



Attn: Docket No. CDC-2022-0024

Subject: Feedback on the CDC Clinical Practice Guideline for Prescribing Opioids

The Sickle Cell Disease Association of America, Inc., (SCDAA), is pleased to learn that the Centers for Disease Control and Prevention (CDC) is updating the 2016 opioid guidelines. However, the guidelines do not go far enough in providing guidance to providers on how to manage sickle cell disease (SCD) pain. Decades of misinformation, poor guidance, and systemic racism created barriers to receiving adequate care for pain.

SCD is an inherited red blood cell disorder affecting about 100,000 Americans, disproportionately impacting Black and Brown populations. In people with sickle cell disease, red blood cells become crescent-shaped, sticky, and hard. This condition increases the chances of blood clotting, causing pain crises, strokes, and organ damage. People with sickle cell disease also frequently experience a shortage of red blood cells, as these cells die much faster than sickle cell blood cells. Pain can occur throughout the body and can be excruciating, affecting a person's mental and physical well-being. Despite being discovered in Western medicine over 110 years ago, no universal cure for SCD exists.

Opioids are crucial to treating SCD pain. Healthcare providers need to rely on opioid treatment to mask pain until the underlying causes subside, but Americans with SCD often face skepticism and disbelief about their experience of pain. Racist notions that Black people have a higher tolerance for pain than white people¹ and are more drug-seeking than white people² severely impact SCD patients' chances of receiving treatment and accessing opioids. SCD patients experience excruciating pain crises their entire life

¹PNAS "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites". Retrieved April 7, 2022.

<https://www.pnas.org/doi/10.1073/pnas.1516047113>

² NIH "Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse". Retrieved April 7, 2022. HYPERLINK

"<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4976905/>" <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4976905/>

and tend to not outwardly display pain in the same way as people that have less experience dealing with pain. The CDC compounded and further entrenched these problems with their 2016 opioid guidance, which advised against using opioids in general with only one weakly worded reference to SCD.

SCDAA appreciates the CDC's efforts to update the new guidelines to better emphasize that limiting opioids should not apply to SCD patients. This document, however, does not go far enough. Within the draft guidelines, the CDC needs to clearly explain why SCD is excluded from the guidelines. The CDC needs to provide clear and concise guidance on where SCD pain management evidence-based guidelines are found. Implementation and training on pain management guidelines need to be established with consultation from the SCD community from the beginning of the process. While SCDAA is grateful that the CDC reached out to the community before the draft guidelines were released to the public, more in-depth work between our organizations needs to be done.

The opioid crisis continues to devastate countless lives and families but ending it does not need to be at the expense of the health of already marginalized people with SCD. These guidelines are highly impactful to healthcare providers, and we cannot afford to miss this critical opportunity to craft more carefully worded guidance for SCD.