JOINT COMMISSION ON HEALTH CARE

EXPANDING ACCESS TO SICKLE CELL DISEASE TREATMENT IN VIRGINIA

REPORT TO THE GOVERNOR AND THE
GENERAL ASSEMBLY OF VIRGINIA

REPORT DOCUMENT #938

COMMONWEALTH OF VIRGINIA
RICHMOND
2024

Code of Virginia § 30-168.

The Joint Commission on Health Care (the Commission) is established in the legislative branch of state government. The purpose of the Commission is to study, report and make recommendations on all areas of health care provision, regulation, insurance, liability, licensing, and delivery of services. In so doing, the Commission shall endeavor to ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care. Further, the Commission shall encourage the development of uniform policies and services to ensure the availability of quality, affordable and accessible health services and provide a forum for continuing the review and study of programs and services.

The Commission may make recommendations and coordinate the proposals and recommendations of all commissions and agencies as to legislation affecting the provision and delivery of health care. For the purposes of this chapter, "health care" shall include behavioral health care.

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Assistant Health Policy Analyst

Agnes Dymora
Executive Assistant/Office Manager

Expanding Access to Sickle Cell Disease Treatment in Virginia

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Expanding Access to Sickle Cell Disease Treatment in Virginia

POLICY OPTIONS IN BRIEF

Option 1: Request that VDH provide an update on the plan for the statewide SCD registry.

Option 2: Provide funds to VDH to assess treatment, transition, mental health, and psychosocial support needs for patients at treatment centers.

Option 3: Provide funds to VDH to assess transportation needs for patients at treatment centers.

Option 4: Direct VDH to develop a plan to provide information on patients' sickle cell status for providers in the ED.

Option 5: Direct BON and BOM to require unconscious bias and cultural competency training as a condition for licensure renewal.

Option 6: Direct DMAS to report on the status of participation in Cell and Gene Therapy Access Model.

Option 7: Direct DMAS develop a comprehensive SCD program.

Option 8: Direct DMAS to determine feasibility of state participation in optional SCD benefit or Medicaid health homes for SCD.

FINDINGS IN BRIEF

VDH identifies and monitors cases of SCD in Virginia and is improving surveillance through a statewide registry

VDH programs effectively identify potential cases of SCD at birth, facilitate diagnostic testing and entry into care, and provide education and counseling for individuals with SCD and their families. Recent legislation addresses additional gaps in disease surveillance by requiring VDH to establish a statewide sickle cell disease registry.

SCD treatment centers provide access to specialized SCD care but lack capacity for needed treatment and support services

Most treatment centers receive state funding to cover a portion of the cost of providing support services for patients with SCD. State funds do not cover the full cost of these services nor the costs of treatment. Additional information is needed to understand the resources required to address unmet need at treatment centers.

Providers' lack of knowledge about SCD and bias about individuals with SCD can delay appropriate care

Emergency department providers may be unfamiliar with how to care for SCD patients, feel uncomfortable prescribing opioids, or perceive adults with SCD to have increased risk of substance abuse, despite evidence to the contrary. Delayed treatment may cause worse outcomes than if treatment were initiated in a timely manner.

Addressing cost and insurance barriers could improve treatment access for individuals with SCD

Patients with SCD may delay or avoid care, or discontinue treatment or medications, due to costs. Stakeholders also reported difficulties with insurers' utilization management processes, particularly when seeking approval for opioids and disease-modifying therapies. While Medicaid covers an array of services for eligible individuals with sickle cell disease, opportunities may exist to expand coverage and improve standardization of care across MCOs.

JCHC Analyst: Estella Obi-Tabot

Expanding Access to Sickle Cell Disease Treatment in Virginia

Sickle cell disease is a severe inherited blood disorder that predominantly impacts people of color, particularly African Americans. Individuals living with sickle cell disease can encounter barriers to obtaining quality care such as limited geographic access, financial and socioeconomic barriers, specialist availability, transportation needs, social factors, and lack of public awareness. New available treatments can increase life expectancy and improve quality of life; however, there is a need for more comprehensive coordinated data collection efforts to better understand the impact of sickle cell disease and ensure there is access to sickle cell disease treatment.

During the 2024 Session of the General Assembly, Delegate C.E. Cliff Hayes, Jr., introduced House Joint Resolution 60 (APPENDIX 1), which would have directed the Joint Commission on Health Care (JCHC) to study sickle cell disease in the Commonwealth. House Joint Resolution 60 was tabled in the House Rules Studies Subcommittee and the topic was referred by letter to the JCHC for consideration. In June 2024, the JCHC directed staff to conduct a narrowly scoped study of sickle cell disease in the Commonwealth to address topics identified in House Joint Resolution 60 including:

- Availability of health care and support services for individuals with a diagnosis of sickle cell disease;
- Medications, forms of treatment, and existing reimbursement frameworks and methodologies for sickle cell disease;
- Current data available on individuals diagnosed with sickle cell disease, and whether additional reporting is needed to ensure comprehensive data collection;
- Sickle cell disease educational efforts and materials available to health care providers and Virginians;
- Current state funding and programs focused on sickle cell disease;
- Considerations of ancillary and co-occurring health challenges as result of sickle cell disease and its treatments, including reproductive health issues and iatrogenic infertility; and
- Recommendations for improvements in the delivery of and access to health care services and treatment of individuals with diagnosis of sickle cell disease.

During the 2024 Session of the General Assembly, two other state agencies were also directed to undertake studies of topics related to sickle cell disease. House Bill 820 (Mundon King) directed the Department of Medical Assistance Services (DMAS) to conduct

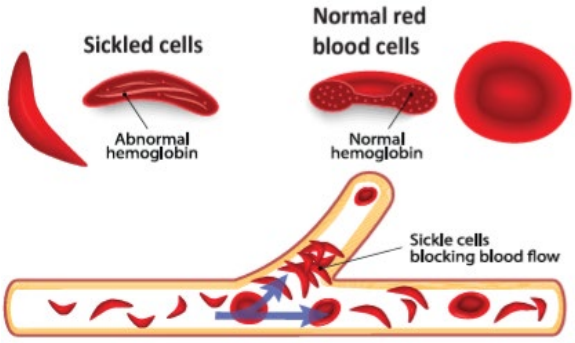
an annual review of all medications, treatments, and services for individuals with Medicaid coverage and to report annually to the Chairmen of the House Committee on Health and Human Services, Senate Committee on Education and Health, and JCHC regarding the results of the review. House Bill 252 (Cole) directed the Virginia Department of Health (VDH) to establish a statewide sickle cell disease registry and to report annually to the Governor and the General Assembly on data and information related to sickle cell disease included in the registry.

Given the ongoing nature of the work required by House Bills 820 and 252, this study does not include issues addressed by those pieces of legislation. This study provides an overview of state programs that identify and monitor sickle cell disease; current data on sickle cell disease; information on available treatment options; current state funding that supports education, monitoring, and treatment; and barriers that individuals living with sickle cell disease must navigate.

Sickle Cell Disease is an inherited blood disorder

Sickle cell disease (SCD) refers to a group of inherited blood disorders that affect hemoglobin, a molecule that red blood cells need to carry oxygen. The disease causes red blood cells, which are regularly round, to curve into a crescent or sickle-like shape, inhibiting their ability to move easily through the body. Sickled red blood cells clump together, break easily, and block blood flow to organs and tissues (FIGURE 1). These blockages in blood flow, called vaso-occlusive episodes or pain crises, create severe medical complications that can affect every organ system in the body. Vaso-occlusive episodes can lead to sudden and severe pain, the primary complication burdening individuals with SCD. In a limited number of cases, stem cell transplantation may provide a cure for SCD. In other cases, therapies and treatments focused on addressing symptoms and preventing crises such as blood transfusions and pain medication can improve quality of life and life expectancy for people with SCD.

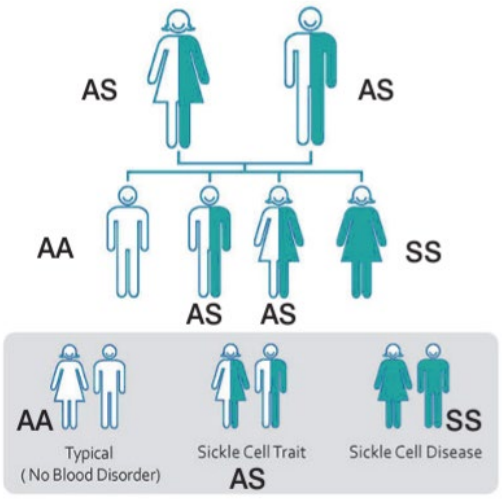
FIGURE 1. Sickle cell disease affects the shape and function of red blood cells



SOURCE: VDH sickle cell educational materials, 2017.

There are several types of SCD (APPENDIX 2) which can range in severity, depending on the specific forms of abnormal hemoglobin an individual inherits. All individuals inherit one hemoglobin gene from each parent. There are many types of abnormal hemoglobin – the hemoglobin "S" gene is the abnormal form that causes red blood cells to sickle. Individuals must inherit two abnormal hemoglobin genes – one from each parent – to have SCD (FIGURE 2). **Sickle cell trait** refers to when a person inherits one abnormal hemoglobin gene and one normal hemoglobin "A" gene. People with sickle cell trait do not usually have symptoms of SCD but can pass the trait on to their children.

