National Sickle Cell Disease Awareness Month Press Kit
September 2020

Contents

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Sickle Cell Disease Association celebrates National Sickle Cell Awareness Month

Conferences, advocacy, blood donations and other events held throughout September

HANOVER, Md.—Sickle Cell Disease Association of America will participate in National Sickle Cell Awareness Month in September by holding a series of events and supporting the events of member organizations. National Sickle Cell Awareness Month was designated by Congress to focus attention on the need for research and treatment of sickle cell disease.

"Individuals and organizations can join our efforts to bring attention to sickle cell disease by engaging elected officials for proclamations, hosting awareness events, distributing educational information to dispel the myths about sickle cell disease and lighting public spaces, buildings and landmarks red," said Beverley Francis-Gibson, president and CEO of Sickle Cell Disease Association.

- The **2020 Sickle Cell Disease Therapeutics Conference** will take place virtually Sept. 15 at 9 a.m. Hosted by Global Blood Therapeutics Inc. in partnership with the Sickle Cell Disease Association, the conference provides a forum to discuss the latest advancements and future trends for treating patients with sickle cell disease. Health care companies, opinion leaders, patients, policymakers and others will present at the conference. Learn more and register online.

- A **Sickle Cell Awareness Month Twitter Party**, an online Twitter conversation hosted by the Sickle Cell Disease Association where participants interact, share, learn and celebrate by posting tweets using the hashtag #SickleCellMatters, will take place Sept. 21, 23 and 25 from 12:30 to 1:30 p.m. Register online.

- **Fight sickle cell disease by donating blood** to the American Red Cross. Donors can make an appointment by downloading the American Red Cross Blood Donor app, visiting RedCrossBlood.org or calling 1-800-733-2767.

- **Sickle cell groups across the country** will hold National Sickle Cell Awareness Month events throughout September, including town halls, webcasts, walks and races, summits and seminars and fundraisers. Learn more online.

Sickle Cell Disease Association invites advocacy organizations, corporate and federal partners and supporters to use the hashtags #SickleCellMatters, #SickleCellAwarenessMonth, #SCDAA2020AwarenessMonth and #SCDSCTMatters in social media posts about sickle cell disease throughout September. More information, including a flyer and fact sheet, is available online.

Sickle cell disease is an inherited blood disease causing red blood cells to take a sickle shape, which leads to blockages that prevent blood from reaching parts of the body. As a result, people with sickle cell

complications can experience anemia, jaundice, gallstones, stroke, chronic pain, organ damage and premature death. No universal cure exists. (sicklecelldisease.net)

Sickle Cell Disease Association of America advocates for people affected by sickle cell conditions and empowers community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. The association and more than 50 member organizations support sickle cell research, public and professional health education and patient and community services. (www.sicklecelldisease.org)

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SICKLE CELL DISEASE
FACTS AND STATS

WHAT?

Sickle cell disease (SCD) is an inherited blood disorder in which red blood cells may become sickle-shaped and harden. For a baby to be born with sickle cell disease, both parents have the sickle cell trait or, one parent has the sickle trait and the other parent has another abnormal hemoglobin trait. Sickle cell disease is not contagious, and there is no universal cure.

The Facts

- About **1 in 13** African Americans carry the sickle cell trait and many do not know they have it
- Estimated **100,000** in U.S. have SCD
- **24,000** babies born with SCD annually in the U.S.
- Average age of diagnosis: **under 5 months**
- **8%** of African Americans are carriers
- Latinos have the **second** most common incidence in the U.S.

The blockage of blood flow caused by sickled cells leads to complications including:

- Chronic severe and unpredictable pain
- Anemia
- Frequent infections
- Fatigue
- Delayed growth
- Vision problems/blindness
- Lung tissue damage
- Kidney disease
- Stroke
- Shortened life expectancy
- Blood clots
- Damage to hip joint
- Skin ulcers at ankles
- Difficult pregnancy

WHERE?

- Sickle cell disease is a global health problem

Staying healthy with sickle cell disease involves:

- Pain management
- Blood transfusions
- Self-care including eating well, exercising and drinking water
- Preventive antibiotics (when prescribed)
- Prescription treatments such as hydroxyurea, glutamine, voxelotor and crizanlizumab to reduce severity of SCD
- Screening tests for early detection of some sickle cell complications

The search for a cure…

Bone marrow (stem cell) transplants can, in some cases, cure sickle cell disease, but not all individuals are eligible for this procedure and there are associated risks. Read more about this NIH initiative: **www.curesickle.org**

Medical and Research Advisory Committee
Sickle Cell Disease Association of America, Inc.

MARAC Advisory Statement for SCD Patients Who are Teachers, Administrators, and Other Support Staff during School Reopening

SHOW THIS TO YOUR EMPLOYER TO HELP THEM HELP YOU.

