

# Meeting the Transfusion Needs of Patients with Sickle Cell Disease: It's About More Than Blood

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# It's About Health Equity

“As an organization dedicated to alleviating suffering, the Red Cross is committed to the health and well-being of all communities, and a diverse blood supply is critical to improving health outcomes for all patients – especially those with sickle cell disease, said “For someone facing a sickle cell crisis, a blood transfusion can make a lifesaving difference.”

Gail McGovern, CEO and president of the Red Cross

# It's About Health Equity

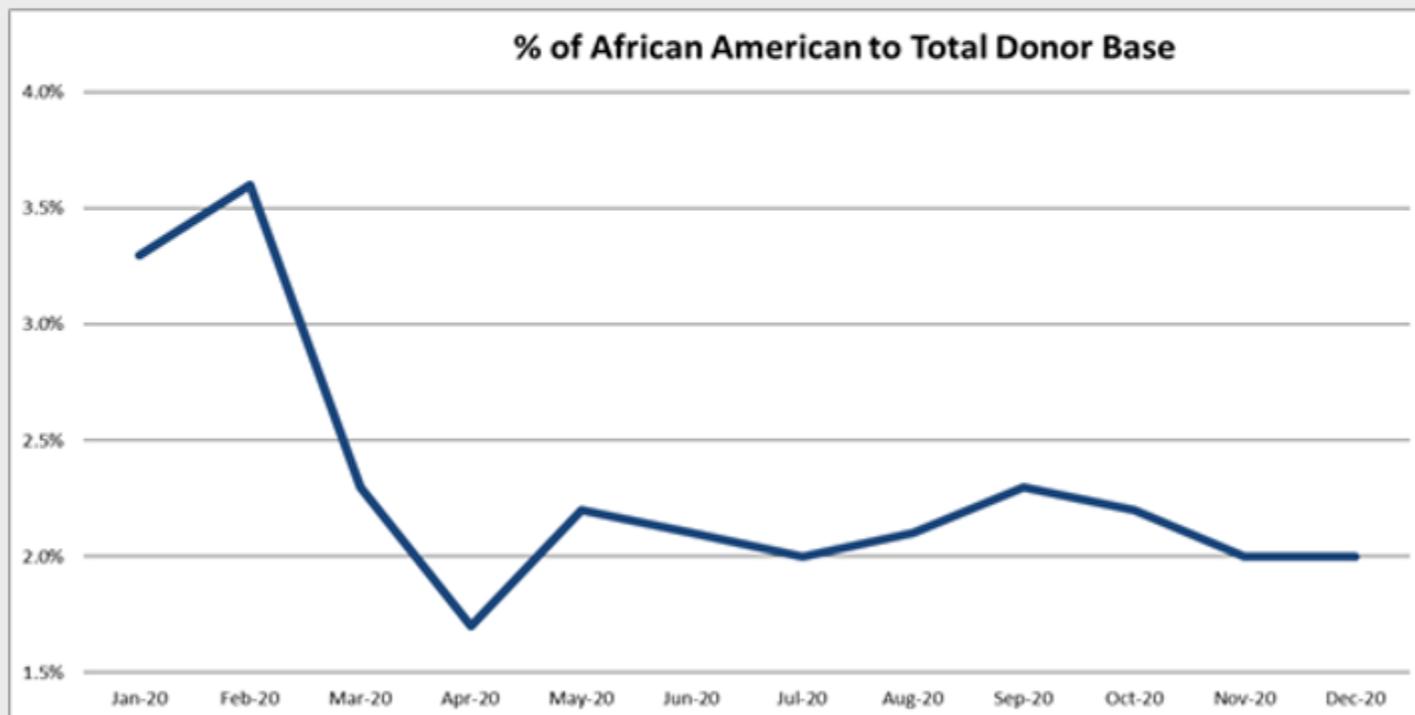
Dr. Francis Collins, director of the National Institutes of Health, was quoted saying the lack of attention paid to sickle cell historically “is one more reflection of the fact that we do not have equity in our country.”

