THE CASE FOR SAFER

FINDING SYNERGY IN HEALTH EQUITY AND QUALITY

A CALL TO PARTNER

WITHIN 30 MINUTES IN THE ED TRIAGE AS ESI 2 PER NIH & AHRQ

STOP the pain. Patient requires proper levels of IV opioids within 30 mins of triage. Assess & re-dose in 30 mins. Pain = vaso-occlusion = tissue anoxia and damage = **emergency**

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

FEVER requires blood cultures and IV antibiotics within one hour to treat possible bacterial sepsis.

EXECUTE the guidelines. Labs screen for underlying complications. They do not rule out pain crisis!

YOU CAN

(R)EDUCE morbidity associated with inadequate acute sickle cell care.

ACCESS CURRENT PRACTICE GUIDES AT
SickleCell911.org

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.

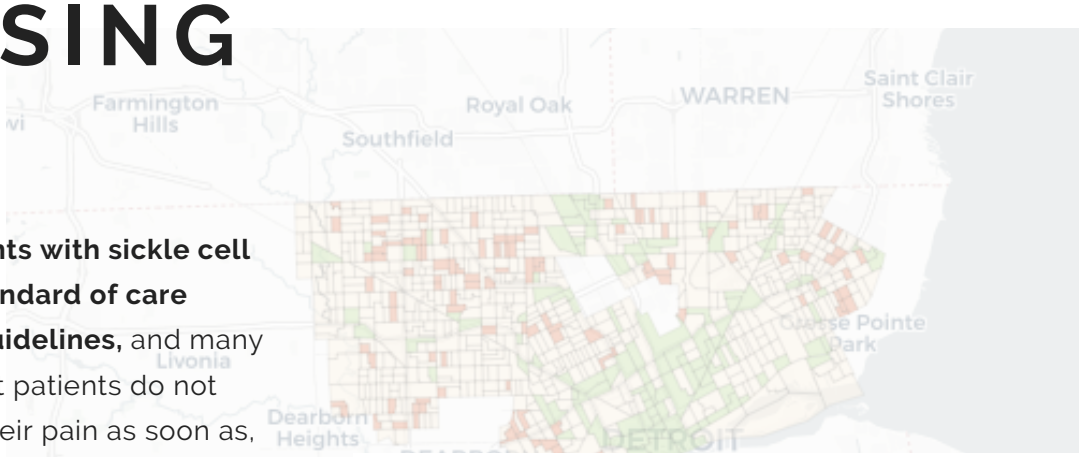
Name _____
SCD Type _____
Baseline Hemoglobin_____
Physician _____
Dr.'s Phone _____

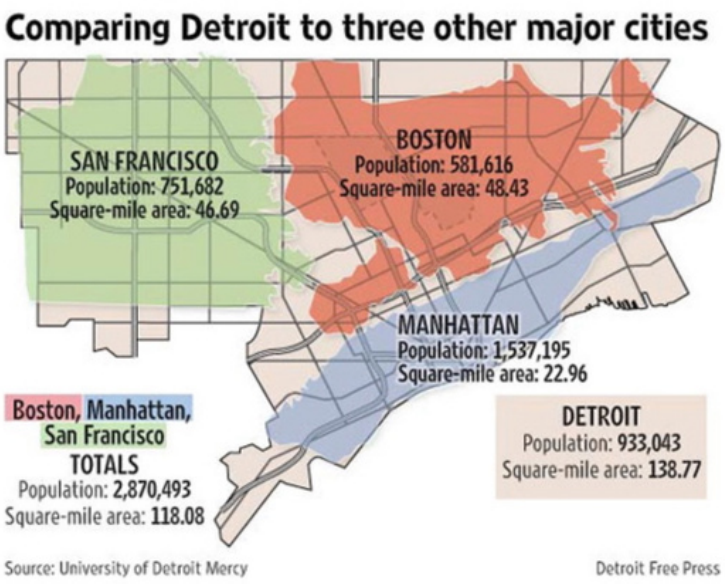
ACCESS CLINICAL GUIDELINES FROM NIH / CDC / ASH / AHRQ

SickleCell911.org

EXPERT GUIDANCE FOR:
vaso-occlusive crises/pain episodes
● fever ● acute complications
● administering opioids ● primary care

A PRESSING NEED





Top photo (courtesy of transitdeserts.org) illustrates Census Block Group areas in the city of Detroit ranked as Transit Deserts (shown in red) where upwards of approx. 40% of residents are (public) transit-dependent and that need is unmet. Lower photo (courtesy of detroitography.com) compares Detroit's geographic size to the cities of San Francisco, Boston, and Manhattan.