FIGURE 2. Sickle cell disease is an inherited blood disorder



SOURCE: VDH sickle cell educational materials, 2017.

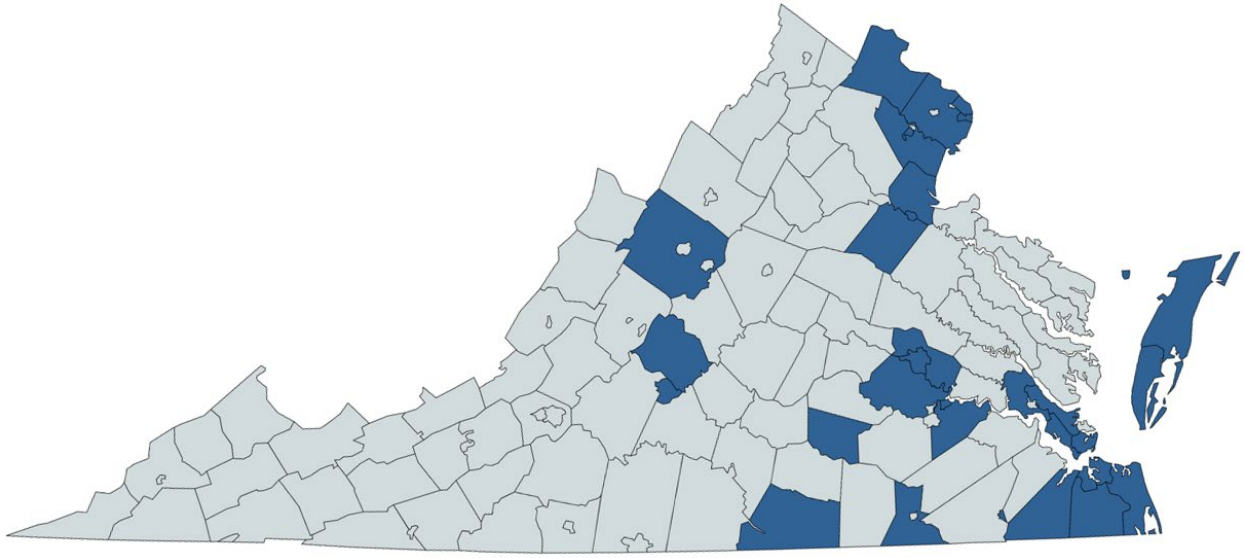
Sickle cell disease primarily affects Black individuals, but data collection is incomplete

SCD is most common among people of African, South American, Central American, Caribbean, Mediterranean, Middle Eastern, and Indian descent. In the United States, SCD primarily affects Black and Hispanic populations.

There is no national disease registry to track individuals with SCD and funding and infrastructure for research and data collection about the disease have historically been limited. As such, there is not enough information to know exactly how many people in the United States are living with SCD. The Centers for Disease Control and Prevention (CDC) estimates about 100,000 people in the United States have SCD, more than 90% of whom are Black. Approximately 1 in 13 Black babies are born with sickle cell trait, and 1 in 365 Black babies are born with SCD.

In Virginia, there are an estimated 4,000 individuals living with SCD. The most recently available data show that in 2021, there were 73 confirmed cases of newborns with SCD in Virginia, or about 1 in 1,250 (0.08%) of all live births in the state that year, and the number of confirmed cases of infants with SCD has stayed relatively steady in the last several years. Thirty-two localities, mostly in Eastern Virginia, had probable or confirmed cases of newborns with SCD. Most had less than five confirmed cases for the year, therefore exact case numbers are not reported by locality to protect patient identity (FIGURE 3).

FIGURE 3. Localities with probable or confirmed newborn cases with SCD in 2023



SOURCE: JCHC analysis of Virginia Department of Health newborn screening data, 2024.

Sickle cell disease impacts all aspects of an individual's life

SCD has cross-cutting impacts on an individual's physical, mental, and emotional well-being which can reduce overall quality of life. Vaso-occlusive episodes, or pain crises, cause both acute and chronic pain and increase in frequency and severity as individuals age. Therefore, these symptoms must be managed over a lifetime. Pain crises have an invisible mental and emotional toll, as the unpredictable nature of when a pain crisis arises also contributes to anxiety, stress, and fatigue. More frequent pain crises are associated with higher rates of depression. Individuals living with SCD are three times more likely to have depression compared to the general population.

Given that SCD is an inherited disease, individuals with SCD also take their disease into consideration when choosing partners and starting families. Pregnant individuals with SCD are at a higher risk of developing several birth complications including intrauterine growth restriction, preterm delivery, increased perinatal mortality, and low birth weight. SCD is considered a high-risk pregnancy condition and being pregnant can exacerbate an individual's SCD symptoms. Providers interviewed by JCHC staff also indicated that individuals with SCD may have difficulty getting pregnant and carrying a baby to term. For Black women, who are already at an increased risk for miscarriage and other adverse birth outcomes compared to all other groups, having SCD further increases the risk of adverse birth outcomes.

In addition to the physical, mental, and emotional toll of having SCD, managing pain and other clinical complications is expensive due to frequent, repeated engagement with the

health care system. The Department of Medical Assistance Services (DMAS) analyzed hospital readmissions between July 2020 and September 2023 and found that SCD is the fourth most common diagnosis associated with hospital readmissions among Medicaid enrollees in Virginia, with one of the highest per claim costs per readmission (APPENDIX 3). Individuals with SCD with commercial health insurance have average lifetime SCD-attributable medical costs of $1.7 million.

SCD also comes with indirect costs, such as productivity loss, education loss, and other non-healthcare costs that individuals with the disease must manage. Students with SCD face disruptions to their education, and adults with SCD may have difficulty gaining and maintaining employment. In a survey of patients with SCD being treated at Virginia Commonwealth University (VCU) Health, employed individuals reported missing an average of 40 percent of workdays in the previous month due to managing their sickle cell symptoms. Most employed respondents also reported going to work despite having adverse symptoms and subsequently having reduced productivity at work. Many individuals with SCD require support from caregivers and family, who often then miss work or have decreased productivity themselves.

VDH is responsible for sickle cell disease monitoring in Virginia

The Virginia Department of Health (VDH) is responsible for primarily monitoring SCD cases across the Commonwealth. This involves identifying potential cases of SCD, confirming SCD diagnoses, and conducting ongoing disease surveillance for confirmed SCD cases to understand the long-term impact of SCD. The current systems and processes for identifying new cases of SCD via Virginia's Newborn Screening Program are effective; however, ongoing disease monitoring for individuals not captured through newborn screening is insufficient.

The newborn screening program is the primary state-level program that identifies potential cases of sickle cell disease

Newborn screening programs are public health programs that intend to identify conditions that can affect a child's long-term health and survival to facilitate timely access to care and treatment. The Virginia General Assembly mandated implementation of a newborn screening program in Virginia in 1966. Following a 1987 recommendation by the National Institutes of Health, Virginia added screening for hemoglobinopathies, inherited blood disorders involving the hemoglobin molecule, including SCD, to the Dried Blood Spot (DBS) newborn screening program in 1989 (SIDEBAR).

The **Virginia newborn screening program** consists of several screening programs including Dried Blood Spot (DBS), Critical Congenital Heart Disease, Early Hearing Detection and Intervention, and VaCARES Birth Defects Surveillance. The DBS screening program facilitates early identification and treatment of infants who are affected by certain heritable disorders and genetic disease.

As part of Virginia's newborn screening program, every infant born in the state is screened for hemoglobinopathies within 48 hours of birth, unless the infant's parent or guardian objects to the screening for religious reasons. The screening process requires collection of a blood sample from the infant, which is sent to the Virginia Department of General Services' Division of Consolidated Laboratory Services (DCLS) for processing. If a screening result indicates the presence of abnormal hemoglobin, DCLS refers the case to the Virginia's Sickle Cell Awareness Program to facilitate additional testing. Because screening conducted as part of Virginia's newborn screening program can only identify the presence of abnormal hemoglobin and cannot determine whether the abnormality is attributed to SCD, additional testing is necessary before an SCD diagnosis can be made (see APPENDIX 4 for additional detail on screening results).

The Virginia Sickle Cell Awareness Program facilitates diagnosis and links individuals to care

The **Virginia Sickle Cell Awareness Program** is one of four programs within Virginia's Children and Youth with Special Health Care Needs (CYSHCN) program, managed by VDH. Virginia's CYSHCN program also includes Care Connection for Children, Child Development Services Program, and the Bleeding Disorders Program.

Virginia's Sickle Cell Awareness Program (SIDEBAR) is responsible for **facilitating diagnostic testing** and **entry into care** for individuals with SCD. When a newborn screening result indicates the presence of abnormal hemoglobin, DCLS refers the case to the Virginia Sickle Cell Awareness Program coordinator, who notifies the infant's family and follows up with the infant's pediatrician to request a second screening. If the second screening test also indicates an abnormality, the Sickle Cell Awareness Program coordinator notifies the pediatrician and refers the infant to their nearest specialist for confirmatory testing and treatment. A physician diagnosis is the only way to confirm an individual has SCD and is required before a patient can begin treatment.

In addition to facilitating diagnostic testing and entry into SCD care, the Sickle Cell Awareness Program is also charged with providing education and counseling for individuals diagnosed with SCD and their families, connecting individuals with SCD with community resources, and raising awareness of SCD in the community. The program is funded through the federal Title V Maternal and Child Health Services Block Grant. Block grant funds are also used to reimburse DCLS for SCD screening for local health department patients.

