

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



Calendar Listings

FEBRUARY Frances Thompson - Walton Scholarship Applications now being accepted. Visit www.sicklecellnewjersey.org events tab on to apply. Deadline May 1st.

6th Connections Support Group
7:00pm-8:30pm AMC Movie Theatre Essex Green in West Orange. Feature film Maze Runner: The Death Cure, co-starring our own Dexter Darden.

Feb 17-March 24th Chronic Disease Self-Management Workshop
9:30AM-12:00PM. Alpha Baptist Church Willingboro, NJ. Enrollment is limited. Contact Darlene Young at 862 371-7138.

Coming up April 21st.



Zeta Phi Beta Sorority, Inc., is honoring members of sororities for their community service. We are pleased that SCANJ Founder, Executive Director, and member of Alpha Kappa Alpha Sorority, Inc., Mary Bentley LaMar, is an honoree. Brunch tickets are \$50.00 for adults and \$30.00 children 12 and under. Call 609 668-3107 for tickets.

SCANJ EVENTS ARE FREE UNLESS OTHERWISE NOTED
REGISTER via the events

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association of America



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Say It Loud!

February 2018

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104

A Message From the Executive Director. . .



Mary Bentley LaMar
Founder
Executive Director

February, Black History Month, is a great time to shine a light on an historical figure in New Jersey, Mrs. Frances Thompson-Walton. The late Mrs. Walton was the first person in our state to establish an organization dedicated to advocating for individuals living with sickle cell disease. The SCANJ is committed to carrying out her legacy of service to the sickle cell community. Please read her story (pg.2).

We also shine a spotlight on the history of sickle cell disease. Did you know that the first patient diagnosed with the disease was a dentist? And did you know that the description of that patient's blood cells led to naming the disease as sickle cell disease?

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.

You can learn these and other interesting facts as you check out this month's newsletter. And of course, you don't have to limit your involvement to reading. You have a standing invitation to participate in our programs. See the calendar listings and register. We welcome your involvement to make history. This world can be better because of you.

~Mary



A Brief History of Sickle Cell Disease

"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.

Iron's 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: African 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 present in all ethnic groups.

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 70,000-150,000 years.

A significant figure in Sickle Cell history is Dr. Charles F. Whitten. During the early 1970s, he realized that services for people with sickle cell disease and their families were sorely lacking. Out of his pioneering efforts to advocate for the needs of people with sickle cell disease, the Sickle Cell Disease Association of America was born.

In 1960 Dr. Whitten started a fund to help minority medical students with financial and academic assistance. He wrote many educational materials and was the recipient of many honors. His papers are archived in the National Institutes of Health Library of Medicine. He was received in the Oval office by three sitting U.S. presidents. Dr. Whitten died in 2008. He is survived by his wife, Eloise (Culmer) Whitten; his daughters Lisa Whitten, PhD and Wanda Whitten-Shurney, MD.

Despite many advances that have greatly improved and helped lengthen the lives of those with sickle cell, there is still no universal cure. With your help. We can make history and change that.

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WWW.SICKLECELLNEWJERSEY.ORG



The Sickle Cell Association of New Jersey
Mailing Address P.O. Box 9501 Newark NJ 07104

EIN# 80-0474935 SCANJ is a 501c 3 agency

1016 Broad St. Newark, NJ
Phone: 973 482-9070 Fax: 973 485-6591
email: info@sicklecellnewjersey.org
or sicklecellanj@gmail.com

Connections Support Group

**Meets the first Tuesday
of each month at 7:00PM**



South Jersey location in the odd numbered months i.e., January, March, May, September and November. **North Jersey** location in the even numbered months i.e., February, April, June, October and December

February Activity: Movie Outing to see Maze Runner

February 6th at the AMC Movie Theatre in West Orange (Essex Green) For more information and to RSVP you may register online via our events tab or call our Community Outreach Coordinator, Darlene Young at 862 371-7138.

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

The Story Behind SCANJ's Frances Thompson-Walton Scholarship:



Frances Thompson-Walton lived from August 3, 1931 to January 4, 2013. She left a legacy of helping others and "championing the underdog." Thompson-Walton, a longtime Jersey City resident, founded Action for Sickle Cell Anemia, Inc. of Hudson County in 1971 and served as president until 1994 when she stepped down due to health reasons.

Elizarea Banks-Martin said that her mother was never satisfied seeing a need that was unmet. "When people would be cynical and criticize other people, she would always say, 'Just keep on living,'" Banks-Martin said.

In 1971, in Jersey City, New Jersey, Mrs. Frances Thompson-Walton was listening to President Richard Nixon deliver his "State of the Union" message, when he declared war on Sickle Cell Anemia. Having been a volunteer worker for such notable organizations as the American Red Cross, Hudson County Tuberculosis Association, The American Heart Association and the Pavonia Girl Scout Council she wondered why no one had organized a volunteer group to work for such a worthy cause as sickle cell anemia. She was appalled at the myths surrounding sickle cell disease and the lack of information available to people wanting to know about the disease.

Mrs. Walton met with William G. Wilkerson, MD and a few other interested persons to sort out facts about the disease. A concerned group of laymen and medical persons became the nucleus for the organization, Action for Sickle Cell Anemia, Inc. of Hudson County (ASCA). Action for Sickle Cell became one of only three organizations in the country addressing Sickle Cell Disease. However through the efforts of Mrs. Walton it was the only organization at the time that offered free testing and follow-up. The group elected Frances Thompson-Walton President in 1971, and she was re-elected each succeeding year until she resigned in 1994 for health reasons.

During the early period when she was nurturing the ASCA, Mrs. Walton attended college receiving her Bachelor's degree in Sociology and her Master's Degree in Reading and Certification as a Reading Specialist. She spent many of her waking hours devising innovative ways of securing funds for sickle cell research. Frequently she took vacation time to visit local schools and agencies where she made film and lecture presentations relative to sickle cell. Over the years thousands of dollars have been sent to Howard University's Research Program and the Sickle Cell Disease Association of America.

Mrs. Walton wrote the Sickle Cell Prayer and dedicated her life to that philosophy which states:

"GOD, Our Heavenly Father and Creator of all mankind, we beseech your divine guidance, as we seek to improve the quality of life for the patients with sickle cell disease. Bless us as we go forth in Thy name, seeking to educate and promote research, so that one day this disease will be eradicated. Dear Father, please grant us the love, the patience, the understanding and the faith that is needed to achieve the goal set before us. Help us to be ever so mindful that the only time one should look down on another is when one is bending over to help another up. In Jesus' name we pray. Amen."

Each year at the Sickle Cellabration, SCANJ awards Frances Thompson-Walton scholarships to individuals living with sickle cell disease. Scholarships are competitive and awarded subject to the availability of funds. Application deadline is May 1st. Visit the events tab on www.sicklecellnewjersey.org to apply.



Coming Soon. . .

March 6th Support Group
 South. JFK Center in
 Willingboro

April 3-6 Peer Leader
 CDSMP 4 Day Certification
 Class in Newark

April 17-18 SCDA Advocacy Day on Capitol Hill
 SCANJ Road Trip

April 21st Zeta Phi
 Beta Sorority Scholarship
 Brunch in Almonesson

June 21, 22, 25 & 26th
 Peer Leader Diabetes Cer-
 tification in Newark

Ongoing: SCANJ Get
 Connected Pop Up Events



Register Now

www.getconnectedscd.org