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.



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# Say It Loud!

Sickle Cell News You Can Use Sickle Cell Association of New Jersey P.O. Box 9501 Newark, NJ 07104

#### Take Time To Reflect on World Sickle Cell Disease Day

#### **Calendar Listings:**

JUNE 5th Connections Support Group. Tuesday 7:00pm –8:30pm Cedarbrook Elementary School 1049 Central Ave in Plainfield.

5th American Red Cross Sickle Cell Blood Drive. 4:00pm-8:00pm Hosted by the Central Jersey Alumnae Chapter of Delta Sigma Theta Sorority, Inc., Cedarbrook Elementary 1049 Central Ave in Plainfield.



9th Liberty State Park. Jersey City, NJ. 9:00am. Support SCANJ's "Walk the Talk Team." and visit our SC Awareness booth.

16th Second Baptist Church 3rd Annual Health Fair and Fun Day. 258 Wesley St. Salem, NJ

21st, 22nd, 25th & 26th Diabetes Self Management 4 Day Peer Leader Certification 9:30am-4:30pm 1016 Broad St. Newark



23rd 10:00am-2:00pm. Funplex in Mount Laurel

ALL EVENTS ARE FREE UNLESS OTHERWISE NOTED.

REGISTER via the events tab on sicklecellnewjersey.org or call 973 482-9070



As we continue to advocate for New Jersey residents with sickle cell disease and their families, it's important to remember that the condition affects people around the world. And it's a growing concern. A 2013 study by UK and Canadian researchers predicted that worldwide by 2050 about 400,000 babies will be born with sickle cell disease each year. Countries in sub-Saharan Africa, where the disease is most common, will be the hardest hit.

Mary Bentley LaMar Founder Executive Director

On Saturday June 23, 2018, SCANJ will join others around the globe to commemorate World Sickle Cell Dis-

ease Day (June 19th). We will host a Sickle Cellabration with a World Festival of fun, food and learning where there will be activities for the young and the young at heart. We will also award the Frances Thompson Walton Scholarships and select **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.

the 2018-2019 New Jersey Sickle Cell Child and Teen Ambassadors. Make sure that you RSVP.

As we move forward, I look back with gratitude. On that note, I thank our volunteers who came out to help raise awareness and register voters during the Univer-Soul Circus run-Dominique Goodson, Kay Diene Robinson, Alexis Harkley, Amanda Koon, Akil Prowell and Kendi Prowell. And thanks to SCANJ staff, Darlene Young and Sakiyyah Burwell-Darden. SCANJ is stronger with your dedication and commitment. Blessings flow. . .

~Mary

#### A Sickle Cellabration Heard Around The World!

Here's what others around the world have done or plan to do on World Sickle Cell Disease Day: In Nigeria, the Coalition of Sickle Cell NGOs (nongovernment organizations) is organizing a charity walk with the theme "SCD: Walk for Hope." The walk will bring together people to advocate for the recognition of SCD as a major public health problem in Nigeria, where 1 in 4 people has sickle cell trait and more than 150,000 babies with SCD are born annually.

The Sickle Cell Disease Association of Canada is taking action by setting up blood drives throughout the country. Potential donors can go online to register.

Last year on World Sickle Cell Day in Guyana, citizens were urged to petition their Members of Parliament to introduce and pass the Sickle Cell Treatment Act, which calls for routine sickle cell screening of all newborns within one week of birth.

In 2016, the African and Caribbean Women's Association (ACWA) in Glasgow, Scotland held an awareness event featuring guest speakers. Scotland had 210 patients with sickle cell in 2015, up from 58 in 2005.

In London, students from the Palmer Catholic Academy held an awareness day where children and staff paid £1 to come to school without being required to wear their uniforms. Sickle cell disease affects 14,500 people in England. In 2015, The Saudi Arabia Ministry of Health organized a series of workshops, lectures and awareness campaigns on the treatment of sickle cell disease at primary health care centers and shopping malls. In 2015, ministry officials reported that 145,750 people in the country had sickle cell disease.

On World Sickle Cell Disease Day in 2015, Jamaica's Minister of Health was a featured speaker at an awareness event. He announced that by 2018 his goal was for all pregnant women and newborns to be screened for sickle cell, for treatment guidelines to be completed and published, and for 90 percent of healthcare workers to be trained in the management of sickle cell disease.

In 2015, medical personnel from the Aga Khan, Moi Teaching and Referral and Homabay County hospitals in Nairobi, Kenya offered free screening, consultation and treatment. According to the University of Nairobi Health Services, SCD affects about two per cent of newborns in western Kenya and parts of the coastal region. About 60 to 80 per cent of those children die before their fifth birthday.

What are you doing to commemorate World Sickle Cell Disease Day? When you raise your voice, it can make a difference. Let the world hear you!

## 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

Phone: 973 482-9070 Fax: 973 991-0297 email: info@sicklecellnewjersey.org or sicklecellanj@gmail.com

## Connections Support Group



Meetings on the first

Tuesday of each month at 7:00PM. South Jersey location in the odd numbered months. North Jersey location in the even numbered months i.e., February, April, June, October and December

June Topic: World Sickle Cell Disease Day This month's meeting is Tuesday June 5th at Cedarbrook Elementary School, 1049 Central Ave in Plainfield. For more information and to RSVP you may register online via our events tab or call 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** 

# www.sicklecellnewjersey.org



Comina Soon. . .

August 18th SCDAA Walk with the Stars! Donate to SCANJ's Walk the Talk team www.sicklecellnationalwalk.org

September Sickle Cell Awareness Month

September 4th Connections Support Group South. JFK Center in Willingboro.

8th Kente Carpet Movies Under The Stars Garden Stroll and Walk in Montclair

29th American Red Cross SCD Awareness Blood Drive in partnership with the Buffalo Soldiers Motorcycle Club. Calvary Baptist Church in Morristown

October 10-13th SCDAA Convention, Baltimore MD. Stay posted for The 24 SEVEN Line Dance Marathon and the Statewide Sickle Cell Symposium