

# Sickle Cell Disease Council For CHANGE

## Improving Vaso-Occlusive Crisis (VOC) Management for Those Living with Sickle Cell Disease

### THE PROBLEM

While sickle cell disease (SCD) was first discovered more than 100 years ago, there remains several—and staggering—unmet needs in patient care. This is especially true with regard to treating vaso-occlusive crises (VOCs), the common and debilitating pain crises that drive SCD patients to the emergency department (ED).

There are limited options for treating SCD, and the current practice is to focus on pain management, often with opioid medications. SCD patients may build a tolerance to these pain medications, and as result, require higher doses over time. Unfortunately, SCD patients have reported that ED staff often misunderstand the legitimacy of their pain, and see them as “drug-seekers,” a situation that has been exacerbated in recent years by the current opioid epidemic.

This stigma has contributed to people with SCD not receiving adequate and timely pain relief—these patients wait an average of 30 minutes longer in the ED for pain medication when compared to people with other extremely painful conditions, like kidney stones.<sup>1</sup> This is in spite of evidence showing that earlier initiation of pain medication improves pain outcomes in SCD patients, which can lead to earlier discharge from the ED and fewer hospitalizations.<sup>2,3</sup>

### THE URGENT NEED FOR CHANGE

Recognizing these challenges, Pfizer Rare Disease brought together a group of leading SCD experts, patients, and advocates to address the issues in an effort to improve management and care for SCD patients.

### THE SICKLE CELL DISEASE COUNCIL FOR CHANGE

The Council For CHANGE (CFC) is a group of national leading experts and patients spanning academia, advocacy, and health care sectors who are passionate about driving forward advances in SCD care. The group, which consists of more than 20 members, recently published its first report, titled *Improving Vaso-occlusive Crisis (VOC) Management*.



Council For CHANGE™

### SCD AT-A-GLANCE

SCD is a lifelong and debilitating disorder that causes an individual's red blood cells to become crescent-shaped, causing blockages that make it difficult for cells to pass through small blood vessels.<sup>5</sup> This can lead to reduced blood and oxygen flow, which results in pain and may additionally cause organ damage.<sup>6</sup>



People with SCD often suffer from compounding health issues and are at risk of reduced life expectancy—in developed countries, average life expectancy is **between 40 and 60 years**<sup>6</sup>



SCD is the most common inherited blood disease in the US, impacting **~100,000 Americans**<sup>7,8</sup>



Most people with SCD are of African descent, with SCD occurring in one out of every **365 African American births**<sup>7</sup>



Estimated US health care costs for SCD-related hospitalizations are **>1.1 billion annually**<sup>9</sup>

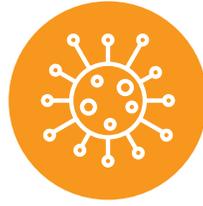
## THE REPORT PRIORITIZES THREE KEY ISSUES TO ADDRESS WITH SPECIFIC RECOMMENDATIONS TO AFFECT POSITIVE CHANGE IN SCD CARE.



### ISSUE #1

#### **Acute care for VOC management needs to be improved.**

Obtaining needed care for the management of SCD and associated pain crises remains a significant challenge. The CFC took its first step in addressing this important issue by developing seven comprehensive principles to use when a patient with SCD arrives in the ED. In the report, the CFC encourages medical centers to use these principles as “best practices.” The CFC members believe that this may “improve SCD outcomes, thereby saving lives, improving patient satisfaction, and lowering costs of care.”



### ISSUE #2

#### **The evolving science behind SCD is not well understood.**

New data has evolved the understanding of SCD, including the underlying mechanisms in the body that result in VOCs. Understanding the science behind SCD and the complexity of pain during VOCs by both health care professionals and patients is critical to ensuring optimal care. The CFC aims to spearhead the development of a variety of customized educational tools to improve understanding of the disease and empower patients to be more engaged about the care they receive.



### ISSUE #3

#### **SCD patients experience unjust stigma.**

The majority of SCD patients are of African descent.<sup>4</sup> Beyond the stigma associated with treating their disease, these individuals also often experience racial and socioeconomic stigma that can be barriers to receiving optimal care. Recognizing this, the CFC is looking to minimize these barriers by engaging medical institutions to remove the stigma and increasing health literacy to improve the patient care experience.

## WHAT'S NEXT...

There is work ahead to implement the vision and initiatives outlined in the CFC report to create positive change for those affected by SCD. The CFC will be providing updates on the efforts underway that address each of the three issues identified.

To download the full report, visit: [www.pfizer.com/CFCReport](http://www.pfizer.com/CFCReport).

*Pfizer Rare Disease supports the mission of the Sickle Cell Disease Council For CHANGE and has provided financial support for their meetings and the report. Pfizer colleagues have contributed to the content in the report in partnership with the members of the Council For CHANGE, but Pfizer does not have editorial control over or responsibility for its final content.*

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