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SCDAA-MI "Shines the Light" for World Sickle Cell Day, June 19

Supporters are asked to #MaskUp4SickleCell, celebrate community grads, and recognize #SickleSabbath

(JUNE 12, 2020 – DETROIT, MICH.) Sickle Cell Disease is the most prevalent inheritable blood disorder in the country, affecting 70,000 – 100,000 individuals, most of whom are African American. "It's a blood disease, not a black disease," says Dr. Wanda Whitten-Shurney, citing one of the takeaways her agency and other community-based sickle cell organizations want people to learn through this year's World Sickle Cell Day events. Sickle cell is genetic – not contagious – and most common among people of African descent and those of Latin American and Middle Eastern heritage, but can affect anyone of any race.

"We have an entire weekend of activities that include generating awareness, honoring our graduates, and learning during worship," says Shurney, CEO and Medical Director of the Sickle Cell Disease Association of America – Michigan Chapter Inc. "We're sending our message out into the world to create change on behalf of a group of individuals who were born with a disease that is almost always automatically discriminated against."

Efforts for World Sickle Cell Day, Friday, June 19, aim to enlighten the community-at-large. A social media blitz featuring the hashtags #MaskUpForSickleCell and #BehindTheMask will feature photos of patients, caregivers and allies in red masks telling their stories and sharing key messages:

- Sickle cell disease affects individuals of all races. It's a BLOOD disease, not a Black disease.
- It is in your genes. It is NOT contagious.
- Individuals with sickle cell disease are not drug addicts, they need pain relief.
- If both parents have sickle cell trait they can have a child with sickle cell disease. GET TESTED to know for sure.

Though medically recognized more than 100 years ago, it was only the introduction of prophylactic penicillin in the 70s and subsequent comprehensive pediatric efforts that now allow most individuals with sickle cell to live far beyond childhood and well into adulthood. **To help celebrate their milestones, World Sickle Cell Day continues on Saturday, June 20 with a Virtual Graduation Open House for students finishing high school, trade school or college.**

On Sunday, June 21, World Sickle Cell Day attention turns to houses of worship varying in size, denomination and membership composition for Sickle Sabbath. This outreach effort focuses on educating people about sickle cell trait, which is carried by approximately 1 in 12 African Americans. SCT is also found among people with ancestry from sub-Saharan Africa; the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy according to the Centers for Disease Control. "Sickle cell disease starts with sickle cell trait" is the message churches are asked to carry to their congregations along with information about chances of inheritance and challenges of the disease.

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SCDAA-MI 2020 WORLD SICKLE CELL DAY (cont.)

"This is an impactful time in America and we hope that World Sickle Cell Day can build on the Black Lives Matter movement to create real change in medical settings for people with sickle cell. I'm calling on my colleagues who knelt in solidarity with White Coats For Black Lives to create a movement that makes the emergency rooms and hospitals safe spaces for sickle cell patients," says Shurney.

"The hallmark of sickle cell is excruciating, unpredictable pain that often drives patients to seek care in emergency departments," Shurney continues. "These are individuals who've often lived with pain since childhood and – being good patients – know their bodies and what they need to control their pain, which is typically opioids. Yet they arrive at hospitals seeking relief and are often accused of being there just to get drugs. You would think they'd be treated like a Type 1 diabetic who shows up needing care and knows their proper insulin dosage, but they're not."

In February, SCDAA-MI launched its SAFE(R) initiative to help counter this reality. SAFE(R) provides medical professionals with quick access to an online portal at SCDAAMI.org/SickleCell911 that provides clinical practice guidelines for sickle cell established by the National Institutes of Health, sickle cell-specific opioid guidance from the CDC, and emergency room triage guidelines from the Agency for Healthcare Research and Quality, as well as best practices and recommendations from the American Society for Hematology and other leading experts in sickle cell treatment.

Only about one in four patients with sickle cell disease receives the standard of care described in current guidelines, and many studies have shown that patients do not receive treatment for their pain as soon as, or in appropriate doses as, other patients, according to the U.S. Health and Human Services Office of Minority Health.

"The world is at a crossroads and so is sickle cell disease. Two new medications were approved by the FDA for treatment at the end of 2019. Yet, patients still face barriers accessing these meds and receiving competent, compassionate medical care," says Shurney. "Too many providers still don't know how to properly treat sickle cell patients. Stereotypical biases prevent many individuals from receiving care according to nationally established guidelines – or any care at all.

"We have a long way to go to reach health equity where sickle cell is concerned. Now is a great time to start."

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Our Mission

To maximize the quality of life of individuals living with sickle cell disease.

To enable individuals with sickle cell trait to make informed decisions with respect to family planning.

To provide education and testing for the general public.

Founded in 1971 by Charles F. Whitten, M.D., the Sickle Cell Disease Association of America – Michigan Chapter, provides education, assistance, and advocacy for individuals living with and families affected by sickle cell disease. Other services include counseling, support groups, referrals for financial assistance and medical care. SCDAA-MI connects students and job seekers with school, college and employment assistance; sends children to summer camp each year, and works to raise public awareness. The agency also serves as the coordinating center for the newborn sickle cell screening program for the Michigan Department of Health and Human Services. The agency also conducts blood tests to diagnose sickle cell trait and other sickle cell conditions at its Detroit office, 18516 James Couzens Fwy, Detroit, MI 48235.

SCDAA-MI's services are available throughout Michigan and span lifetime needs.

For more information, visit www.scdaami.org or call 313-864-4406.