



June 12, 2019

ADM Brett P. Giroir, MD
Assistant Secretary for Health
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

VADM Jerome M. Adams, MD, MPH
United States Surgeon General
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Robert R. Redfield, MD
Director, Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Dear ADM Giroir, VADM Adams, and Dr. Redfield,

The undersigned organizations are concerned about the critical and ongoing challenges that individuals with sickle cell disease (SCD) continue to experience when trying to manage their acute and chronic pain. We recognize that the opioid epidemic in the United States is a public health emergency that requires immediate attention; however, as our nation continues to address this crisis, we want to continue to promote cautious, thoughtful consideration in order to avoid unintended consequences for patients with chronic diseases, such as SCD.

The clinical complexities associated with pain management for people living with SCD have been a focus of our organizational efforts. We seek to ensure that all patients are able to access quality care for SCD, especially in areas of the country that lack providers with the comprehensive knowledge and expertise to care for this population. For example, with a goal of increasing the use of evidence in practice, the American Society of Hematology (ASH) is developing education and training modules for hematologists and other health care providers to ensure proper care. ASH also plans to release new evidence-based clinical practice guidelines to better inform the management of the patients we serve who experience acute and chronic pain. Additionally, the American College of Emergency Physicians (ACEP) formed the Emergency Department Sickle Cell Care Coalition to provide a national forum dedicated to the improvement of the emergency care of patients with SCD in the United States, including the education of emergency department providers about the appropriate management of SCD-related pain.

We commend you for the steps that you and your colleagues at the U.S. Department of Health and Human Services (HHS) have taken to address issues related to pain management, such as the release of the [HHS Strategy to Combat Opioid Abuse, Misuse, and Overdose – A Framework Based on the Five Point Strategy](#) and creation of the [HHS Pain Management Best Practices Inter-Agency Task Force](#). We are pleased that the Task Force invited patients with SCD to share their perspective on the

unique challenges they encounter managing pain and that the Taskforce's [Final Report](#) reflects this by including a dedicated section on SCD in the *Special Populations* portion of the Report.

We also appreciate the Centers for Disease Control and Prevention's (CDC) recent [clarification](#) of its *Guideline for Prescribing Opioids for Chronic Pain*, which conveys that the guideline is not intended to deny clinically-appropriate opioid therapy to any patients who suffer acute or chronic pain from conditions such as cancer and sickle cell disease, but rather to ensure that physicians and patients consider all safe and effective treatment options for pain management with the goal of reducing inappropriate use.

Despite these important steps, we continue to receive reports that individuals with SCD and their medical providers are unable to obtain access to appropriate medication, because of opioid prescribing policies regarding duration and dosage. We are extremely concerned about these issues and encourage you to take additional action to raise awareness about the challenges that individuals with SCD continue to face.

Specifically, we respectfully request that you:

- Make a public statement about the challenges individuals with SCD currently face receiving the care they need and deserve;
- Highlight the CDC's clarification regarding opioid prescribing in public-facing materials on this issue;
- Encourage health care providers to utilize current and forthcoming clinical practice guidelines specifically addressing pain in SCD to help guide treatment and reimbursement practices; and
- Call for additional research to understand underlying mechanisms of acute and chronic pain and develop mechanistic nonopioid pharmacologic therapies and nonpharmacologic approaches for SCD pain management.

Our organizations would be happy to provide additional background information and expertise on this subject as you consider these requests.

We welcome any discussion on this issue. If you have any questions or require further clarification, please contact Stephanie Kaplan, ASH Senior Manager, Government Relations and Public Health at skaplan@hematology.org or 202-292-0263.

Sincerely,
American College of Emergency Physicians
American Society of Hematology
Sickle Cell Disease Association of America