickle cell disease. Kevin continues to spread the word that "he has sickle cell disease – sickle cell doesn't have him."

Kevin's hard work and dedication coupled with his political skills will, no doubt, help put us in good stead as we head to Washington, D.C. to advocate for sickle cell on March 31st.



Kevin and his wife Ashanti after receiving the Whitten Award for Advocacy.

Donate
Now

Donations to SCANJ are fully tax deductible and fund local programs and services to fight sickle cell disease.

www.sicklecellnewjersey.org

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 SCDA's new national fundraising and awareness initiative \$1 Million in 100 Days. Text the word BREAK to 52000 to donate \$10 to fund social service programs, treatment, and advocacy for increased research. Help "break the cycle of pain" locally and nationally.

Thank You

Phone: 973 482-9070

Fax: 973 485-6591



Poster Child Savion, sharing his story with sickle cell disease on the air with Gary Byrd on 107.5 WBLS Radio in New York leads to Blood Donors saving lives.

SCANJ goes to Washington for SCDA's Advocacy Day

Have you ever heard of the National Sickle Cell Anemia Control Act? Signed into law in 1972, it was the first major legislation concerning the treatment of sickle cell disease. The funding that resulted from this legislation led to the development of comprehensive sickle cell centers, research into treatment, and public awareness campaigns. The introduction and passage of this legislation had much to do with the advocacy efforts of Dr. Robert B. Scott. His report in the *Journal of the American Medical Association* in 1970 focused a spotlight on the disparities in Federal government funding for sickle cell disease compared with that for other diseases that were equally or even less common.

Today, funding for sickle cell research continues to rely heavily on the Federal government. Such funding has been and continues to be crucial for advances in care and treatment—advances that have helped reduce mortality and increase life expectancy. But much remains to be done. There is a need for more research to find a cure for everyone afflicted by sickle cell, for additional comprehensive sickle cell treatment centers to ensure that all people with this disease receive the best care available,

for better means of transitioning adolescents to adult care, and for more caregivers for adult patients with sickle cell.

Decisions regarding how much money the Federal government devotes to funding for research and other issues, including funding for sickle cell disease, are made by our U.S. Senators and Representatives. Each year, in an effort to help make these legislators more aware of issues impacting the sickle cell community, the Sickle Cell Disease Association of America (SCDA) sponsors Advocacy Day in Washington, D.C. On Advocacy Day people from sickle cell organizations around the country meet with their state's legislators to advocate for sickle cell disease. This year, Advocacy Day will be held on Friday, April 1, with advocacy training to be held on March 31, at 5 p.m.

We invite you to join SCANJ as we head to Washington D.C. to speak with our New Jersey legislators and advocate for support for sickle cell disease. If you would like more information, contact KEVIN BAXTER, SCANJ's Advocacy Chair at 973-482-9070 or send an email to sicklecellanj@gmail.com. Let's make sure our voices are heard—there is strength in numbers.

Coming Up Soon...

Register now for SCANJ supported American Red Cross drives:

April 2, 9am to 3pm NAACP Montclair Chapter and Montclair 4th Ward Blood Drive at 63 Park St in Montclair & **April 9, 8am-1pm Alpha Kappa Alpha North Atlantic Region Community Health Fair and Blood Drive**. MLK School in Atlantic City, NJ. **To sign up go to RedCrossblood.org** and enter sponsor code **9853** for the **AKA Drive** or **14560** for the **NAACP Drive** or call **1 800 26-BLOOD**.

March 31– April 1 Sickle Cell Disease Association of America (SCDA) Advocacy Day Capitol Hill, May 3rd New Jersey Governors Conference on Women, Atlantic City Convention Center Visit SCANJ at the conference' Health Fair. Register today online go to njwomensconference.com.

May 7th Be Sickle Smart Empowerment Day 10:00am-4:30pm workshops and celebrity Dr. Ian Smith. Robert Treat Hotel, Newark. Check out sicklecellnewjersey.org for details as they unfold.

May 18-19th SCANJ 2011 Road Trip to the Baltimore MD for the New York Mid Atlantic Consortium (NYMAC) Summit. Registration information will be posted on sicklecellnewjersey.org

June 18th Sickle Cellabration to commemorate World Sickle Cell Disease Day. Jersey Explorers Children's Museum in Orange NJ.

The "Say It Loud" newsletter is published monthly.

Beverly Lucas-Editor