

## CMS Listening Session on Sickle Cell Disease

On Thursday, February 17, 2022, Sick Cells joined five other organizations in a meeting with the Center for Medicare & Medicaid Services (CMS) Administrator Chiquita Brooks-LaSure and other key staff to discuss sickle cell disease.

This meeting was hosted virtually and was attended by representatives from the [American Society for Hematology](#) (ASH), [Sick Cells](#), the [Sickle Cell Disease Association of America](#) (SCDAA), [Sickle Cell Reproductive Health Education Directive](#) (SC RED), [MTS Sickle Cell Foundation](#), and the [American Medical Association](#) (AMA), as well as CMS staff.

Administrator Brooks-LaSure opened the meeting by welcoming attendees and reaffirming her commitment, and CMS's commitment, to addressing the needs of the sickle cell disease (SCD) community through their programs and through partnerships with other federal agencies.

Each organization spoke for four minutes about challenges the SCD community faces and how CMS can help close gaps in care, address disparities, and enhance their programs to meet changing needs. Comments are outlined below, in speaking order:

- **American Society of Hematology**
  - Patients with SCD are living longer, but instances of poor clinical care and increased costs continue. H.R. [6216](#)/S. [3389](#) outlines a five-year Medicaid demonstration program that could help address these issues.
- **Sick Cells**
  - Utilization management practices continue to act as barriers to accessing new treatments. There is also a general lack of awareness and understanding of SCD among members of Medicaid coverage decision committees.
- **Sickle Cell Disease Association of America**
  - There is a lack of published national guidelines and quality metrics of success in SCD for providers to use as guidance. Therefore, It is difficult for low-resource institutions and institutions with few SCD patients to provide dependable & quality care for the SCD community.
- **MTS Sickle Cell Foundation**
  - There is a crucial need for CMS to continue testing innovative payment models to address current issues in payment and reimbursement.
- **American Medical Association**
  - Federal opioid prescription guidelines have unintentionally harmed the SCD community; CMS should remove policies based on flawed guidelines.
- **Sickle Cell Reproductive Health Education Directive**
  - Individuals with SCD should have access to fertility coverage under Medicaid in the same way that individuals with malignancies or other health issues do.

We are optimistic that this meeting will bring an increasing level of awareness to sickle cell disease and future action to ensure federal programs address the needs of the community.