Virginia encourages health care providers to offer sickle cell screening and testing for adults but does not require reporting of results

While Virginia's newborn screening program is an effective method for identifying new cases of SCD in infants born in the state, individuals born before 1989, when testing for SCD was added to the state's newborn screening program, may not be aware of their sickle cell

status. To address this issue, in 2024, the General Assembly enacted House Bill 255 (Mundon King), which provides that every adult resident of the Commonwealth may be offered screening tests for SCD or SCT and requires that, if such screening is performed, the health care provider who ordered the test must provide education and appropriate counseling regarding the test results. The bill emphasizes screening tests for individuals of reproductive age, as well as those who are unaware of their SCT status. Screening tests performed in accordance with House Bill 255 are voluntary for the patient and the results of such screening tests are not required to be reported to any program or entity.

VDH is developing a statewide sickle cell disease registry to support patient care and ongoing disease surveillance

Virginia does not currently collect information about cases of SCD other than those identified through the newborn screening program. To better understand and monitor the SCD landscape in Virginia, in 2024, the General Assembly enacted House Bill 252 (Cole), directing VDH to establish a statewide sickle cell disease registry to collect information about patients having sickle cell disease. This registry will be used to improve diagnosis and treatment of SCD; determine the need for and means of providing better long-term and follow-up care to individuals with SCD; conduct epidemiological analysis of the impact of SCD in Virginia; improve rehabilitative programs for individuals with SCD; and assist in training hospital personnel. The bill requires health care providers and other health care entities to report patient case information to VDH for inclusion in the registry unless the patient opts out of having their screening results reported to the registry. The General Assembly appropriated $405,260 in Fiscal Years (FY) 2025 and 2026 to support development of the SCD registry.

The SCD registry could address the gap in existing state programs, which do not provide additional information on how to support SCD care after newborns and adults with SCD are identified. Once the registry is established, VDH could have a strong infrastructure in place to revisit the possibility of sharing de-identified data with CDC's Sickle Cell Data Collection Program to contribute to national disease surveillance efforts (SIDEBAR).

VDH is currently designing the registry required pursuant to House Bill 252 (Cole). The agency reports that the design process will include reviewing sickle cell registry models implemented in other states and identifying the types of data to be included in the registry. While VDH is required to report annually to the Governor and the General Assembly annually on information contained in the sickle cell registry, additional

The CDC Sickle Cell Data Collection Program provides funding for states to share newborn screening data and other relevant data to build a comprehensive health database to better understand the health care needs of individuals living with SCD. Seventeen states currently share or are planning to share data as part of the program. While Virginia does not currently participate in the program due to difficulties obtaining and delays in reporting de-identified information, VDH reports that it will consider participating in the program following establishment of the statewide sickle cell disease registry required by House Bill 252 (2024).

transparency regarding the plan for the design of registry and progress towards implementation of the registry could allow the General Assembly to ensure the final product meets its intended goals.

➔ **OPTION 1:** The Joint Commission on Health Care could write a letter to request that the Virginia Department of Health provide an update, by September 1, 2025, on the plan for and status of the statewide sickle cell disease registry, including information about the types of data that will be collected, how the data will be used, and who will be able to access the data.

Sickle cell disease treatment is complex and long-term

Advances in disease management and expanded treatment options allow individuals with SCD to live longer, yet treatment remains multifaceted and complex. SCD treatment primarily focuses on preventing sickling and managing pain and other complications from the disease (TABLE 1). Given the wide range of complications and symptoms that people with SCD must manage, optimal treatment is individualized and interdisciplinary.

TABLE 1. SCD treatment focuses on preventing sickling and managing pain and complications

Purpose	Treatment
Pain Management	• Non-opioid pharmacological therapy (e.g., nonsteroidal anti-inflammatory drugs, regional anesthesia, ketamine, gabapentinoids) • Non-pharmacological therapy (massage, yoga, transcutaneous electrical nerve stimulation, cognitive and behavioral pain management) • Opioid therapy
Disease Modifiers	• Crizanlizumab (brand name: Adakveo) • Hydroxyurea (brand name: Droxia, Siklos) • L-glutamine (brand name: Endari) • Voxelotor (brand name: Oxbryta)*
Therapeutic Interventions	• Blood transfusions
Complication Prevention	• Infection prevention (e.g., children with sickle cell anemia should receive oral penicillin twice daily until age 5 to help prevent invasive pneumococcal infection) • Screening for renal disease, hypertension, retinopathy, risk of stroke, pulmonary disease

Purpose	Treatment
Education and Counseling	• Genetic counseling • Mental health counseling • Reproductive counseling
Curative Therapies	• Allogeneic hematopoietic stem cell transplantation

SOURCE: JCHC analysis of peer-reviewed literature.
NOTE: As of September 2024, voxelotor (brand name: Oxbryta) is being voluntarily withdrawn from the market by the manufacturer due to safety concerns, and the U.S. Food and Drug Administration has announced health care providers should stop prescribing the drug.

Appropriate pain management for individuals with sickle cell disease is a primary concern

People living with SCD often experience both acute and chronic pain as a result of their disease. The sickled cells that flow through the body block necessary oxygen and blood flow causing pain and serious damage across multiple organs throughout the body, including the heart, lungs, kidneys, and brain. These episodes of pain, called vaso-occlusive crises or pain crises, range from mild to severe, start abruptly, and can last for an undetermined period of time. Over time, individuals with SCD may experience multiple complications across organ systems which can lead to more chronic pain from organ damage, lingering pain after a pain crisis, or chronic joint pain.

Pain management strategies include non-opioid pharmacological therapy (e.g., ketamine), and non-pharmacological strategies (e.g., yoga, massage), but patients seeking treatment are most frequently managed with opioids. Clinical guidelines for SCD emphasize the need for rapid assessment and initiation of pain medication, within one hour of arriving in an emergency department, with re-assessments every 30 to 60 minutes to repeat doses until pain is under control. It is recommended that opioid dosing be adequate to start, based on a patient's baseline opioid therapy levels and prior effective therapy. Given the severe and ongoing nature of pain that individuals with SCD experience, individuals with chronic pain who have received consistent treatment with opioids and have higher opioid tolerance will likely require larger starting doses than a typical individual without SCD may receive.

Disease modifiers and therapeutic interventions focus on reducing sickling

Most clinical treatments for SCD focus on reducing sickling to minimize pain and complications from the disease. **Disease modifiers**, or disease-modifying treatments, are drug therapies that target the main physiological processes of SCD. For example, hydroxyurea increases the amount of fetal hemoglobin, hemoglobin "F," an individual produces, which helps keep red blood cells from sickling and clumping together. Disease modifiers effectively reduce sickling, pain crises, and disease complications.

Other **therapeutic interventions** can help manage symptoms of SCD, even if they are not disease modifiers. Blood transfusions are commonly used to treat anemia associated with SCD – the infusion of healthy donor blood can reduce the risk of complications from sickling as well as increase oxygen flow.

Prevention, education, and counseling support patient health and wellbeing

In addition to addressing patients' pain and disease pathways, appropriate care includes prevention, patient education, and counseling. The inhibited and abnormal flow of blood in individuals with SCD means they are susceptible to infection and complications across all major organ systems. Infection prevention and increased screening for conditions like renal disease and stroke can help reduce individuals' risk. Patients should also receive ongoing education on SCD management, as well as genetic counseling, reproductive counseling, and mental health support as SCD impacts every facet of their lives.

Stem cell transplantation is the only curative therapy for sickle cell disease but is not recommended for everyone with sickle cell disease

Allogeneic hematopoietic (blood) stem cell transplants, also known as bone marrow transplants, are the only known cure for SCD. Despite its effectiveness, transplantation is not an option for all individuals with SCD as the treatment is risky and requires a stem cell donor. Transplantation is most effective in children under 16 years old who also have a fully matched sibling donor – under these conditions, clinical outcomes show a 95 percent survival rate five years after the procedure. However, less than 20 percent of patients with SCD in the United States have a matched donor. Patients can attempt transplantation with matched but unrelated donors, and only half-matched or partial-matched donors in certain cases. The main risks are graft failure or the chance that transplanted cells attack a patient's own cells. Additionally, the procedures required to prepare patients for transplantation, such as chemotherapy to destroy the patient's own bone marrow and stem cells, are damaging and can lead to organ injury, infection, infertility, and other complications. Patients and providers must weigh the potential benefits against the risks before attempting transplantation.

New sickle cell disease gene therapies make stem cell transplantation more effective

In December 2023, the U.S. Food and Drug Administration approved two new gene therapy treatments for SCD – Lyfgenia and Casgevy. The treatments involve genetically modifying a patient's own blood stem cells before giving them back to the patient as part of a stem cell transplant. These genetic modifications increase production of healthy hemoglobin and can help prevent red blood cells from sickling. Because the gene therapies use patients' own stem cells, they can avoid the difficulty of finding a donor match that traditional stem cell transplants require.

Gene therapy treatments are new and not yet considered a cure for SCD. They are also very expensive – Lyfgenia is priced at $3.1 million per patient, and Casgevy at $2.2 million per patient. These costs do not include the other procedures patients must undergo before receiving gene therapy, such as chemotherapy. In addition, the number of providers available to provide gene therapy treatment is limited. Currently, VCU Health is the only hospital system in the state that is certified as an authorized treatment center to provide the new SCD gene therapies. Pediatric patients also have the option to travel to Children's National Hospital in Washington, D.C., which is also certified. One provider JCHC staff spoke with noted that while gene therapy is remarkable, given the risks of stem cell transplantation it may not be an appropriate treatment for all patients, and they would rather have additional funding to spend on other disease modifying treatments, wraparound services, and opioid reduction therapy.

