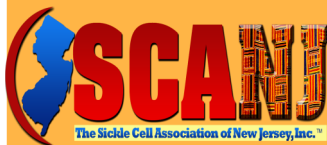


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings:

February

6 Pink Goes Red For A Day Heart Health Program. 6:30pm-9:00pm
25 Maple Ave. Glenfield School, Montclair Omicron Xi Omega Chapter of Alpha Kappa Alpha Sorority. SCANJ presents on the Chronic Disease Self Management Program

28 Black History Celebration with a focus on Sickle Cell Awareness. 3:00pm-5:00pm at the Evergreen Senior Center 400 Inman Ave. Colonia NJ. sponsored by the Independent Club of Colonia. Soul Food Dinner served. This program is FREE however please donate a non-perishable food item for the Woodbridge Food Bank.

February 28-April 4 Take Control of Your Health CDSMP 6 Week Community Workshop 10:00am-12:30pm Alpha Baptist Church 15 Rose Street. in Willingboro **CDSMP enrollment is limited to 20 participants.**

We encourage you to register as soon as possible for programs via www.sicklecellnewjersey.org on the events page or via www.eventbrite.com



SCANJ is the
New Jersey Chapter of the



"Break The Sickie Cycle"SM
Sickle Cell Disease Association
of America



Volume 6
Issue 2

Say It Loud!

February 2015

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

In Light of Black History Month -- Let's Dispel a Myth



Mary Bentley LaMar
Founder
Executive Director

Cypriots. Sickle cell disease also appears in Middle Eastern countries and Asia. It is estimated that 100,000 individuals are affected by sickle cell disease in the United States.

Myth: Sickle Cell Disease is a "Black" disease.

Reality: Sickle Cell Disease affects all ethnic groups including; persons of African descent, Portuguese, Spanish, French Corsicans, Sardinians, Sicilians, mainland Italians, Greeks, Turks and

History: Sickle Cell Disease primarily affects persons of African descent because 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).

Challenge: Become a researcher and a historian (see below). You can accomplish both by recording your family medical history. When you know where you come from, you have a better sense of where you are going and how to deal with challenges.

As you read through this newsletter, be sure to check out the calendar listings and stay posted for other exciting happenings coming up.

-Mary

SCANJ Mission Statement

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

Know Your History; Know Your Family Ties.

You, and your health, are connected to your family's past present and future. So it's important to know your family medical history, or record of health information about you, and your family. A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins.

What you share in common with your family can give insight into health conditions that may run in your family. This information will be helpful to healthcare professionals in determining if you, other family members, or future generations may be at an increased risk of developing common disorders, such as heart disease, high blood pressure, stroke, certain cancers, and diabetes. These complex disorders are influenced by a combination of genetic factors, environmental conditions, and lifestyle choices. A family history also can provide information about the risk of sickle cell disease which is caused by mutations in a single gene.

To begin your family medical history talk to relatives about their health. To help you get started we suggest you use the *Does It Run in the Family?* Toolkit from the Genetic Alliance. The toolkit includes two FREE booklets, *A Guide to Family Health History* and *A Guide to Genetics and Health*.

The first booklet describes the importance of family health history and the ways your genes affect your health. It details information that individuals should collect when compiling a health history and offers tips for asking family members about their health. It also explains how to organize the information to share with family members and healthcare providers. The second booklet goes more in-depth into the role genetics plays in your health, explaining why some diseases run in families and why it is so important for a physician to be aware of a patient's family health history. The online version of the toolkit allows users to customize the booklets for their family, organization, or community to help start conversations about health. Visit www.familyhealthhistory.org to customize your own *Does It Run in the Family?* toolkit.

This article is adapted from information provided by the Genetic Alliance; an organization that engages individuals, families and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network and includes more than 1,200 disease-specific advocacy organizations, including the SCANJ, as well as thousands of universities, private companies, government agencies, and public policy organizations. For more information about Genetic Alliance, visit www.geneticalliance.org.

