

PRESS RELEASE For Immediate Release June 17, 2019

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## "Shine the Light on Sickle Cell" Campaign Celebrates the 10<sup>th</sup> Anniversary of World Sickle Cell Awareness Day

Sickle Cell Community Launches 24-hour Awareness Campaign Across the Country

(June 14, 2019 – BALTIMORE) SiNERGe and Sickle Cell Disease Association of America, Inc. (SCDAA) are collaborating with sickle cell advocacy groups, community-based organizations, hospitals, governments and other key stakeholders in the sickle cell community on *Shine the Light on Sickle Cell*, a 24-hour awareness campaign to celebrate the 10<sup>th</sup> anniversary of World Sickle Cell Awareness Day on June 19, 2019.

June 19th was officially designated by the United Nations as World Sickle Cell Awareness Day. The international awareness day is observed annually with the goal to increase public knowledge and an understanding of sickle cell disease (SCD) and sickle cell trait (SCT), and the challenges experienced by patients and their families and caregivers. On June 19<sup>th</sup> and within the month of June, individuals and organizations are hosting a number of activities across the country.

"June 19 is a day of unity and purpose for the sickle cell community," says Dr. Sophie Lanzkron, associate professor of medicine at the Johns Hopkins University School of Medicine and co-director of the SiNERGe collaborative. "We're proud to work with the SCDAA to highlight the need for increased awareness about sickle cell disease and its impact on individuals and their families here in the U.S. and abroad."

SCD is a global health problem affecting millions of people around the world. It is estimated that approximately 100,000 Americans have the disease, and more than 1,000,000 worldwide have sickle cell trait. Each year, approximately 1,000 babies in the United States are born with SCD, and there is no universal cure for this life-threatening disease.

"SCDAA is proud to collaborate with SiNERGe on this important national awareness campaign that has brought together the diverse stakeholders within the sickle cell community to create events, activities and opportunities to bring attention to sickle cell disease and to encourage individuals to get involved in our efforts to advocate on behalf of the those affected by this disease," said SCDAA President and CEO Beverley Francis-Gibson.

Visit the Shine the Light on Sickle Cell Campaign Facebook page at <a href="https://www.facebook/com/pg/ShineTheLightOnSickleCell/events">www.facebook/com/pg/ShineTheLightOnSickleCell/events</a> to learn about the events happening across the country on June 19 and in the month of June. Here's a few to mark on your calendar:

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- June 19, 2019 Australia Sickle Cell Advocacy Launch in Australia, 7:30am-9:30am
- June 19, 2019 Five Philadelphia Landmarks Go Red in Philadelphia, PA, 6pm-6am
- June 19, 2019 Philadelphia Boathouse Row Lighting in Philadelphia, PA, 6-8pm
- June 19, 2019 NY Shine the Light on SCD in Jamaica, NY, 11am-8pm
- June 19, 2019 Strike Out Sickle Cell in Highpoint, NC, 10:30am-12:30pm
- June 19, 2019 Jam for Sickle Cell in Columbia, SC, 6pm-7:30pm
- June 19, 2019 Virginia World Sickle cell Day Observation in Norfolk, VA, 4pm-8pm
- June 19, 2019 New Jersey World Sickle cell Day Celebration in Newark, NJ, 7pm-9pm
- June 19, 2019 6<sup>th</sup> Annual World Sickle Cell Day Symposium in Washington, DC, 1pm
- June 21, 2019 Citizens for Quality Sickle Cell Care Night at Dunkin Donuts Park in New Britain, CT, 7-10pm
- June 22, 2019 SCDAA 6th Annual Walk with the Stars & Move-a-thon in Baltimore, MD, 9-12pm
- June 22, 2019 Shine the Light on SCD in Puerto Rico in Puerto Rico, 4-8pm

## **About SiNERGe**

Sickle cell Improvement across the NorthEast ReGion through Education (SiNERGe) is a multi-state collaborative that includes sickle cell providers and community-based organizations dedicated to improving care for individuals with sickle cell disease throughout the Northeastern United States, Puerto Rico, and the U.S. Virgin Islands. The collaborative is led by Johns Hopkins Medicine and is funded by the Health Resources and Services Administration through the Sickle Cell Disease Treatment Demonstration Program. Together SiNERGe members are working to improve access to high quality care for individuals living with sickle cell disease and increase number of providers who possess the knowledge, skills and attitudes to deliver high quality care. SiNERGe's community-based organization (CBO) initiative is led by the William E. Proudford Sickle Cell Fund, Inc.

## **About SCDAA**

SCDAA's mission is: To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. Visit <a href="https://www.sicklecelldisease.org">www.sicklecelldisease.org</a>.

## About SCD

SCD, an inherited blood disease, causes red blood cells to have a sickle shape. Because of their stiffness and unusual form, blood flow is blocked to different tissues, ultimately damaging them. These sickle-shaped red blood cells contain an abnormal type of hemoglobin, hemoglobin S; normal red blood cells have hemoglobin A. Hemoglobin is important because it helps carry oxygen throughout the body. There is currently no universal cure for SCD.

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