Sickle cell disease treatment can cause fertility issues that patients and providers must navigate

About 95 percent of individuals with SCD live to reproductive age, which has sparked growing interest in understanding the impact of SCD and SCD-related treatments on fertility. Intense SCD treatments, particularly those for patients preparing for stem cell transplantation, often cause infertility because of the ways they indirectly or directly damage egg quality and quantity. When infertility is an adverse side effect to a necessary or unavoidable medical procedure or treatment, it is called iatrogenic infertility.

Advocates JCHC staff spoke with identify fertility care as an essential part of a comprehensive care model for SCD. However, providers were uncertain about the extent to which appropriate patient education is offered for common SCD medications like hydroxyurea that can lead to decreased fertility. Since hydroxyurea is a primary treatment for SCD, contraceptive use and genetic counseling are important factors of reproductive health for individuals living with SCD. Research also indicates that stem cell transplants expose the body to toxic agents that are associated with up to an 80 percent risk of premature ovarian failure. For this reason, patients are often referred to fertility preservation treatment before undergoing stem cell transplant.

Individuals with sickle cell disease and their providers must weigh the benefits and risks of pursuing fertility preservation treatments

There is no standard approach to addressing fertility preservation treatment for individuals with any type of SCD. Concerns about fertility preservation are complicated by the fact that individuals with SCD who receive a stem cell transplant may be too young to conceptualize the magnitude of fertility preservation treatment. In the largest cohort study done with individuals with SCD before stem cell transplant, about 75 percent had not reached puberty at the time of treatment.

Individuals with SCD who want to pursue fertility preservation face significant barriers, including high costs, increased risk of health complications, and delays in treatment. Some fertility preservation methods require multiple rounds to achieve the optimal yields of oocytes for future fertility treatments to be effective. Multiple rounds may not be economically or emotionally feasible for some patients. Additionally, in situations where there are complications, providers may not be willing to risk jeopardizing patient safety for an elective treatment. And even without these complications, there may still be risks to prolonging necessary treatment like stem cell transplant. Ultimately, a relatively small population – less than 10 percent of patients with SCD - utilize any kind of assisted reproductive technology, including insemination and in vitro fertilization (IVF), to become pregnant after stem cell transplant.

Individuals with SCD and their providers must mitigate potential health risks of pursuing fertility preservation treatments while balancing the important psychosocial and economic factors they may also be facing. One provider cited a utilitarian approach to the matter and urged for more access to necessary life-saving sickle cell treatment before diverting funds for a smaller population of individuals who wish to pursue fertility preservation. Another provider identified there will likely be growing concern about fertility preservation treatment coverage when gene therapy becomes more widely available.

The General Assembly appropriated $1.4M annually for FY 25-26 to support individuals with sickle cell disease

The Virginia General Assembly has consistently funded programs for individuals with SCD for the last twenty years. Appropriations have increased over time, and for FY 2025 and FY 2026, the General Assembly appropriated $1.4M annually. A small fraction of funding is provided to regional community-based organizations that serve individuals with SCD. Most of the funds – a little more than $1.3M – are distributed through VDH to provide support services for pediatric and adult SCD patients receiving care at comprehensive sickle cell treatment centers in the state.

The General Assembly provides funding to regional community-based organizations that serve individuals with sickle cell disease

The Statewide Sickle Cell Chapters of Virginia (SSCCV) are a network of nine community-based SCD organizations that support individuals living with SCD across Virginia. The regional chapters are located in Danville, Fredericksburg, Hampton, Lynchburg, Norfolk, Richmond, Rocky Mount, and Northern Virginia. They provide resources to address unmet social, psychosocial, and educational needs for individuals and families impacted by SCD, including stress-reducing activities, sickle cell education, referral assistance, and assistance with obtaining employment or disability benefits. Services vary from chapter to chapter.

SSCCV has received state funding annually since FY 2008 to provide grants to community-based programs that offer patient assistance, education, and family-centered support for individuals suffering from SCD. Initial appropriations were administered through VDH, but beginning in FY 2011, budget language specified funds would instead be administered via contract with SSCCV. Funding has stayed flat in the last decade, at $105,000 annually.

SSCCV manages distribution of the grant funding to the various network chapters. SSCCV annual reports show that in most years, grant funding is distributed to three or four member organizations (see APPENDIX 5 for funding distribution). The chapters primarily use their grant funding for SCD health educational materials and multimedia advertising. For example, the Sickle Cell Association of Richmond has purchased radio time to run SCD and sickle cell trait awareness campaigns, and regularly mails information related to SCD disease management (pain management, stress management, healthy eating) to chapter members.

VDH contracts with treatment centers to fund wraparound services and supports for individuals with sickle cell disease

SCD care is primarily provided through SCD treatment centers that have the staff, knowledge, and resources to provide comprehensive SCD care. SCD treatment center models differ depending on the organization's size, patient population, staffing, structure, and services. Treatment centers may be:

- Located within larger hospital systems or academic centers but have dedicated clinical space with dedicated staff,
- Embedded within larger programs such as a hospital's cancer center with which it shares space and staff,
- Specialized medical homes co-located with primary care, or
- Hub-and-spoke models where care is provided through a network of a full-service care center with secondary satellite centers.

The American Society of Hematology outlined five essential components that all SCD treatment centers, regardless of their model, must have to provide comprehensive care:

- Multidisciplinary, team-based, evidence-guided care that is coordinated throughout the institution,
- Recognized authority within the larger institution for managing patients with SCD,
- A physician lead who is considered an SCD specialist,
- Social workers, patient navigators/case managers, and nursing staff, and
- Ability to offer acute and chronic pain management, transfusion, and timely access to specialists.

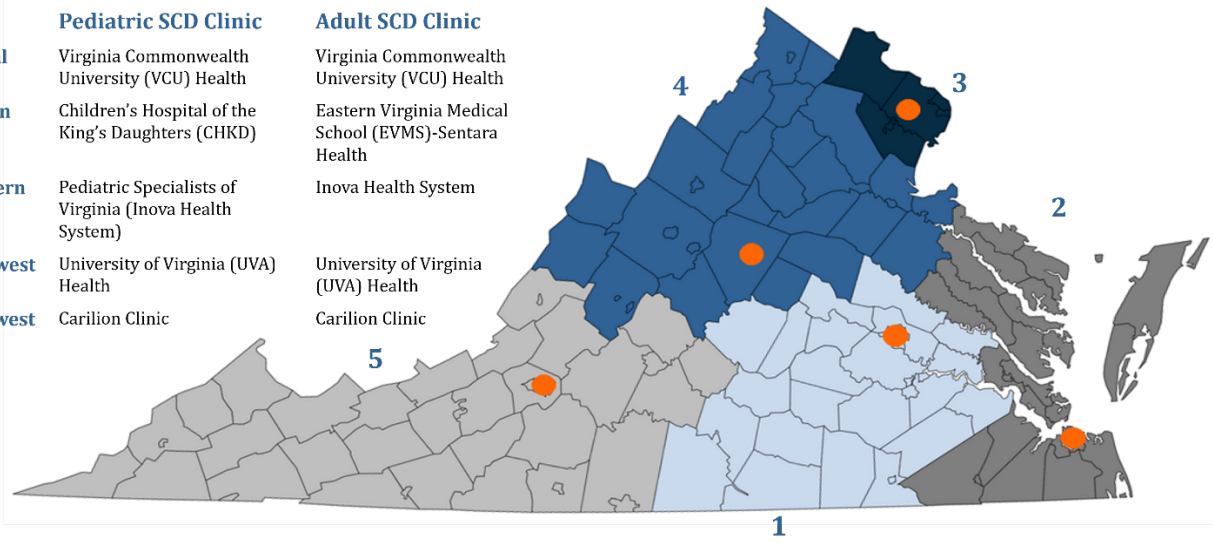
Access to SCD treatment centers allows patients to receive care from providers who specialize in SCD care and have both the knowledge and resources to provide evidence-based treatments.

Treatment centers are the primary source of specialized SCD care in Virginia

Virginia's SCD treatment centers most commonly have embedded care models, where their SCD services are part of larger hospital systems' hematology/oncology departments. Centers specialize in either pediatric or adult care. Pediatric sickle cell treatment centers provide services to individuals from birth to their 21st birthday and adult sickle cell treatment centers provide services to individuals 18 years of age and older. There are currently five pediatric treatment centers and five adult treatment centers in Virginia, with one adult and one pediatric facility located in each region of the state (FIGURE 4). In some regions, pediatric and adult comprehensive treatment centers are provided by a single hospital system, while in other regions adult and pediatric treatment centers are operated by separate hospital systems. Approximately 2,000 patients receive care across five adult and five pediatric treatment centers across the state, which is estimated to be about half of the total number of individuals with SCD in Virginia.

FIGURE 4. Localities with comprehensive sickle cell treatment centers.

