



*Sickle Cell Disease Association of America, Michigan Chapter, Inc.*

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**SCDAA-MI ANNOUNCES SAFE(R) INITIATIVE TO IMPROVE EMERGENCY SICKLE CELL CARE  
Effort aims to assist medical community in proper treatment of long-misunderstood disease**

Today, the Sickle Cell Disease Association of America - Michigan Chapter launched a new initiative designed to help advance the care and well-being of individuals living with sickle cell disease. The initiative, known as SAFE(R), provides medical professionals with quick access to an online portal at [SCDAAMI.org/SickleCell911](http://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 Centers for Disease Control, as well as best practices and recommendations from the American Society of Hematology and other leading experts in sickle cell treatment.

Though medically recognized more than 100 years ago, it was only the introduction of prophylactic penicillin in the 80s and subsequent comprehensive pediatric efforts that now allow most individuals with sickle cell to live far beyond childhood, although their lifespan still falls short of the national average by about 30 years. Yet, while research and treatments for the disease are now gaining more attention, individual's lives are at stake daily due to a lack of adult medical providers trained in sickle cell's complexities. In fact, there is a peak in mortality at the time of transition from pediatric to adult care.

"For more than 30 years, I've had the privilege of serving as pediatrician to Michigan children with sickle cell disease – caring for them and their families, and advocating for their needs. Along with my colleagues across the country, we've achieved levels of success in their healthcare that my father only dreamed of when he started SCDAA-MI 49 years ago," says Dr. Wanda Whitten-Shurney, CEO and Medical Director. "Now we've reached this pivotal point in sickle cell history where research and treatment possibilities are at an all-time high, yet, we are losing far too many patients we've brought all this way for the past four decades to a medical system unprepared to receive them."

The emergency room – a frequent stop for our patients – is an extremely perilous place for adults. Individuals out-of-state have often reached out to their former pediatricians at the Children's Hospital of Michigan Sickle Cell Clinic asking them to coach a doctor in charge of their care unfamiliar with the disease. The situation has produced a skepticism among patients that they'll be adequately cared for, sometimes causing them to take their chances and not go to the ED at all.

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## SCDAA-MI SAFE(R) INITIATIVE (cont.)

Central, then, to the SAFE(R) Initiative is the wallet-sized Sick Cell 911 (SCD911) card, which directs providers to the SAFE(R) site at [SCDAAMI.org/SickleCell911](http://SCDAAMI.org/SickleCell911). In addition to guidelines, recommendations and best practices, the medical professional-focused pages also provide educational resources about the disease and its potential complications.

Sickle cell patients are advised to carry the SCD911 card with them and present it when they need emergency care – whether at home or away. Patients and caregivers have shared stories about ED providers resorting to the internet or medical journals to find information about treating the disease. The SAFE(R) initiative puts that information at providers' fingertips in an easily accessible and usable format, hopefully saving crucial acute care time that in turn leads to saving lives.

"I'm appealing – no, challenging – my counterparts in adult primary, specialty, and emergency medicine to partner with us in changing this narrative by committing to SAFE(R) treatment. It's time for a plot twist, so to speak, and we invite you to help re-write the future chapters of the sickle cell story. Patients throughout Michigan are looking for SAFE(R) spaces for care every day. Let us know we can confidently refer them to you and your health systems for this compassionate, equitable, and guideline-based treatment. History will thank you and so will we."

I'm experiencing a sickle cell emergency requiring immediate, specialized treatment. I've been encouraged to share this card to help support you in my care.

Name \_\_\_\_\_  
SCD Type \_\_\_\_\_  
Baseline Hemoglobin \_\_\_\_\_  
Physician \_\_\_\_\_

**ACCESS CURRENT CLINICAL  
PRACTICE GUIDELINES FROM  
NIH NHLBI / CDC / ASH AT  
[scaami.org/  
SickleCell911](http://scaami.org/SickleCell911)**

**EXPERT GUIDANCE FOR:**

- vaso-occlusive crises/pain episodes  
● fever ● acute complications  
● administering opioids ● primary care

**COMPILED COURTESY OF Sickle Cell Disease  
Association of America — Michigan Chapter**

**PER NIH NHLBI GUIDELINES, WITHIN  
30 MINUTES IN THE ED:**

**STOP the pain.** Appropriate levels of narcotics are essential! Pain = vaso-occlusion: tissue anoxia and damage

**ADMINISTER appropriate amounts of IV fluids.** IV fluids treat and prevent dehydration.

**FEVER requires immediate blood cultures and IV antibiotics** to treat possible bacterial sepsis.

**EXECUTE the guidelines.** Prevent organ damage, stroke, and other life-threatening complications.

— **YOU CAN** —  
**(R)EDUCE morbidity** associated with inadequate acute sickle cell care.

 *Keep sickle cell patients **SAFE(R)**!*  
**ACCESS NIH NHLBI /ASH/CDC GUIDES  
[scaami.org/SickleCell911](http://scaami.org/SickleCell911)**