

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!

February 2011

Volume 2 Issue 2

Sickle Cell News You Can Use



Calendar Listings

February 26 8:00am-2:00pm
SCANJ Celebrates Black History Month by teaming up with 107.5 **WBLS Radio and Omega Psi Phi Fraternity 2nd District** for the "100 Units for 100 Years" **American Red Cross Blood Drive**. Thanks to the hospitality of **New Jersey City University (NJCU)**, come to the **Student Center-Multi Purpose Room, 2039 Kennedy Boulevard, Jersey City, New Jersey**. Register online to donate. Go to RedCrossblood.org and enter the sponsor code 15603.

During the drive come and party at the **SCANJ Website Launch Par-tay** to launch www.sicklecellnewjersey.org. **WBLS' DJ's** will be on site to help with the festivities and most of all raise awareness about sickle cell disease and the importance of blood donations.

March 7-10 Take Control of Your Health Peer Leader Training Workshops, part of the Stanford University CDSMP program. Enrollment is limited so register now to be part of this empowering program offered by SCANJ.

March 23-24 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.

Currently from SCDAA; Kermit B. Nash Jr. Scholarship to reward academic achievement of high school seniors with SCD and to promote their pursuit of educational goals. Application deadline is in April. **And, Post Doctoral Research Fellowship** to support young investigators in SCD related research. Application deadline is in July. For details call 1 410 528-1555 or go to sicklecelldisease.org.

A Note 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."

We honor a rich heritage with February, Black History Month. This is the perfect opportunity to share some of the history of sickle cell disease, dispel the myth that it is a "black" disease (see below) and learn of Dr. Charles Drew and the origin of the blood bank (page 2).

While great strides in treatment have been made thanks to the discoveries of scientists, it's important to remember that you are making history right now with your actions. What will the annals of time say about your contribution? Right now you have the power to effect change in this society for the better.

Help SCANJ make history by registering now to save lives with your

blood donation at one of our upcoming blood drives. If you are ineligible to donate, recruit a donor who can. *Make History...*

Come with us to SCDAA's Advocacy Day in Washington DC and effect change with our elected officials. *Make History...*

Help us raise awareness with the SCANJ Website Launch *Par-tay* on February 26th during the 107.5 WBLS and Omega Psi Phi Blood Drive. Celebrate...

www.sicklecellnewjersey.org.

You're invited to make a change!

~ Mary

And The Rest is History...

"Peculiar elongated and sickle-shaped" is how sickle cells were first described in 1904 by intern Ernest Edward Irons when examining the blood of Walter Clement Noel, a 20-year-old first-year dental student from a wealthy Black family in Grenada. Noel had been admitted to the Chicago Presbyterian Hospital suffering from anemia and was readmitted several times over the next three years before completing his studies and returning to Grenada to successfully practice dentistry. He died of pneumonia in 1916.

Irons' supervising physician, James B. Herrick, wrote a paper published in 1910 in the *Archives of Internal Medicine* documenting the first known case of sickle cell disease in the United States.

Although this was the first known US case, elements of the disease had been recognized earlier: Afri-

can medical literature reported this condition in the 1870s, when it was known in some areas as "ogbanjes" ("children who come and go") because of the very high infant mortality rate caused by this condition. There are reports of the condition tracking back to 1670 in one Ghanaian family.

While sickle cell disease primarily affects persons of African descent, it is also present in Portuguese, Spanish, French Corsicans, Sardinians, Sicilians, mainland Italians, Greeks, Turks and Cypriots. Sickle cell disease also appears in Middle Eastern countries and Asia.

Linus Pauling and colleagues were the first, in 1949, to demonstrate that sickle cell disease occurs as a result of an abnormality in the red blood cell. This historical finding was the first time a genetic disease was linked to a mutation of a specific protein.

The origin of the mutation that led to the sickle-cell gene derives from at least four independent mutational events, three in Africa and a fourth in either Saudi Arabia or central India. These independent events occurred between 3,000 and 6,000 generations ago, approximately 70-150,000 years.

