

Pioneering Program Tackles Major Pain Point For People with Sickle Cell Disease

Improving Access to Effective Emergency Care

TURLOCK, CA, UNITED STATES, September 24, 2024 / EINPresswire.com/ -- There's one thing



every person with sickle cell disease dreads: having to go to the ER and fight for care during a pain crisis.

But now there's a beacon of hope for the 100,000 Americans living with the blood disorder.

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> Karen Cassel, CEO & President, MedicAlert Foundation

MedicAlert Foundation and Sickle Cell Disease Association of America (SCDAA) have partnered on a groundbreaking initiative to improve their experience in the emergency room.

The non-profits' goal is to speed up treatment and improve outcomes when someone with sickle cell disease (SCD) seeks emergency care during a debilitating pain crisis.

The Pain of Sickle Cell

SCD is a hereditary disease, characterized by misshapen red blood cells that don't flow freely through the body.

These cells become lodged in small blood vessels, blocking blood flow and causing episodes of excruciating pain - the hallmark symptom of SCD known as a sickle cell pain crisis.

Pain crises can be frequent, and last from a few hours to a few days, or even weeks. Severe pain crises need immediate emergency treatment to avoid potentially life-threatening complications. Often, the only medications that can treat this level of pain are opioids.

Battles in the Emergency Room

In the U.S., 90% of people with sickle cell disease are Black. Often, they face an uphill battle to get timely and appropriate care in an emergency setting. Because sickle cell is a rare disease, many

healthcare providers are unfamiliar with protocols for treating a pain crisis. In addition, implicit or explicit bias in the healthcare community can result in patients being wrongly labeled as "drug seekers" when seeking pain relief for SCD.

Sickle cell patients report that even when they're in intense pain, they clean themselves up and dress nicely to go to the ER, in hopes they'll be taken more seriously. Although they're taught to be well versed on the pain meds in their care plan, ER personnel are sometimes suspicious if patients name specific drugs and dosages.

As a result, SCD patients often endure agonizingly long waits for the medication they desperately need. They suffer unnecessarily, and the risk of serious or even fatal complications escalates quickly the longer they wait for adequate care.

Improving the ER Experience

This joint program leverages MedicAlert's recognition in the medical community - and longstanding reputation for providing valuable patient information in an emergency - to help people with SCD easily communicate their medical history during a pain crisis.

"Our sickle cell warriors suffer because medical personnel don't believe them. They don't believe the individual is sick or in pain. They don't believe the patient can tolerate the high dose of pain meds they're asking for.

That's why this partnership with MedicAlert is so exciting. Doctors already know MedicAlert. There's a level of credibility and familiarity health care providers have when a sickle cell patient presents their MedicAlert card," said Regina Hartfield, SCDAA's President and CEO.

Participants are armed with two potent weapons: a MedicAlert ID card and an extensive digital health profile. Every participant receives an ID Card with a personalized QR code to present when they visit the ER. It grants emergency personnel instant access to the patient's health profile, including their medical history, physician-approved pain management plan, and hematologist contact information. This cuts through confusion and delays, enabling ER staff to make faster and more informed treatment decisions.

Thanks to initial funding from a corporate donor, during the program's pilot phase these tools are provided free of charge to adults living with SCD.

"We're so happy to work with SCDAA on this vital initiative - especially during Sickle Cell Awareness Month," said Karen Cassel, CEO and President of MedicAlert Foundation.

"What these sickle cell warriors face in getting emergency care is daunting. Our goal is to provide tools that improve the ER experience for everyone with SCD. This program is a significant step forward in tackling the unmet needs of the SCD community - and it aligns perfectly with

MedicAlert's mission of protecting and saving lives."

Taking Action for Better Care

During the pilot phase, the non-profit organizations are collecting pre- and post-ER visit feedback from participants to measure the success of this intervention so it can be rolled out more broadly. The pilot program is now open to U.S. adults 18 and over with sickle cell disease. Every participant helps advance development of tools that can benefit the entire sickle cell community. Individuals interested in participating can apply online at: <u>Sickle Cell Intervention Pilot</u>.

About MedicAlert Foundation

MedicAlert Foundation is a nonprofit 501(c)(3) organization, and the creator of the original medical ID. Since 1956, MedicAlert has helped people with chronic medical conditions receive fast and accurate emergency care. The MedicAlert emblem is globally recognized by first responders and emergency personnel, who engage MedicAlert's live emergency response specialists for the patient's full health details and connection to emergency contacts. For more information, visit <u>medicalert.org</u>.

About Sickle Cell Disease Association of America

The Sickle Cell Disease Association of America is a national organization working to advocate for individuals living with sickle cell disease, provide education and support, and promote research to ultimately improve the quality of life for those affected. With over 50 years of service, SCDAA plays a pivotal role in advancing the awareness and understanding of sickle cell disease. For more information, please visit <u>www.sicklecelldisease.org</u>.

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