WWW.SICKLECELLNEWJERSEY.ORG



The Sickle Cell Association of New Jersey

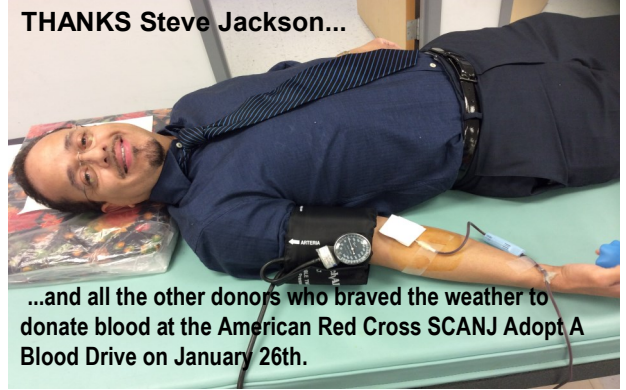
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THANKS Steve Jackson...



...and all the other donors who braved the weather to donate blood at the American Red Cross SCANJ Adopt A Blood Drive on January 26th.

The Say It Loud Newsletter is published monthly except for July and August. Archived copies are available for download from our website.

Beverly Lucas-Editor

Tax deductible donations accepted by mail and via
www.sicklecellnewjersey.org



Patients and Medical Providers...What Do You Think?

Researchers at University of California at Davis have developed an inexpensive optical device that accurately measures the size of blood cells. Ideally, a community health worker would be able to take a finger-prick of blood, dilute it in a stable and inexpensive reagent, and then place it into a machine, which would then read, analyze, and report the results. By probing red blood cell shape and size, they believe they can differentiate diseases like sickle cell and thalassemia minor from iron deficiency for the vast majority of subjects, with a small minority being sent for further testing. They envision the test to be applicable in regions where hemoglobinopathies are prevalent, such as South East Asia, but where there is not enough medical infrastructure to provide gold-standard testing such as gel electrophoresis.

The research is still in the early stages, but based on their 10 patient pilot study, they got cell sizing results that are about as accurate and consistent as current clinical gold-standard measurements (<5% deviation on average from clinical values). Based on those early results they have been accepted into an NSF program (I-Corps, http://www.nsf.gov/news/special_reports/i-corps/about.jsp) whose goal is to enable university researchers to do early-phase market research to determine whether their technology truly solves a need in the marketplace and whether or not they have a viable idea for commercialization.

The National Science Foundation (NSF) is allowing them to get out of the lab and talk to individuals living with sickle cell disease and medical providers who treat sickle cell disease so they can get feedback from those as close to the source as possible. Your insight could help inform the researchers who are developing tools to improve treatment of sickle cell disease.

Although this program is not affiliated with the SCANJ, we encourage informed participation in research and clinical trials. This is your opportunity to voice your unique insight as it relates to this new technology. If you are interested in participating in this market research please contact: Kaiqin Chu: kqchu@ucdavis.edu, 585-8310193(cell) or Zachary Smith: zsmith@ucdavis.edu, 585-8310194(cell)


Coming Soon...

March Women's History Month

In honor of Women's History Month we will launch a special social media campaign celebrating New Jersey Women who are making a difference in sickle cell disease. Stay posted for details...**this is going to be fashionably BIG!**

March 21-April 25 Take Control of Your Health CDSMP 6 Week Community Workshop 10:00am SCANJ in partnership with the Independent Club of Colonia

April is Minority Health Month.



- **April 11th Hands On**
A Wellness Initiative
Location TBA

- **15th SCDAA National Advocacy Day** Road Trip to Capitol Hill.
- **June 20 Sickle Collaboration**
Commemorating World Sickle Cell Disease Day
- **August 29 SCDAA National Walk**-Baltimore, MD
- **September 22-26th** SCDAA National Convention Baltimore, MD

SCANJ appreciates the support of the Pan Hellenic Community.

Special shout out to Delta Sigma Theta Sorority-Monmouth County Alumnae Chapter and Alpha Kappa Alpha Sorority Omicron Xi Omega Chapter for supporting our programs and services.