- **Only about 1 in 4 patients with sickle cell disease receive 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. -HHS Office of Minority Health
- While metro Detroit lacks a comprehensive adult sickle cell center, **the city's geographic size presents its own barrier to access for many patients.** Detroit's land mass is nearly three times the size of San Francisco and Boston, and six times the size of Manhattan. Yet unlike each of these cities, Detroit's southeast Michigan region has no regional transportation system and city/suburban transit (bus only) is often spotty, particularly in cold months.
- **This means that a person with sickle cell living in Detroit may have to travel 3-6 times as far for care as SCD patients in other major cities.** Moreover, the city's lack of transit correlates to residents' lack of personal transportation. In Michigan, which has long boasted the highest priced auto insurance in the country, the cost of owning a vehicle is yet another barrier to care.
- Anecdotally, **care across metro Detroit's EDs (even among Level I and Level II facilities) varies significantly** based on whether patients have established PCP or hematology care, which physician they encounter, or a host of other circumstances beyond their control.
- **Patients with personal transport will drive as far as 45 minutes away to receive quality, compassionate care.** Others are forced to take their chances with the nearest facility.

- Sidebar conversations with area physicians have revealed that **many ED doctors aren't even aware that guidelines for acute sickle cell treatment exist.**
- SCDAA-MI serves people throughout Michigan. **City challenges are often magnified in out-state settings** where the population of people with SCD is more scattered and hospital EDs are more likely to be Level III or Level IV.
- The root causes of poor sickle cell care - **stigma, bias, and lack of or mis-education - transcend geography.** Tools to level the treatment playing field should do the same.

CONSTRUCTING CHANGE

SAFER is a need-driven, guideline-based, quality improvement initiative created to help re-frame misperceptions of sickle cell pain within the medical community; eliminate the inadequate, traumatizing treatment experienced by too many patients in a medical setting - especially EDs and hospitals; and bolster patient confidence in our commitment to improving their lives in a way that immediately resonates with them:

- Fueled by a personal ED encounter experienced with my son and the mental takeaway of an internet printout titled “Sickle Cell Anemia” in use by nurses.
- Reinforced by stories from patients across the country, revealing incidents of unwitting physicians resorting (on-the-spot) to books, journal articles, and online searches in an attempt to provide care.
- Meant to re-envision the reality that individuals with sickle cell have offered documents for verification of their disease and treatment requirements, yet ED medical providers have dismissed or overridden them.

My Warrior. Photo used with permission.

NURSING WITH A DIFFERENCE: Patricia Worth, a registered nurse, is assistant director of nursing and patient coordinator for the psychiatric department at Christian Hospital Northwest. (Post-Dispatch Photo)

THE SPARK

- My 78-year-old mom’s **40+ years** with chronic sarcoidosis. *(Shared with permission)*
- She's always told new doctors **how to treat her condition**. They listen.
- But my mother is a former nurse and **brings built-in medical credibility** to her instructions.

THE CHALLENGE

- How to instill mom’s **presumed credibility** in SCD patients.
- How to amplify the **patient’s voice** over inherent biases.
- How to present as **authoritative and even-keeled** in acute situations where a patient’s ability to **advocate** for him or herself could be hampered by pain.
- How to fit all this in an **easy**-to-carry, easy-to-present, easy-to-understand, and easy-to-use **tool** (simple for both patients and hurried ED medical professionals).

Find SAFER at www.SickleCell911.org

OUR SOLUTION

- The **tool** evolved as a **wallet-sized card** - convenient to carry, inexpensive to leave behind.
- **Credibility** is rooted in the **guidelines** - NIH NHLBI, CDC, ASH, and AHRQ - modifiable as new science requires.
- **Easy** emerged in the form of an **acronym,** a familiar tactic used in health marketing and every day communications.
- **Simple** became the SAFER / Sickle Cell 911 **online portal**, which houses guidelines in quick-access formats, opioid guidance for sickle cell patients, videos on how to assess pain, and more.

Side one of SAFER card shown actual size.