# Our Objective

- By December 31, 2025, **triple our African American blood donor base** to eliminate the gap in our ability to meet hospital demand and provide the most compatible units for patients with sickle cell disease



# COVID Context



# The Need

- About 1 in 13 Black or African-American babies is born with sickle cell trait (SCT)
- SCD *is the most common inherited blood disease in US\**; SCD affects approximately 100,000 Americans\*\*the majority of whom are African American or of African descent
- SCD affects 1 of every 365 Black or African American births and about 1 out of every 16,300 Latinx births\*\*

\*<https://ghr.nlm.nih.gov/condition/sickle-cell-disease#statistics>

\*\*<https://www.cdc.gov/ncbddd/sicklecell/data.html>

# Red Blood Cell/ Rh Group Antigens

## African-American/African ancestry

- 73% C neg
- 78% E neg
- 98% K neg
- 67% Fy(a-b-)
- 52% Jk<sup>b</sup> neg

## European-American/European ancestry

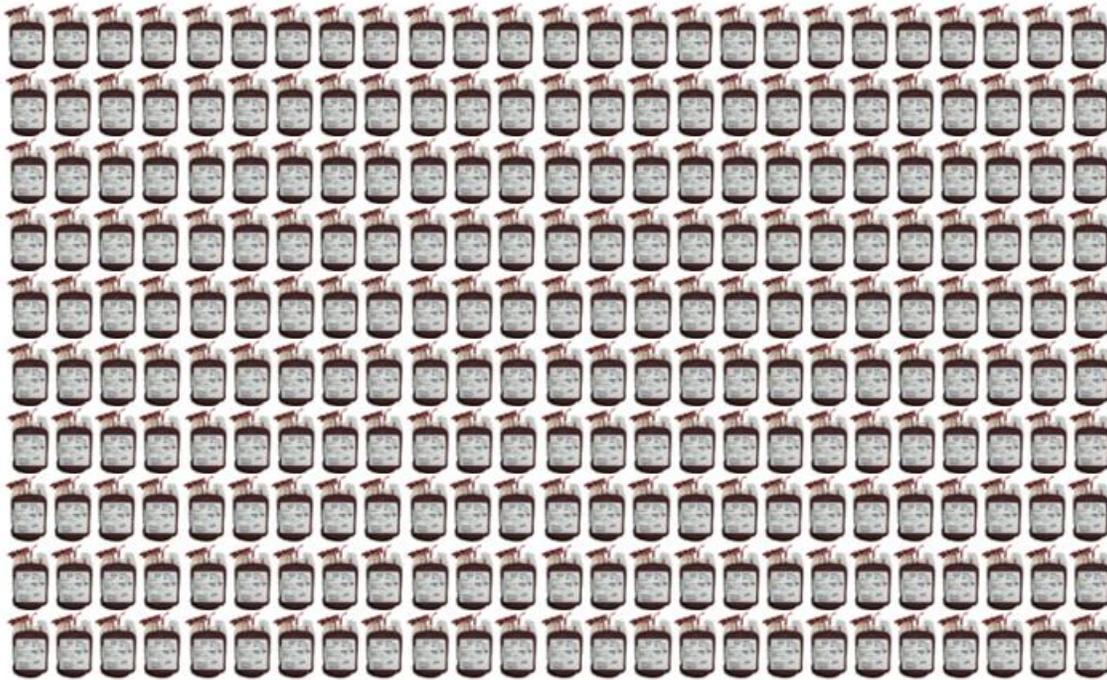
- 32% C neg
- 71% E neg
- 91% K neg
- 0% Fy(a-b-)
- 26% Jk<sup>b</sup> neg