July 31, 2020 – The Medical and Research Advisory Committee (MARAC) of the Sickle Cell Disease Association of America finds that individuals with sickle cell disease are more vulnerable to severe COVID-19 than the general population. This position has also been supported by the Centers for Disease Control (CDC) and the American Society of Hematology (ASH) COVID-19 guidelines.[1,2] **We recommend that all vulnerable teachers, administrators, and support staff should work from home if they are able to do so.** Educators with sickle cell disease should be given priority for providing distance learning from home, if possible. Innovative approaches should be used such as lecturing from home or an isolated location away from students in the classroom supervised by paraprofessionals on site. Administrators should make special accommodations for vulnerable individuals at work if working from home is not possible. Recommendations about controlling exposure have been put forth by the CDC[1] and National Institute for Occupational Safety and Health with modification by Johns Hopkins University.[3] An excellent framework for implementation has been provided in a monograph by the American Federation of Teachers.[4] Measures to be considered include but are not limited to:

- Maintaining physical distancing.
- Implementing an effective system for testing, tracing, and isolating new cases.
- Using public health tools and age appropriate education to minimize risks of transmission to students, teachers and support staff stressing:
    - Physical distancing
    - Screening
    - Personal protective equipment and sanitation
    - Campus programing and organization to minimize unnecessary contact between people.
- Strong psychological and social support for all staff members.

What does this mean for individuals living with sickle cell disease?
We recommend that individuals with sickle cell disease follow the advice of their local healthcare providers and their local and state authorities. They need to follow the rapidly changing local COVID-19 infection status and have ongoing discussions with their education administrators about how to minimize their health risks while providing their students the best educational, psychological, and social experience possible.

For More Information, contact info@sicklecelldisease.org

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3. Caitlin Rivers et al., "Public Health Principles for a Phased Reopening During COVID-19: Guidance for Governors," Johns Hopkins Bloomberg School of Public Health, April 17, 2020, https://www. centerforhealthsecurity.org/our-work/publications/public-health-principles-for-a-phased-reopeningduring-covid-19-guidance-for-governors.
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Office of the Press Secretary

FOR IMMEDIATE RELEASE

August 31, 2020

NATIONAL SICKLE CELL DISEASE AWARENESS MONTH, 2020

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BY THE PRESIDENT OF THE UNITED STATES OF AMERICA

A PROCLAMATION

As our Nation recognizes National Sickle Cell Disease Awareness Month, we do so with an unwavering commitment to a future in which people with the condition live fully, without pain and impediments, and ultimately experience a cure. My Administration, through the Department of Health and Human Services (HHS), is leading unprecedented activity in research, medical education, and models of care in support of people with Sickle Cell Disease (SCD). A cure is within reach, the Food and Drug Administration (FDA) has approved new treatments and more are on the horizon, and several initiatives are underway to make better use of all available tools in the battle against this disease.

SCD is a chronic, debilitating, inherited condition that afflicts 100,000 Americans -- primarily African-Americans

and Hispanic-Americans. One in 13 African-Americans and approximately one in 100 Hispanic-Americans carry the gene for this disease. Those individuals with two copies of the gene have blood cells that are sickle-shaped, instead of cylindrical, which causes a disruption in blood flow that can damage many organs, including the brain and kidneys. A person with SCD can begin experiencing the negative effects in early childhood, including pain, organ damage, and risk of stroke. Unfortunately, it is estimated that only one in four patients with SCD in America receive the care that they need.

My Administration puts action behind our words, which is why I signed into law the "Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018" (Public Law 115-327). The bill reauthorizes an SCD prevention and treatment program and authorizes initiatives for research, surveillance, prevention, and treatment of heritable blood disorders. HHS is leading the way to identify and address barriers to care for patients, and several organizations have joined in developing education and training programs to better equip healthcare providers to identify and treat this disease. HHS has also begun collaborating with States on new payment models that will enable children living with SCD to receive the care they need.

We have made exciting progress towards our goal of extending the lives of Americans with SCD by 10 years and finding a cure by 2029. In January 2020, HHS launched a new, one-of-a-kind Sickle Cell Disease Training and Mentoring Program (STAMP), to train primary care providers on the basics of SCD evaluation and management. This innovative program is the result of critical collaboration between the Office of Minority Health and the Health Resources and Services Administration. The FDA has

approved two new drugs to help prevent the complications of SCD, is providing leadership to reduce barriers and hasten the development of new treatments, and has developed multi-media educational resources for patients and their families. The National Institutes of Health (NIH) has initiated an aggressive portfolio of research, education, and capacity building, including the "Cure Sickle Cell Initiative" to accelerate gene therapies to cure the disease. NIH reports that the most promising genetic-based curative therapies for SCD could be available in clinical trials in the very near future.

My Administration is leading on SCD advancements both in the United States and throughout the world. In May 2019, HHS leaders convened a roundtable with African health ministers, international health leaders, and SCD experts to chart a course to save hundreds of thousands of children around the world. Through NIH, we will continue to support the Sickle Pan African Research Consortium, and other Public Private Partnerships to develop gene-based cures.

The United States is helping raise the profile of SCD as a public health priority, by drawing attention to the work underway to create meaningful programs that immediately improve patients' lives. My Administration is committed to advancing treatment, research, and quality-of-care to improve the lives of people with SCD -- and ultimately to deliver a cure to the world.

This month, we take a moment to recognize all Americans with SCD and celebrate our progress toward future treatments. Together, we will secure a healthier future for all Americans.

NOW, THEREFORE, I, DONALD J. TRUMP, President of the

United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States do hereby proclaim September 2020 as National Sickle Cell Disease Awareness Month. I call upon all Americans to observe this month with appropriate programs and activities to eliminate a disease we have known about for more than a century and to work to improve the quality of life of those living with SCD.

IN WITNESS WHEREOF, I have hereunto set my hand this thirty-first day of August, in the year of our Lord two thousand twenty, and of the Independence of the United States of America the two hundred and forty-fifth.

DONALD J. TRUMP

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