"IF YOU BUILD IT THEY WILL COME"

- **Not necessarily.** My many years in marketing taught me **that Field of Dreams statement doesn't automatically hold true** for programs and initiatives - or guarantee positive outcomes for even the best promotional campaigns.
- **SAFER was no different.** We launched pre-pandemic in late February via press releases, social media, and patient distribution - without much public response.
- We knew from the outset that despite its promise, **the initiative itself still needed to overcome the stigma and misunderstanding** that shadows sickle cell.

COLLABORATION

Collaboration is key to taking SAFER out of the field of dreams - moving beyond aspiration - and making it a reality.

The initiative needs leverage that can be achieved through combined power, **strength in numbers**, and allies.

Obstacles:
Do potential partners have the **bandwidth** or **interest** to strategically support SAFER?

We're demanding **attention** amid the din of COVID-19, a floundering economy, and the swell of #BlackLivesMatter.

Will anybody hear us?

Find SAFER at www.SickleCell911.org

YES! WE'VE BEEN HEARD!

- Clients and physicians have reacted positively to SAFER, commenting on its ease-of-use and that it is "non-confrontational"
- There is interest in partnership from a national association
- A local hospital system has now expressed interest in implementing SAFER throughout all its EDs
- We'd like to strengthen SAFER's power through collaboration with other professional groups
- We'd like to strengthen its reach through collaboration with other CBOs and sickle cell advocacy groups
- Creation of a non-branded site to house SAFER is underway to help facilitate broader partnerships

IMPLEMENT QUALITY, ELIMINATE INEQUITIES

- Sickle cell is the most prevalent inherited blood disorder in the U.S., affecting approximately 100,000 people - primarily African American. Yet, despite being medically recognized since 1910, **it remains largely misunderstood with only four disease modifying treatments in the past 30 years - two of those approved by the FDA less than one year ago.** Thus, palliative pain care has been sickle cell's primary treatment.
- While advances in pediatric care have extended the lifespan of patients well into adulthood, bias, stigma, and structural racism along with a lack of disease knowledge often lead to **inadequate treatment that contributes to a higher death rate among patients between 18 and 35 years old**.
- **SAFER can help create change that health systems can see and patients can feel**, significantly improving the quality of life for people who've often come to mistrust the medical community.
- Potential partnerships with local hospital systems around SAFER align with **statements and commitments many made following George Floyd's murder** and could lead the way for SAFER's implementation in healthcare facilities statewide.
- Equitable care for people whose educational, career, and life dreams are often stymied by health discrimination is **a civil rights and social justice win for individuals, families, our community, and our country.**

Find SAFER at www.SickleCell911.org

THE TIME IS RIGHT FOR SAFER

COVID-19's constantly evolving status has increased the need for and use of in-the-moment information.

> Without access to a single source of expert information that delivers the latest guidance, there is a greater likelihood that clinical teams will turn to unvetted online sources when they need information—resources that may or may not be reputable or provide the most current guidance. These practices also open the door to care variability that can impact outcomes and costs.

This quote is taken from the whitepaper, "Supporting clinicians in a world of dynamic medical knowledge: The case for current, reliable clinical information" by Elsevier. Written in support of ClinicalKey's technical ability to provide in-the-moment information, yet just as applicable to SAFER's access to streamlined information through the Sickle Cell 911 web portal on any device, 24/7.

August 6 ·

Hello I currently got admitted into the hospital for sickle cell pain. I just want to ask if I should stay or leave because they don't want to give me any I.V meds.....

Sep 5 · I hate Jackson Hospital here in Montgomery they don't care about Sickle Cell Warriors at all

14 15 Comments

Sep 6 · My Boyfriend was admitted into the hospital. He's in pain (10). They can't get in touch with doc to write a order for pain...