# Importance of Diverse Donors

**Need:** Blood Type O, C-, E -, K-, and Jkb –

- If we screen 250 units of blood from **Caucasian donors...**



We will find

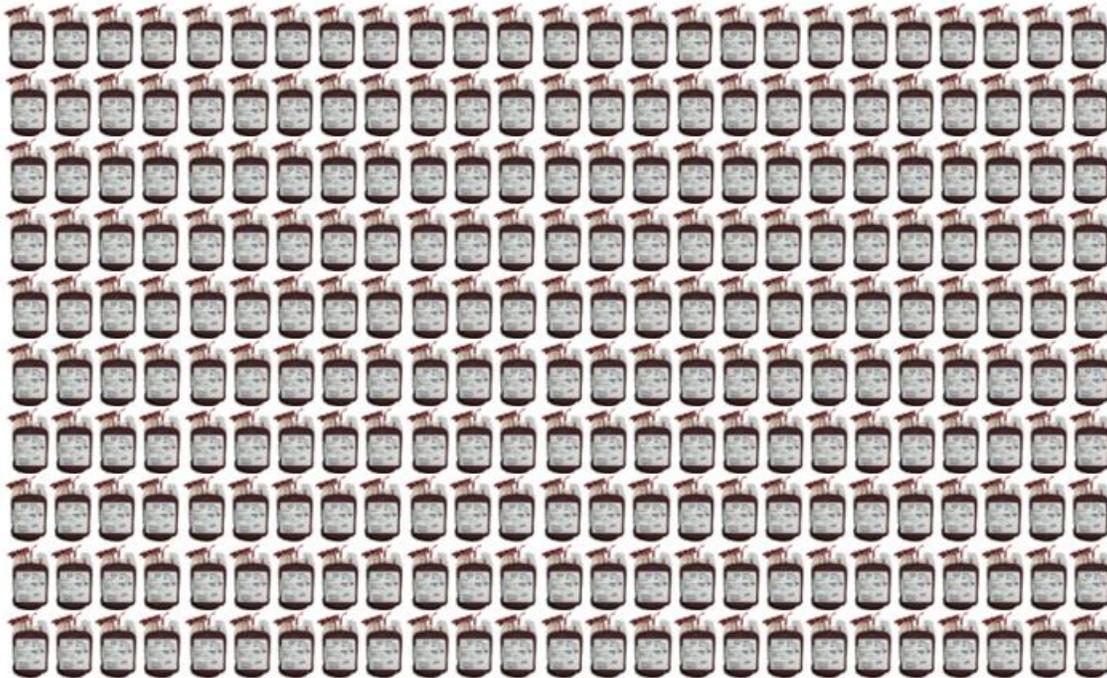


**1 in 250 units**

# Importance of Diverse Donors

**Need:** Blood Type O, C-, E -, K-, and Jkb –

- If we screen 250 units of blood from **African American donors...**



We will find



**28 in 250 units**

# The Plan

- Increase the frequency of donations by our current African American donors
- Attracting new African American donors; this has been challenging due to:
  - COVID-19 disproportionately affecting the Black community
  - Many blood drives in the Black community are mobiles vs fixed site traffic
  - It takes time to build trust, attract new sponsor relationships, schedule and plan blood drives

# The Plan

- Educating and socializing the Red Cross staff and volunteers to the message of why it is critical for African Americans to donate blood to meet the transfusion needs of patients with SCD, the majority of whom in the U.S. are African American or of African decent
- Create welcoming environment & more conveniently located blood drives, enhance cultural competence of staff and volunteers
- Strengthen donor recruitment focus with African American donors; developing culturally appropriate outreach, communication, marketing materials, advertising that reflects the community
- Building capacity to test, type and match an increased number of units

# It's About More Than Blood

- The work of supporting patients and families with SCD involves listening to their stories; they can best describe their priorities and needs which can be varied:
  - “Life” support, SCD is disruptive to school, work, family time
  - Transportation can be a challenge
  - Transition from pediatric to adult care
  - Child care when parent has SCD
  - Self advocacy, self care
- Discussing race and ethnicity is part of the conversation ultimately about *addressing health disparities and health equity*

# What Are Health Disparities? What Is Health Equity?

- The term *disparities* is often interpreted to mean racial or ethnic disparities, many dimensions of disparity exist in the United States, particularly in health. If a health outcome is seen to a greater or lesser extent between populations, **there is disparity**. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health
- “**Health equity**” means that everyone has the opportunity to be as healthy as possible. Equitable opportunity includes equal access to and distribution of resources.
- <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities>
- <https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html#print>

# What Is Structural Racism?

- There is no official definition, but any definition should make it clear that racism is not solely the result of private prejudices held by individuals
- Structural racism and bias is produced and reproduced by laws, rules, and practices, sanctioned and implemented by various levels of government, and embedded in the economic system as well as in cultural and societal norms.