Region	Pediatric SCD Clinic	Adult SCD Clinic
1. Central	Virginia Commonwealth University (VCU) Health	Virginia Commonwealth University (VCU) Health
2. Eastern	Children's Hospital of the King's Daughters (CHKD)	Eastern Virginia Medical School (EVMS)-Sentara Health
3. Northern	Pediatric Specialists of Virginia (Inova Health System)	Inova Health System
4. Northwest	University of Virginia (UVA) Health	University of Virginia (UVA) Health
5. Southwest	Carilion Clinic	Carilion Clinic



SOURCE: JCHC analysis of Virginia Sickle Cell Awareness Program document data, September 2024.

Comprehensive Sickle Cell Clinic Networks were established to provide access to specialty care and promote the health of individuals with sickle cell disease

The General Assembly established the Pediatric Comprehensive Sickle Cell Clinic Network in 2008 to provide children in the Commonwealth living with SCD access to specialty care and services that promote optimal health. The Adult Comprehensive Sickle Cell Clinic

Network was created in 2021 to provide similar services for adults with SCD. The Comprehensive Sickle Cell Clinic Networks are tasked with providing multidisciplinary evaluation, treatment, direct care services, and support services including care coordination, genetic counseling, services to support transition from pediatric to adult SCD care, and education about SCD.

The Virginia Sickle Cell Awareness Program contracts hospital systems with SCD treatment centers to participate in the Comprehensive Sickle Cell Clinic Networks. While the state is reliant upon treatment centers participating in the Networks to provide the direct services and clinical care that individuals with SCD needs, the state does not provide funding to support these services. As with most other health care providers, sickle cell treatment centers bill patient's health insurance to receive reimbursement for clinical services. Treatment centers participating in the Comprehensive Sickle Cell Clinic Networks receive state funds for support services provided to patients with SCD.

Of the five treatment centers that provide **pediatric** SCD treatment, VDH has contracted with Children's Hospital of The King's Daughters (CHKD), Pediatric Specialists of Virginia (part of Inova Health System), University of Virginia (UVA) Health, and Virginia Commonwealth University (VCU) Health to participate in the Pediatric Comprehensive Sickle Cell Clinic Network (TABLE 2). The fifth pediatric treatment center in Virginia, Carilion Clinic, coordinates with the Virginia Sickle Cell Awareness Program to accept patient referrals when new SCD cases are identified in their region by the state's newborn screening program but has not entered into a contract with VDH and does not receive any funding from the state. With increased funding available for comprehensive treatment centers, VDH reports that the agency could enter a contract with Carilion Clinic to participate in the Pediatric Comprehensive Sickle Cell Clinic Network in the future.

As of June 2024, the four clinics participating in the Pediatric Comprehensive Sickle Cell Clinic Network reported serving 1,131 pediatric patients, with CHKD serving the largest number of patients (n = 441) and UVA Health serving the smallest number of patients (n = 62). Carilion Clinic does not report data to the Virginia Sickle Cell Awareness Program but estimated that they serve about 50 pediatric patients with SCD.

TABLE 2. There are five pediatric comprehensive sickle cell treatment centers in Virginia

Health Region	Hospital System	Location	Contract with VDH	Number of SCD Patients Served
Central	Virginia Commonwealth University (VCU) Health	Richmond	Yes	313
Eastern	Children's Hospital of the King's Daughters (CHKD)	Norfolk	Yes	441
Northern	Pediatric Specialists of Virginia (part of Inova Health System)	Fairfax	Yes	315
Northwestern	University of Virginia (UVA) Health	Charlottesville	Yes	62
Southwestern	Carilion Clinic	Roanoke	No	Unknown
			Total Patients	1,131

SOURCE: JCHC analysis of Virginia Sickle Cell Awareness program data, as of June 2024.
NOTE: Carilion Clinic has not entered into a contract with VDH to participate in the Pediatric Comprehensive Sickle Cell Clinic Network and therefore does not report data to the Virginia Sickle Cell Awareness Program.

All five treatment centers that provide **adult** SCD treatment in Virginia participate in the Adult Comprehensive Sickle Cell Network (TABLE 3). As of June 2024, comprehensive sickle cell clinics at Carilion Clinic, Inova Health System, UVA Health, and VCU Health reported serving a total of 866 adult patients. Because the comprehensive sickle cell clinic at EVMS/Sentara did not begin accepting patients until October of 2024, numbers are not available for this center. Of the four treatment centers for which data is available, VCU served the largest number of patients (n=583), or almost 70 percent of all adult patients across the state.

TABLE 3. There are five adult comprehensive sickle cell treatment centers

Health Region	Hospital System	Location	Contract with VDH	Number of SCD Patients Served
Central	Virginia Commonwealth University (VCU) Health	Richmond	Yes	583
Eastern	Eastern Virginia Medical School (EVMS) and Sentara Health partnership	Norfolk	Yes	Not available
Northern	Inova Health System	Fairfax	Yes	153
Northwestern	University of Virginia (UVA) Health	Charlottesville	Yes	64
Southwestern	Carilion Clinic	Roanoke	Yes	66
			Total Patients	866

SOURCE: JCHC analysis of Virginia Sickle Cell Awareness program data as of June 2024.
NOTE: Data from EVMS and Sentara Health will not be available until the treatment center has been in operation for a full fiscal year.

General Assembly funding for Comprehensive Sickle Cell Clinic Networks has increased

The General Assembly has appropriated state general funds for the Pediatric Comprehensive Sickle Cell Clinic Network for almost twenty years, starting in FY 2008. Total annual appropriations have remained relatively steady over the years, with two increases – from $200,000 to $305,000 in FY 2016, and then again to $450,000 in FY 2025.

In contrast, state appropriations for adult sickle cell treatment centers only began in FY 2021 (see APPENDIX 6 for full funding history). Prior to FY 2021, VDH provided a small amount of funding from discretionary funds available to the state through the federal Title V Maternal and Child Health grant to adult sickle cell treatment centers in the state. In FY 2021, the Adult Comprehensive Sickle Cell Clinic Network received the same amount as the pediatric network – $305,000 – but saw a substantial increase to $805,000 in FY 2022. Recently, the General Assembly allocated an additional $75,000 to the Adult Comprehensive Sickle Cell Clinic Network, bringing total annual funding for the network to $880,000 for FY 2025 and FY 2026 (TABLE 4). Because state funding for the Adult Comprehensive Sickle Cell Clinic Network was only initiated in FY 2021, the adult sickle cell treatment system is less established and does not have the same capacity to provide services as the pediatric system.

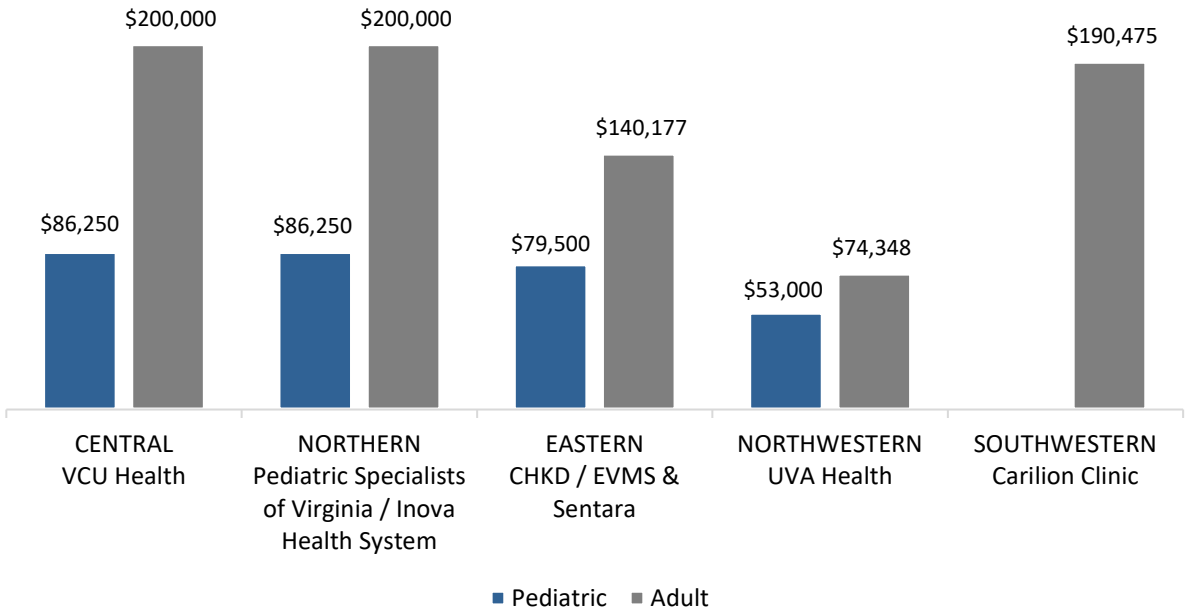
TABLE 4. General Assembly appropriations for SCD primarily support comprehensive treatment centers

	FY 21 Funding	FY 22 Funding	FY 23 Funding	FY 24 Funding	FY 25 Funding
Pediatric Comprehensive Sickle Cell Network	$305,000	$305,000	$305,000	$305,000	$450,000
Adult Comprehensive Sickle Cell Network	$305,000	$805,000	$805,000	$805,000	$880,000
Total	$610,000	$1,110,000	$1,110,000	$1,110,000	$1,330,000

SOURCE: JCHC analysis of Virginia State budget.