5 57 Comments

#QUALITYMATTERS

PATIENTS NEED SAFER NOW

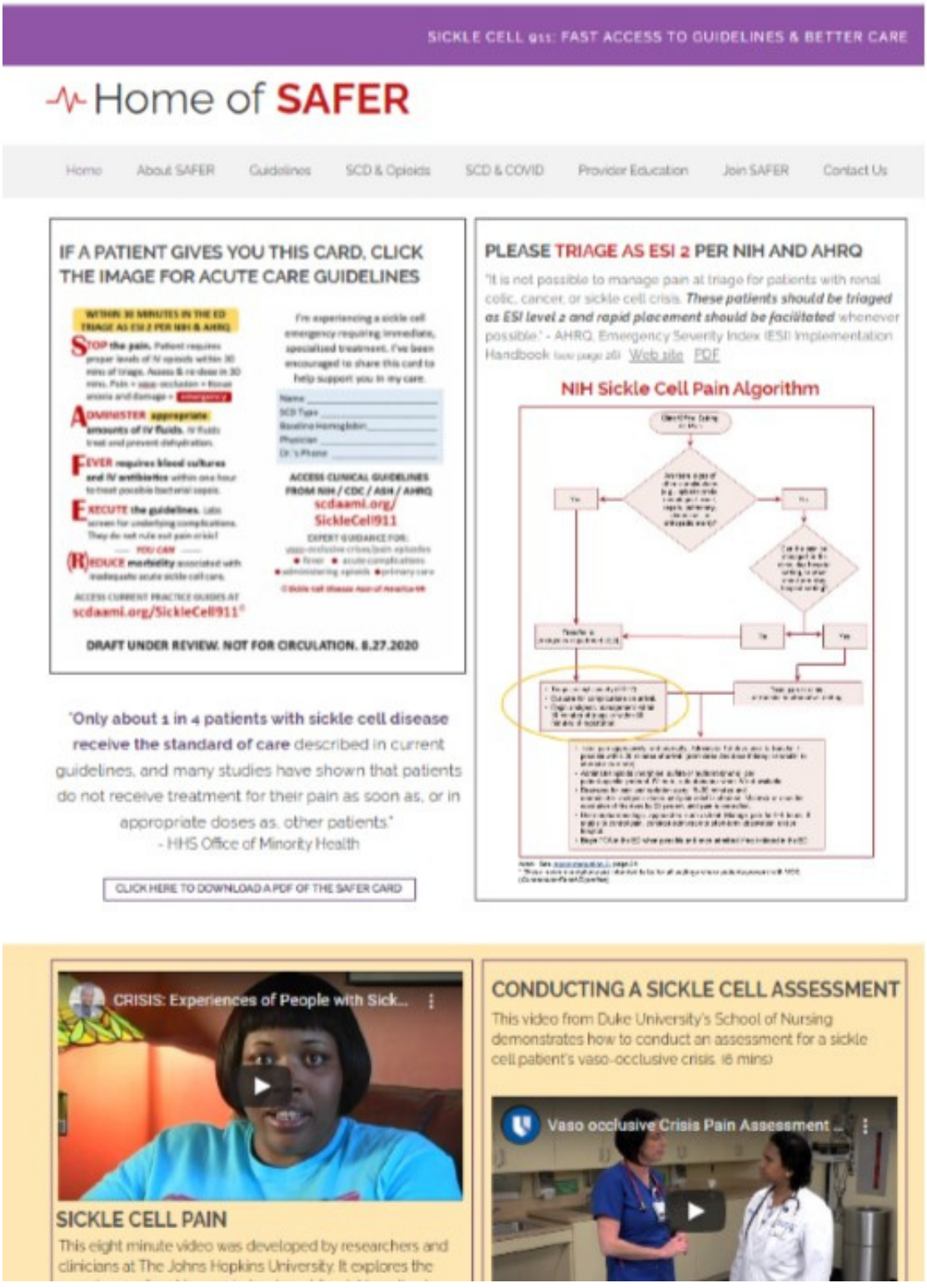
SAFER provides an opportunity to collaborate with vested partners in transforming the acute care experience for sickle cell patients. Because the high-impact initiative is easily replicated across locations and facilities, SAFER will serve as a catalyst for change we can measure and evidence we can amass. Making quality a basic requirement of sickle cell care increases patients' access, improves their outcomes, and counters the inequities they face.

YOU CAN

(R)EDUCE morbidity associated with inadequate acute sickle cell care.

SAFER/SICKLE CELL 911 WEB PORTAL

www.SickleCell911.org



SAFER / Sickle Cell 911 landing page

NIH NHLBI | ASH 2020 Guidelines | ASH Pocket Guides

NIH EVIDENCE-BASED MANAGEMENT OF SICKLE CELL DISEASE

NIH full recommendations

Click the image at left for a PDF of the full 161-page NIH recommendations.

This link will take you directly to the full document at NIH's site.