# Structural Racism in Medicine

- Hospitals were segregated until 1965 when Medicare was implemented
- Black doctors had no or limited privileges at white hospitals
- Black doctors only treated black patients, lack of Black MDs then and now
- AMA apology to National Medical Association
  - For more than 100 years, the AMA **actively reinforced or passively accepted** racial inequalities and the exclusion of African-American physicians. In an address to the **National Medical Association (NMA)** Annual Meeting in Atlanta, Georgia, on July 30, 2008, Ronald M. Davis, MD, then the AMA's immediate past president, **apologized for more than a century of AMA policies** (PDF) that excluded African-Americans from the AMA, in addition to policies that also barred them from some state and local medical societies.
  - Davis pledged that the AMA would "do everything in our power to right the wrongs that were done by our organization to African-American physicians and their families and their patients."

<https://www.ama-assn.org/about/ama-history/history-african-americans-and-organized-medicine>

# Social Determinants of Health

## Economic Stability

People from some racial/ethnic, marginalized groups have lower incomes, experience barriers to wealth accumulation, and carry greater debt.

## Social and Community Context

People from racial/ethnic, marginalized groups are disproportionately represented in areas with few or no grocery stores, limited public transportation, exposure to high personal and environmental stressors and violence.

## Neighborhood and Environment

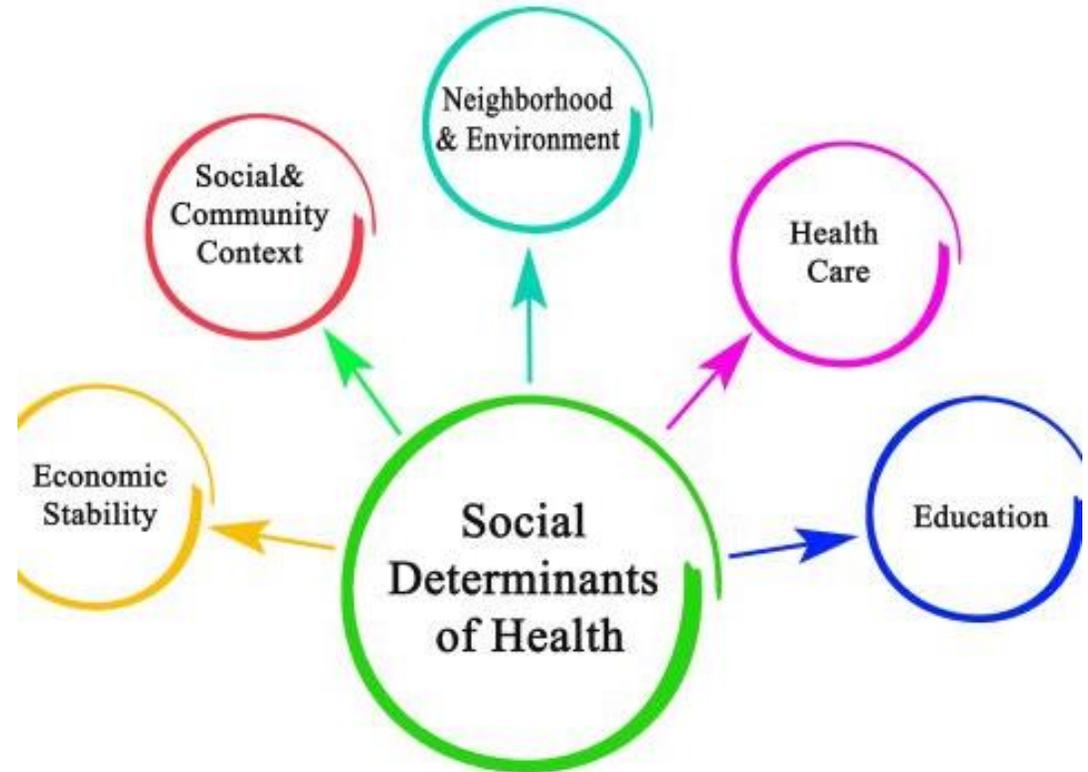
People from racial/ethnic, marginalized groups are disproportionately affected by difficulties finding affordable and quality housing, reside in areas with unsafe environmental conditions and without safe recreational areas.