Funding for each Comprehensive Sickle Cell Treatment Network is distributed to the regional treatment centers (FIGURE 5). For the pediatric centers, the largest centers with higher patient volume – VCU Health, Pediatric Specialists of Virginia, and CHKD – receive more funding. Funding distribution for the adult centers is similar, though Carilion Clinic received additional funding, even with their lower patient volume, to help them expand capacity for their treatment center.

FIGURE 5. State funding for the Comprehensive Sickle Cell Clinic Networks by region



SOURCE: JCHC analysis of Virginia Sickle Cell Awareness program data, 2024.
NOTE: Carilion Clinic does not receive state funding to participate in the Pediatric Comprehensive Sickle Cell Clinic Network.

Individuals living with sickle cell disease navigate systemic and structural barriers to accessing care

Individuals with SCD face a number of systemic barriers related not only to issues within health care and the medical care they receive, but also their health-related social needs, such as housing, education, and income, and psychosocial factors. One sickle cell treatment center provider said their social worker and community health worker were their strongest assets because of their ability to address the structural barriers that patients must navigate, such as transportation and food insecurity. Most stakeholders also talked about the gaps and opportunities within the health care system that need to be addressed to better care for patients with SCD.

Individuals with SCD also face a range of individual and structural barriers to accessing health care in general and specialized care for their SCD specifically. Lack of accessible, appropriate health care services, lack of information and education for health care providers, and stigma and unconscious bias directly impact the ability of individuals with SCD to receive the treatment and support services they need.

Stakeholders report that treatment centers lack capacity to meet need for treatment and support services

The complex nature of SCD means patients not only need access to evidence-based clinical care, but also require an array of support services. In Virginia, comprehensive treatment centers participating in the Pediatric and Adult Comprehensive Sickle Cell Clinic Networks are the primary source of treatment and support services for individuals with SCD. While Virginia's comprehensive sickle cell treatment centers provide a broad array of services, stakeholders report that gaps exist in treatment centers' ability to meet patients' needs.

Treatment centers lack capacity to meet patients' need for treatment services

Patients with SCD can realize the best clinical outcomes when they have access to providers who are familiar with treating the disorder. Clinical guidelines recommend that patients receive care in facilities that specialize in the treatment of SCD from providers that have the expertise to manage their care and any complications they may experience. Virginia's comprehensive sickle cell treatment centers provide a range of specialized diagnostic and clinical care services for patients with SCD, but stakeholders report that treatment centers lack capacity to meet patients' needs.

Virginia's comprehensive sickle cell treatment centers are embedded in larger programs operated by health systems that provide staffing and resources to support the centers. This model allows treatment centers to utilize specialists affiliated with the health system but also means that clinic staff are usually shared across multiple departments – most frequently hematology/oncology. The lack of dedicated clinical staff for SCD means that treatment centers may not have the staff to expand their service hours or reach to meet patient need. Because treatment centers do not receive state funding for staff to provide direct and clinical care services, they must rely on the hospital systems with which they are affiliated for resources to expand their programs. However, stakeholders report that because SCD treatment does not generate substantial revenue, it can be hard to justify requests for additional staff or resources.

Treatment centers need additional capacity to support patients transitioning from pediatric to adult care

As life expectancy for individuals with SCD rises and patients with SCD live longer into adulthood, managing patients' transitions from pediatric to adult care becomes increasingly important to ensure appropriate disease management. Stakeholders described early adulthood as a particularly difficult time for individuals with SCD, as the disease progresses with age, causing more severe symptoms and higher risk of complications, and patients must contend with the psychosocial challenges of entry into adulthood. At the same time, patients with SCD are transitioning from the supportive pediatric treatment environment to the adult treatment system. Without connections to the adult treatment system and support during the transition period, young adults may be more likely to fall through the

cracks, becoming disconnected from treatment and experiencing negative health outcomes. Evidence collected by VDH in 2018 shows that the rate of emergency department visits for SCD was highest in the 18-30 age group, highlighting the challenges that individuals in this age group face.

VDH encourages strong relationships between treatment centers participating in the Pediatric and Adult Comprehensive Sickle Cell Clinic Networks to improve outcomes for transitioning patients. Pediatric sickle cell treatment centers in Virginia are required to provide services to support the transition from pediatric to adult services and all pediatric treatment centers have staff who help manage their patients' transitions to adult care. For example, CHKD has a social worker who begins preparing pediatric patients for transition when they turn 14 years old. Carilion Clinic also starts the process three years before patients must go into the adult care system, walking them through the adult facilities, introducing patients to the providers they will be seen by as adults, and even accompanying patients to their first adult appointment. Three treatment centers report employing dedicated transition specialists who guide pediatric patients as they approach adulthood and prepare to transition to the adult treatment systems.

Stakeholders report that care transitions are much more difficult when the pediatric treatment center does not have a counterpart in the adult treatment center to collaborate with during the transition process. Treatment centers that participate in Virginia's Adult Comprehensive Sickle Cell Clinic Network are expected to partner with pediatric sickle cell treatment centers to facilitate and coordinate the transition of adolescents and young adults from pediatric to adult care, but four stakeholders report that adult treatment centers do not have adequate capacity to do so.

Treatment centers do not have capacity to meet patients' need for mental health and other psychosocial support services

Individuals with SCD must navigate the unique psychosocial impacts of life with a chronic condition. Stakeholders described the immense toll having a chronic condition can have on patients with SCD, including stress and anxiety around pain crises, missing school or work due to sickness or appointments, and potentially missing milestones their peers may experience, such as going to college or starting a career. Stakeholders also noted the grief that individuals who experience challenges conceiving due to their SCD or SCD treatment may face. Additionally, individuals with SCD have an increased likelihood of developing a substance use disorder since they have a greater long-term exposure to opioid prescriptions to manage pain, however, research shows individuals with SCD are no more likely to have a drug use disorder compared to Black adults with other chronic conditions. Behavioral health and other psychosocial support services can help individuals living with SCD navigate these challenges.

Comprehensive sickle cell treatment centers currently provide some access to behavioral health and other psychosocial support services for patients but stakeholders report that

treatment centers are not able to meet the need for such services. Stakeholders indicate that resources available to treatment centers are not sufficient to cover the cost of dedicated mental health providers on treatment center care teams. Other stakeholders reported difficulty getting mental health providers to provide services at their treatment center, particularly providers that accept Medicaid or offer virtual appointments.

The General Assembly could provide funding to expand capacity at comprehensive sickle cell treatment centers

Funding for Virginia's Pediatric and Adult Comprehensive Sickle Cell Clinic Networks pays a portion of the cost of providing transition, behavioral health, and support services for patients with SCD but does not cover the full cost of these services. For example, UVA Health's funding covers one percent of the cost of employing a nurse practitioner, 15 percent of the cost of employing a nurse coordinator, and 27 percent of the cost of employing a social worker. CHKD reported using most of the state funds the center received to pay the salary for a transition coordinator, but that the total amount of the funding provided does not cover the full cost. State funding for treatment centers has not, historically, supported any direct or clinical care services. However, the General Assembly could appropriate funding for treatment centers to cover the cost of treatment services and additional support services in the future.

A budget amendment patroned by Delegate McQuinn and Senator Locke during the 2024 Session of the General Assembly provides some guidance on the amount of funding that would be required to provide sufficient treatment, transition, and mental health and support service capacity at Virginia's comprehensive sickle cell treatment centers. The amendment would have provided $5.5 million for the Adult Comprehensive Sickle Cell Clinic Network, including $2.6 million to support additional clinical staff to provide direct care services and $1.6 million to support staff to provide mental health services and to support patients transitioning from pediatric to adult care. (TABLE 5).

TABLE 5. Adult comprehensive SCD treatment centers requested $2.6M in funding for clinical staff and $1.6M for staff to provide mental health and care transition supports

Position Type	Requested Position Title	Total Funding Requested
Clinical staff for direct care services	Advance Practice Providers (e.g., Physician Assistant)	$1,025,000
	Physicians (specializing in SCD, hematology, pain management)	$728,000
	Registered Nurse Coordinators/Physician for gene therapy	$285,000
	Registered Nurses for infusion/pain clinic	$560,000
	Total funding requested for clinical staff	**$2,598,000**

Position Type	Requested Position Title	Total Funding Requested
Staff for mental health and care transition supports	Community Health Worker	$340,000
	Licensed Clinical Social Worker/Masters in Social Work	$517,000
	Nurse Navigator	$50,000
	Psychiatrist/Clinical Psychologist	$378,000
	Transition Patient Navigator	$276,000
	Total mental health and care transition supports funding	**$1,561,000**

SOURCE: Sickle Cell Association of Virginia, 2024 budget amendment request for funding to support adult comprehensive SCD treatment centers.
NOTE: The full budget amendment request also included requests for ancillary staff (e.g., project coordinator, medical assistant, lab technician), community outreach, and educational resources.

However, while the budget amendment provides some insight as to the need for funding to build capacity at adult treatment centers, additional information may be necessary to fully understand the extent of unmet need at Virginia's comprehensive sickle cell treatment centers and the resources required to meet such need. A needs assessment that quantifies each treatment center's current capacity for supporting and serving individuals with SCD and the scope of the need for additional capacity to serve individuals with SCD could help appropriators more accurately determine the amount of funding needed to build sufficient capacity at the treatment centers. Such needs assessment could include analysis of need at both adult and pediatric comprehensive sickle cell treatment centers and clarification as to whether increased funding would allow the treatment centers to provide more comprehensive services to their existing patients or enable them to and provide services to individuals with SCD who are not currently receiving services.