Despite these and many other advances that have greatly improved and helped lengthen the lives of those with sickle cell, there is still no universal cure. In the United States it is estimated that over 80,000 people have sickle cell disease. Over 1,000 babies are born with the disease each year in America.. With your help we can make history and change that.

Information in this article is licensed under the Creative Commons Attribution-ShareAlike License

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

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



One blood donor helps to save 6 lives

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.

—Beverly Lucas-Editor

Let’s Talk About The Dr Charles Drew Blood Drives

Q. Why are some blood drives called “Dr. Charles Drew” blood drives?

A. They’re named to honor the man responsible for designing and directing the first large-scale blood-banking program-- African American surgeon, researcher, and educator, Dr. Charles Drew. Dr. Drew was a member of Omega Psi Phi Fraternity and his fraternity partnered with Red Cross blood drives in his honor to increase blood donations from African Americans.

In 1938, Dr. Drew conducted exhaustive research on blood plasma preservation techniques as a part of his doctoral research at Columbia University in New York. In 1939, at the dawn of World War II, he set up a trial blood bank at Columbia’s Presbyterian Hospital, and in June of 1940, he was awarded a doctorate for his thesis, “Banked Blood.”

At the same time, WWII had begun to escalate. Although the United States had not officially entered the war, it wanted to aid the British, who desperately needed blood and plasma (the watery yellowish portion that remains after red blood cells are removed). By that time, Dr. Drew was recognized as the foremost authority in blood collection and storage procedures, and, as such he was tapped to head the Blood for Britain project.

As medical director of the project, Dr. Drew worked with colleagues at Presbyterian Hospital to draw up a blue print for a large-

scale blood banking operation. Ultimately, he successfully supervised collection of 14,500 pints of plasma for the British program. And in 1941, he was appointed director of the first American Red Cross Blood Bank, in charge of blood for use by the U.S. Army and Navy.

Q. Why is it important to increase blood donations from African Americans?

A. Donated blood can be given to anyone with the same blood type, regardless of race (and type O, the universal blood type, can be given to anyone). However, scientific research has shown that the best match, and that least likely to cause an allergic reaction, is blood donated from someone of the same ethnic group. Having such blood available is particularly important for people with sickle cell disease, who typically need several transfusions throughout their lifetimes.

Q. How can I help?

A. Please sign up to donate blood for the WBLS Blood Drive at New Jersey City University (NJCU). You can also help by becoming a frequent blood donor. Whenever you donate blood, you can help ensure that your blood donation goes to help a Sickle Cell patient by identifying yourself as African American or Black. The Red Cross staff will place a blue tag on your blood donation, designating it for the Sickle Cell Donor Program. If your blood is not a match for the Sickle Cell Donor Program, it is stored until it can be used by another patient in need.

Coming Up Soon...

Register now for SCANJ supported American Red Cross drives:

- **February 26th 8:00am-2:00pm WBLS Radio & Omega Psi Phi Blood Drive** including SCANJ Launch Par-tay at New Jersey City University
- **To sign up go to RedCrossblood.org** and enter sponsor code **I5603** for the **WBLS Drive**

March 7-10 Get certified to teach Take Control of Your Health. 4 Day Peer Leader Training is from 9:30am to 3:30pm. at Grace Baptist Church, Fords NJ.

NEW Take Control of Your Health 6 week session workshops begin in April. Enroll through SCANJ for these programs.

March 23-24 Sickle Cell Disease Association of America (SCDAA) Advocacy Day Capitol Hill, Call SCANJ if you are interested in going with us.

May 3rd New Jersey Governors Conference on Women, Atlantic City Convention Center . Visit SCANJ at the conference’ Health Fair. To register online go to www.njwomensconference.com.

May 7th Be Sickle Smart Empowerment Day SC workshops and celebrity Dr. Ian Smith. More TBA

May 18-19th New York Mid Atlantic Consortium (NYMAC) Summit. Baltimore MD. Call SCANJ if you are interested in going with us.

June 19th Sickle Cellabration to commemorate World Sickle Cell Disease Day. More TBA

For information call SCANJ-973 482-9070 or,

email us at sicklecellanj@gmail.com