## Health and Healthcare

People from racial/ethnic marginalized groups are disproportionately affected by lack of access to quality health care, health insurance, and/or linguistically and culturally responsive health care.

## Education

People from racial/ethnic, marginalized groups are disproportionately affected by inequities in access to high-quality education which can lead to lower literacy and numeracy levels, lower high school completion rates, and barriers to college entrance



# Crucial Conversations about Structural Racism, Equitable Access to Healthcare and Social Justice

- **How did we get to this crucial conversation? COVID-19**
  - Moore JT, Ricaldi JN, Rose CE, et al. **Disparities in Incidence of COVID-19 Among Underrepresented Racial/Ethnic Groups in Counties Identified as Hotspots During June 5–18, 2020 — 22 States, February–June 2020.** MMWR Morb Mortal Wkly Rep 2020;69:1122–1126.  
DOI: <http://dx.doi.org/10.15585/mmwr.mm6933e1>
- **What is already known about this topic?**
  - Long-standing health and social inequities have resulted in increased risk for infection, severe illness, and death from COVID-19 among communities of color.
- **What is added by this report?**
  - Among 79 counties identified as hotspots during June 5–18, 2020 that also had sufficient data on race, a disproportionate number of COVID-19 cases among underrepresented racial/ethnic groups occurred in almost all areas during February–June 2020.
- **What are the implications for public health practice?**
  - Identifying health disparities in COVID-19 hotspot counties can inform testing and prevention efforts. Addressing the pandemic's disproportionate incidence among communities of color can improve community-wide health outcomes related to COVID-19

# Sickle Care Solutions, LLC

'Personal Connection meets Clinical Expertise'



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# Sickle Care Solutions, LLC

**'Personal Connection meets Clinical Expertise'**

## **TO EDUCATE**

- Educate healthcare professionals, students, and the public on sickle cell disease and the management of its medical complications.
- Provide first-hand practitioner and patient perspectives on sickle cell, race, and advocacy.

## **TO SERVE**

- Guide clinicians/healthcare providers on how to establish dedicated clinics for the care of individuals living with sickle cell disease; special focus will be given to the critical role of the nurse.
- Through consultation and mentoring, clinicians will be equipped to provide quality and individualized care.

# The Fifth Vital Sign-Pain Management

- <https://magazine.nursing.jhu.edu/2012/07/the-fifth-vital-sign>
- When she was 16 years old, Nicklaine Paul, BSN, RN, woke up one night with excruciating pain in her lower back and legs. Growing up with sickle cell disease, she was familiar with the condition's side effects. But this pain was more intense, like a "storm of daggers on your bones." Paul's family rushed her to the emergency room, where she sat in a wheelchair, screaming for three-and-a-half hours. "It was just unbearable. We have to do better [for our sickle cell patients],"
- Sickle Cell Infusion Center at Johns Hopkins Hospital, with a 35 member group multidisciplinary Pain Management Taskforce force meets monthly to maintain and update pain policy, review reported patient safety events, and recommend improvements in care related to pain management.
- Patients with SCD have been labeled 'drug seekers' even before the opioid abuse scandal, denied adequate pain control
  - The Opioid Drug Epidemic and Sickle Cell Disease: Guilt by Association article
  - <https://academic.oup.com/painmedicine/article/17/10/1793/2270349>

# The Fifth Vital Sign-Pain Management

AJH Research Article:

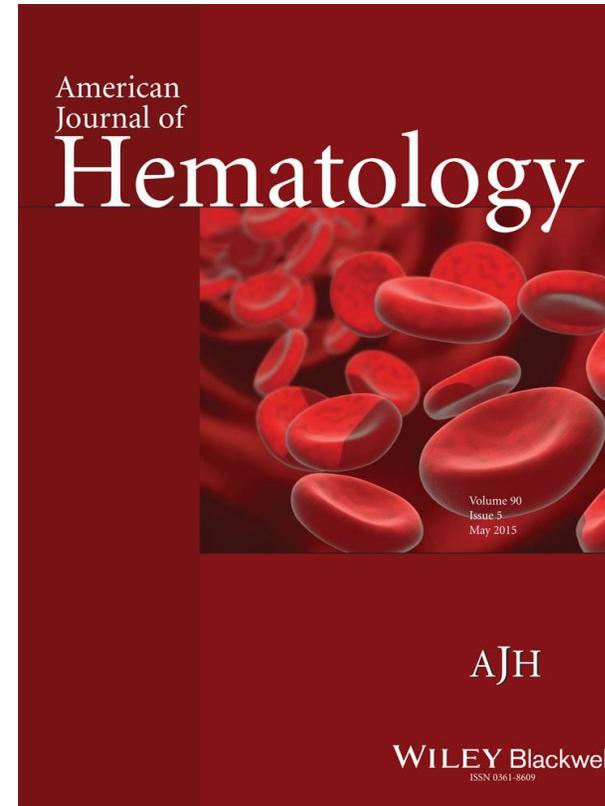
**Impact of a dedicated infusion clinic for acute management of adults with sickle cell pain crisis**

Sophie Lanzkron, C. Patrick Carroll, Peter Hill, Mandy David, Nicklaine Paul, Carlton Haywood Jr.

Volume 90, Issue 5

May 2015

Pages 376-380



# The Fifth Vital Sign-Pain Management

CLINICAL GUIDELINES



## American Society of Hematology 2020 guidelines for sickle cell disease: management of acute and chronic pain

Amanda M. Brandow,<sup>1</sup> C. Patrick Carroll,<sup>2</sup> Susan Creary,<sup>3</sup> Ronisha Edwards-Elliott,<sup>4</sup> Jeffrey Glassberg,<sup>5</sup> Robert W. Hurley,<sup>6,7</sup>  
Abdullah Kutlar,<sup>8</sup> Mohamed Seisa,<sup>9</sup> Jennifer Stinson,<sup>10</sup> John J. Strouse,<sup>11,12</sup> Fouza Yusuf,<sup>13</sup> William Zempsky,<sup>14</sup> and Eddy Lang<sup>15</sup>

# The Fifth Vital Sign-Pain Management

- <https://www.commonwealthfund.org/publications/newsletter-article/2021/jan/medical-mistrust-among-Black-americans>
- studies have found Black Americans are consistently undertreated for pain relative to white patients; one study revealed half of medical students and residents held one or more false beliefs about supposed biological differences between Black and white patients, like the former have higher pain tolerance than the latter.
- <https://www.aamc.org/news-insights/how-we-fail-black-patients-pain>
- “Black people’s nerve endings are less sensitive than white people’s.” “Black people’s skin is thicker than white people’s.” “Black people’s blood coagulates more quickly than white people’s. Half of white medical trainees believe such myths as black people have thicker skin or less sensitive nerve endings than white people. An expert looks at how false notions and hidden biases fuel inadequate treatment of minorities’ pain.

# What Can You Do?

1. Listen to and learn from patients
2. Continue to explore more about SCD, treatments are changing, knowledge and focus are growing
3. Understand the challenges of having SCD that don't involve transfusion
4. **Do of course, donate blood. Everybody wins.**

# SUMMARY

- Health disparities have an impact on the quality of care for patients with SCD.
- Patient and families with SCD can have challenges outside medical care
- Longstanding health disparities have to be addressed from a systemic perspective

# THANK YOU