➔ **OPTION 2**: The Joint Commission on Health Care could introduce a budget amendment to provide funds to the Virginia Department of Health (VDH) to conduct a needs assessment to determine the extent of the need for treatment, transition, and mental health and other psychosocial support services for patients receiving services at comprehensive sickle cell treatment centers participating in the Pediatric and Adult Comprehensive Sickle Cell Clinic Networks, and to develop a plan for and an estimate of the cost of addressing such need to meet the needs of current patients and provide necessary services to new patients. VDH should report the results of the needs assessment and the plan and cost estimate to the Chairmen of House Committee on Appropriations, Senate Committee on Finance and Appropriations, and Joint Commission on Health Care by October 1, 2025.

Stakeholders report that lack of transportation is a major barrier to accessing care for individuals with sickle cell disease

Lack of transportation is a barrier to accessing health care for many individuals in Virginia. For patients with SCD who must travel long distances to access appropriate care, the problem may be even more acute. Many stakeholders identified lack of transportation as a barrier to SCD treatment. Some stakeholders reported traveling more than two hours to their nearest sickle cell treatment center.

Individuals with Medicaid coverage may use non-emergency medical transportation (NEMT) to get to their appointments. However, several stakeholders reported that NEMT can be unreliable, often cancelling travel arrangements or failing to collect patients as previously arranged. In addition, NEMT must be booked several days in advance, which is not feasible when a pain crisis or other urgent need for care arises. Individuals who are not covered by Medicaid and not eligible for NEMT may not have any access to transportation services.

While patients with SCD could benefit from strategies to address transportation related barriers to care generally, because treatment centers provide most of SCD care, working with treatment centers to address transportation barriers may offer more timely solutions. Treatment centers participating in Virginia's Pediatric and Adult Comprehensive Sickle Cell Clinic Networks are allowed to use state funding to pay for transportation services for patients. For example, a treatment center may use funds provided pursuant to their agreement with VDH to contract with a rideshare company to provide transportation to appointments for patients. However, stakeholders report that many treatment centers opt to use funding to support other services for patients instead.

The General Assembly could provide additional funds to treatment centers for the purpose of addressing transportation related barriers to care. As a first step, a needs assessment could help appropriators more accurately determine the amount of funding required to address the need for transportation services for patients receiving services at comprehensive sickle cell treatment centers in Virginia.

➔ **OPTION 3:** The Joint Commission on Health Care could introduce a budget amendment to provide funds to the Virginia Department of Health (VDH) to conduct a needs assessment to determine the extent of need for transportation services for patient receiving services at comprehensive sickle cell treatment centers participating in the Pediatric and Adult Comprehensive Sickle Cell Clinic Networks and to develop a plan for and an estimate of the cost of addressing such need. VDH should report the results of the needs assessment and the plan and cost estimate to the Chairmen of House Committee on Appropriations, Senate Committee on Finance and Appropriations, and the Joint Commission on Health Care by October 1, 2025.

Stakeholders report that providers' lack of knowledge about sickle cell disease interferes with timely treatment for individuals in crisis, particularly in the emergency department

Patients with SCD and advocates on behalf of individuals with SCD often report that health providers, other than providers specializing in the treatment of SCD, lack education and training about the disease, creating barriers to accessing appropriate care. While patients and advocates identified primary care, obstetrics-gynecology, and pediatrics as specialties that could benefit from additional awareness of and training in the treatment of patients with SCD, most identified emergency care as the area in which providers' lack of knowledge about SCD most impacts access to and quality of care. The issue is particularly acute for patients with SCD who seek treatment in hospital emergency departments during a pain crisis.

Because availability of and access to SCD treatment services is very limited, patients with SCD who are experiencing pain crises are often directed by their provider to go to their nearest emergency department. However, many emergency department providers are unfamiliar with how to care for individuals living with SCD and feel uncomfortable prescribing the volume of opioids patients typically need for appropriate pain management, even when patients share their diagnosis and other relevant documentation. As a result, treatment may be delayed and patients with SCD experiencing pain crisis may have worse outcomes than if treatment were initiated in a timely manner.

Sickle cell treatment providers report taking a number of steps to overcome barriers created by lack of familiarity with treatment of individuals with SCD and reduce barriers to timely and appropriate care in emergency departments. One provider reported providing a patient with a signed, written treatment plan with the provider's phone number that could be shared with an emergency department provider should the patient ever require emergency treatment during a pain crisis. Multiple providers cited maintaining a list of the nearest emergency departments for their patients and corresponding contact information, so they could be prepared to reach out on their patient's behalf in an emergency. Despite these efforts, individuals with SCD consistently report being denied timely and appropriate care when presenting to the emergency department in a pain crisis.

Some stakeholders suggest that development of a registry containing information about individuals living with SCD that is available to providers in hospital emergency departments could help streamline access to timely and appropriate care during a pain crisis. Some stakeholders believe that the statewide sickle cell registry being developed by VDH pursuant to House Bill 252 (Cole) adopted by the General Assembly during the 2024 Session could be expanded to accomplish this purpose. It is not clear from the enabling legislation whether VDH's statewide sickle cell registry could be utilized for this purpose, or if an alternative method of providing access to information about patients with SCD for health care providers in emergency departments may be more effective. As a first step toward addressing this issue, the JCHC could direct VDH to determine, as part of the

planning process for the statewide sickle cell registry, whether the registry could be designed to provide access to information about individuals with SCD for health care providers in hospital emergency departments and, if VDH determines that the statewide sickle cell registry could not feasibly be designed to accomplish such purpose, to provide recommendations as to alternative methods by which to information about individuals with SCD for health care providers in hospital emergency departments to improve access to timely and effective care.

➔ **OPTION 4**: The Joint Commission on Health Care could introduce a Section 1 bill directing the Virginia Department of Health (VDH) to develop a plan to ensure health care providers in hospital emergency departments have access to information about individuals with sickle cell disease to confirm patients' sickle cell status and facilitate timely and appropriate access to care. In developing such plan, VDH shall (i) consider alternative models for providing access to information about sickle cell disease for health care providers in emergency departments including determining whether the statewide sickle cell registry or other existing programs could be expanded to serve such purpose and (ii) identify any statutory or budgetary changes necessary to implement such plan. VDH shall report to the Joint Commission on Health Care regarding the plan by October 1, 2025.

Stigma and provider bias about individuals with sickle cell disease can delay appropriate patient care

Research shows that unconscious racial bias can lead to delays in treatment for pain-related conditions, including SCD, contributing to disease progress and poorer outcomes for patients. Studies of patients with SCD experiencing pain crises who seek treatment in hospital emergency departments have found that these patients experience significant delays in receiving care, waiting, on average, 70 to 75 minutes longer to receive initial doses of pain medication than is recommended by the American Pain Society. Research also shows that health care providers often perceive adults with SCD to have increased risk of substance abuse, making them hesitant to administer opioids for pain treatment, despite evidence to the contrary.

Stakeholders consistently report experiencing stigma and bias that interfere with access to timely and appropriate care during a pain crisis. Many stakeholders provided explicit examples of being labelled a drug seeker by a provider while seeking treatment during a pain crisis. Stakeholders noted that even when providers did provide pain medication, they frequently initiated treatment with dosages lower than dosages appropriate to treat pain crises caused by SCD and were slow to increase dosages, unnecessarily prolonging the crisis and the patient's pain. Some stakeholders report intentionally changing their appearance or behavior to avoid these negative perceptions to streamline their care. For example, one individual cited wearing a friend's Ivy League sweater in the hospital waiting room, and another individual cited staying calm in all circumstances despite significant pain and recognizable delays in their care.

Requiring health care providers to receive training and education regarding the impact of stigma and unconscious bias on access to and the quality of health care could help providers better understand the issue. During the 2024 Session, the General Assembly Session considered Senate Bill 35 (Locke) and House Bill 1130 (Hayes) which would have directed the Boards of Medicine and Nursing to require unconscious bias and cultural competency training as part of a continuing education requirement for license renewal. While these bills sought to address the impact of unconscious bias and the way unconscious bias contributes to health disparities in the context of perinatal care, similar legislation could require training on the impact of unconscious bias in additional contexts including treatment in hospital emergency departments.

➔ **OPTION 5:** The Joint Commission on Health Care could introduce legislation directing the Boards of Medicine and Nursing to require unconscious bias and cultural competency training as part of the continuing education and continuing competency requirements for renewal of licensure.

Addressing cost and insurance barriers could improve treatment access for individuals with sickle cell disease

Even for patients who can physically access comprehensive treatment centers and receive care from knowledgeable and unbiased providers, insurance coverage gaps and high care costs are barriers to timely access. Research estimates that individuals with SCD who have commercial health insurance pay on average $44,000 in out-of-pocket costs over their lifetime.

High costs of care mean some individuals with SCD delay or avoid treatment

Patients with SCD may delay or avoid care, or discontinue treatment or medications, due to costs. Stakeholders interviewed by JCHC staff reported affordability as a major barrier to treatment for patients and noted high costs are a bigger problem for SCD patients with commercial insurance, where out-of-pocket costs to patients are higher. One advocate noted one of their daily SCD medications costs $11,700 a month, which they can only afford through a combination of their insurance and a grant their provider helped them secure. However, the grant will run out in December, and they do not know how they will cover the drug costs next year.