NIH Quick Guide to Recommendations

"The purpose of this Guide to Recommendations is to provide clinicians with a digital resource of the treatment recommendations extracted from the full report. For more information, please refer to the full report. . . ."

Click the image at right for a pdf of the 48-page Quick Guide. This link will take you directly to the Quick Guide document at NIH's site.

NIH GUIDELINES: ACUTE CARE BREAKOUT

For ease-of-access, this section contains a breakout of individual acute complications of sickle cell with links to corresponding PDFs from the Quick Guide and the full recommendations.

What does the patient report? Remember: LABS ASSESS FOR COMPLICATIONS. Labs do not rule out or confirm pain crisis or a patient's level of pain!

Acute Chest Syndrome: Quick Full

Acute Stroke: Quick Full

Anemia: Quick Full

Fever: Quick Full

Hepatobiliary: Quick Full

Multi-System Organ Failure: Quick Full

Ocular Conditions: Quick Full

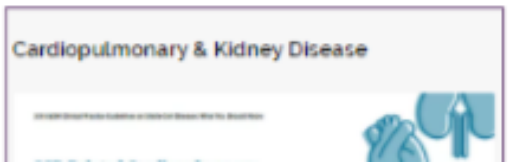
Priapism: Quick Full

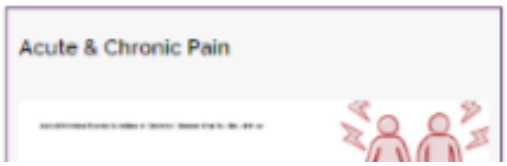
Renal Failure: Quick Full

Splenic Sequestration: Quick Full

Vaso-occlusive crisis./pain episode: Quick Full

AMERICAN SOCIETY OF HEMATOLOGY 2020 SICKLE CELL GUIDELINES





Provider education

Partner with SAFER

Join the movement for quality, equitable sickle cell treatment.

Learn more about sickle cell disease and providing proper care

Improving Emergency Department-Based Care of Sickle Cell Pain

"Presented in this article are 4 tenets of implementing guideline-adherent emergency sickle cell care gleaned from the available literature and continuous quality improvement efforts at our institution." . . "Application of the principles discussed within can improve patient and provider satisfaction, quality, and safety." (From the American Society of Hematology)
PDF Online

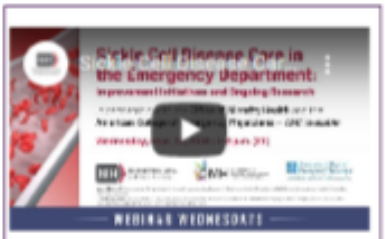
American College of Emergency Physicians

ACEP's Emergency Department Sickle Cell Care Coalition offers a substantial list of training and informational resources for medical professionals providing treatment in emergency and acute care settings here

Duke University Educational Resources

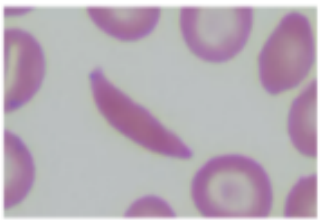
Videos, presentations, algorithms, and other information to improve emergency department sickle cell treatment and adult health maintenance here

Acute and Emergency Department Assessment and Treatment



Sickle Cell Disease Care in the Emergency Department: Improvement Initiatives and Ongoing Research (1 hour) - a webinar from NIH, OMH and ACEP.

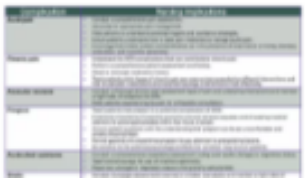
SCD Core Concepts for the Physician and Nurse - Sickle Cell Pain (PowerPoint): A presentation from Duke University and The Johns Hopkins School of Medicine



Emergency care for sickle cell – Podcast (1 hour): A focus on assessment and treatment. *NOTE: The interviewer uses the term "sickler" throughout the podcast. This term is NOT well-received by sickle cell patients here.*

Sickle Cell is More Than Pain: Managing Complications

Major Complications of Sickle Cell Disease and Nursing Implications - PDF download



Sickle Cell Disease: When to Transfuse

Sickle Cell Disease TeleECHO Clinic - Didactic Video Series

Collaboration. Credibility. Quality. Change.

Join us. Contact Stefanie Worth at worths@scdaami.org or 248.464.2505

THANK YOU FOR YOUR TIME AND CONSIDERATION.