



# Study Information Form

## **Expanding Access to Sickle Cell Treatment in Virginia**

Authorized by the Joint Commission on Health Care on June 11, 2024.

---

**STRATEGIC OBJECTIVES ADDRESSED:** Affordability, Accessibility & Equity

**SOURCE OF STUDY REQUEST:** HJ60 (Hayes) referred by letter to JCHC

**ESTIMATED WORKLOAD:** MEDIUM

### **BACKGROUND:**

Sickle cell disease is a term used to describe a group of inherited blood disorders that affect the shape and function of red blood cells, causing them to become crescent or “sickle” shaped. These sickled red blood cells do not move easily through the body and can block blood flow, leading to serious health complications such as stroke, eye problems, infections, and episodes of pain called pain crises. Sickle cell disease is a lifelong illness, but it can be managed. The Virginia Department of Health requires all newborns to be screened for sickle cell disease to ensure timely care coordination. Medicines and blood transfusions can be used to prevent sickling, minimize pain, and reduce complications. Some patients may need a bone marrow transplant, the only known cure until December 2023, when the Food and Drug Administration approved two new gene therapy drugs to treat sickle cell disease.

Constituents have raised concerns about the lack of disease awareness among providers and access to appropriate treatment, which led to legislative action in the 2024 General Session to address various barriers.

### **STUDY ISSUES:**

- What is the prevalence and impact of sickle cell disease in the Commonwealth?
- What state-funded programs and services support individuals with sickle cell disease?
- What forms of evidence-based treatment are available for individuals with sickle cell disease? What barriers exist to access these treatments options? What are the potential reproductive health challenges related to sickle cell disease or that result from treatment?

### **RECENT/ONGOING STUDIES IN THIS AREA:**

- HB 820 - DMAS will conduct an annual review of all medications, services, and forms of treatment for sickle cell disease available under Virginia Medicaid. The Department will report findings and recommendations by November 15, 2024.

- HB 252 - VDH will create a statewide registry of sickle cell disease patients to which patients may self-report information. The State Health Commissioner will report on information obtained from the registry by November 1, 2024.