In FY 2020, the Virginia General Assembly appropriated $250,000 to VDH to establish the Virginia Sickle Cell Patient Assistance Program to provide health insurance premium assistance and cost sharing assistance to patients diagnosed with SCD who do not qualify for Medicaid. However, this funding was removed in FY 2021, the same year that the General Assembly began funding the Adult Comprehensive Sickle Cell Clinic Network.

The CMS Cell and Gene Therapy (CGT) Access Model aims to increase affordability of cell and gene therapies for Medicaid members. It is a voluntary model in which CMS helps negotiate outcomes-based agreements between state Medicaid programs and drug manufacturers. Starting in 2025, states agree to pay a lower drug price in exchange for improved health outcomes for participants. The CGT Access Model's first area of focus is sickle cell disease, though it may expand to address other conditions in the future.

The cost of gene therapy will be a barrier to treating eligible patients

Three stakeholders JCHC staff spoke with said the price of gene therapy is a barrier that will need to be addressed to make the treatments more accessible. One provider noted that even with the high cost of gene therapy, it would still be cost-effective when considering the lifelong cost of care for a person with SCD. DMAS has submitted a Letter of Intent to participate in the Centers for Medicare and Medicaid Services' (CMS) Cell and Gene Therapy Access Model (SIDEBAR), which is designed to make gene therapies more affordable and accessible to state Medicaid programs. However, even with participation in the model, stakeholders – particularly payers – expressed concern about the gap between how many individuals DMAS can financially cover and how many individuals may potentially be eligible for gene therapy. One recent analysis estimated there are 339 individuals potentially eligible for SCD gene therapy in Virginia. DMAS' actuary has indicated coverage for up to 15 individuals in 2025, though this would include all gene therapies across several diagnoses, not just SCD gene therapy.

➔ **OPTION 6:** The Joint Commission on Health Care could introduce a Section 1 bill directing the Department of Medical Assistance Services (DMAS) to include information on the status of the Commonwealth's participation in the Cell and Gene Therapy Access Model in the annual report on the results of the annual review of all medications, services, and forms of treatment for sickle cell disease covered under the state plan for medical assistance submitted to the Chairmen to the House Committee on Health and Human Services, Senate Committee on Education and Health, and the Joint Commission on Health Care by November 15, 2025.

Insufficient coverage and health plan utilization management can hinder timely and appropriate access to SCD treatment

Nationally, more than half of individuals with SCD are covered through Medicaid or the Children's Health Insurance Program (CHIP). This is also true in Virginia, with most patients seeking care at the comprehensive sickle cell treatment centers reporting Medicaid coverage (59 percent), followed by commercial insurance (28 percent of patients), and Medicare (14 percent of patients).

Even when individuals with SCD have insurance, their plan may not provide coverage for all their SCD-related needs or have a sufficient provider network. Three stakeholders spoke of the importance of whole-person care for individuals with SCD, as blood disorders affect every organ system in the body. In particular, they noted challenges patients have accessing appropriate ophthalmological and dental care. The lack of ophthalmologists who accept

Medicaid makes it difficult for patients to receive appropriate eye care, particularly in rural areas. The same is true for finding dental providers who accept Medicaid. Additionally, one patient-advocate noted that after being diagnosed with periodontal disease in their twenties and learning of the potential for bacterial infections to exacerbate SCD crises, they now require four dental cleanings a year as well as periodic deep cleans to manage their oral health effectively with SCD. However, those additional cleanings do not qualify for coverage.

Differing utilization management guidelines across insurers create delays in accessing care

Most stakeholders JCHC staff spoke with reported difficulties with insurers' utilization management processes that created delays or lapses in patient care, particularly when seeking approval for opioids and the four main FDA-approved disease-modifying therapies. Three treatment centers disagreed with insurance company decisions around medical necessity and rules that do not allow patients to be on multiple disease-modifying therapies at the same time. Payers instead implement step therapy requirements, where patients must "fail" a medication before being approved to try another. While this is a common cost containment measure, providers noted each of the four drugs work differently to target different disease pathways, and that using multiple drugs simultaneously to address the issue from multiple angles is very common and allowed in other complex diseases such as cancer or diabetes. The administrative requirements also create delays in care resulting from required waiting periods or lengthy prior authorization processes, with one provider noting it might take two or three months from deciding to start a patient on a specific medication until the patient can begin treatment.

➔ **OPTION 7:** The Joint Commission on Health Care could introduce a Section 1 bill directing the Department of Medical Assistance Services (DMAS) to develop a plan for a comprehensive sickle cell disease program to ensure that provisions governing access to sickle cell disease treatment are consistent across Medicaid managed care organizations. DMAS should report the results of the plan to the Joint Commission on Health Care by October 1, 2025.

Medicaid covers an array of services for eligible individuals with sickle cell disease, but opportunities may exist to expand coverage and improve access to care

Currently, Virginia's Medicaid program covers all sickle cell disease-modifying therapies, as well as pain management, inpatient hospital stays, emergency room visits, nutritional services, and genetic counseling. Medicaid also covers in-state transportation for enrollees traveling to receive any covered Medicaid service. House Bill 820 (Mundon King), adopted by the General Assembly during the 2024 Session, directs DMAS to conduct an annual review of all treatments, medications, and services available to Medicaid enrollees with SCD to determine if available coverage adequately meets patient needs and evaluate whether

Medicaid coverage should be expanded. DMAS' final report is due in November of 2024, and the report will be submitted to the JCHC when completed.

Two treatment centers reported differences across Medicaid managed care organizations (MCOs) regarding treatment guidelines and utilization management processes such as prior authorizations and treatment/drug approvals. One treatment center said there were fewer administrative barriers with commercial insurance. This is consistent with the findings from an environmental scan of national Medicaid fee-for-service and MCO coverage of SCD therapies, which found that while MCOs generally require prior authorization more frequently than fee-for-service programs, they apply less step therapy and have greater documented criteria for beneficiaries and providers to understand how to access different therapies. Existing Medicaid flexibilities could offer opportunities to expand coverage and access to services.

Optional SCD benefit. One potential Medicaid flexibility that Virginia currently does not utilize is an optional Medicaid SCD benefit. CMS allows states to create an optional Medicaid SCD benefit to cover additional SCD services that are not included in the state plan or increase the rates at which Medicaid reimburses currently covered SCD benefits. For example, states may set a higher reimbursement rate for SCD blood transfusions as compared to all other Medicaid-covered blood transfusions. The optional benefit also allows states to set different coverage limits for SCD services. Administrative activities specific to SCD such as public education campaigns and patient education are also eligible for matching federal funds.

Missouri was one of the first states to take advantage of the optional Medicaid benefit, adding SCD to its chronic care improvement program (CCIP) to give patients access to chronic disease management services. North Carolina also added SCD management as a covered preventive service and Michigan expanded its targeted case management services to include adults aged 26 and over with inherited red blood cell disorders such as SCD.

Medicaid Health Homes for SCD. Another potential coverage pathway available to states looking to expand access to SCD services is the Medicaid Health Homes model, an optional Medicaid State Plan benefit that allows states to establish Health Homes to coordinate care for Medicaid members who have chronic conditions. New York received CMS approval to create Health Homes for adults and children with SCD. This allowed SCD Health Home providers to access an enhanced federal match on Medicaid dollars spent providing whole-person care to individuals with SCD in their first two years in the program. Even after the enhanced match period, individuals with SCD continued to receive comprehensive care management, transitional care, care coordination, and support as part of Health Home services.

➔ **OPTION 8**: The Joint Commission on Health Care could introduce a Section 1 bill directing the Department of Medical Assistance Services (DMAS) to determine the feasibility of participating in an optional Medicaid benefit for sickle cell disease or establishing Medicaid Health Homes to coordinate care for individuals with sickle cell disease to provide

comprehensive sickle cell treatment services. DMAS should report their findings in the annual report on the results of the annual review of all medications, services, and forms of treatment for sickle cell disease covered under the state plan for medical assistance submitted to the Chairmen to the House Committee on Health and Human Services, Senate Committee on Education and Health, and the Joint Commission on Health Care by November 15, 2025.

Appendix 1: Study Resolution

HOUSE JOINT RESOLUTION NO. 60

Offered January 10, 2024

Prefiled January 10, 2024

Directing the Joint Commission on Health Care to study sickle cell disease in the Commonwealth. Report.

Patron––Hayes

Referred to Committee on Rules

WHEREAS, sickle cell disease is a severe, life-shortening, and inherited blood disorder that

predominantly impacts people of color, particularly African Americans; and

WHEREAS, sickle cell disease is a disease in which a person's body can produce abnormally shaped red blood cells that resemble a crescent or sickle; and

WHEREAS, sickle cell disease typically first appears in children around the age of six months; and

WHEREAS, symptoms of sickle cell disease may include anemia, pain, swelling of hands and feet, frequent infections, delayed growth or puberty, and vision problems; and

WHEREAS, according to the Virginia Department of Health, it is estimated that between 2,500 and 4,500 African American Virginians are living with sickle cell disease; and

WHEREAS, sickle cell disease occurs in approximately one out of every 365 Black or African American births nationwide; and

WHEREAS, individuals living with sickle cell disease encounter barriers to obtaining quality care, such as limited geographic access, financial and socioeconomic barriers, specialist availability, transportation needs, translation service needs, and social factors, such as stigma, bias, and lack of public awareness; and

WHEREAS, due to new treatments, individuals with sickle cell disease now have a longer life expectancy, improved quality of life, and survival rates past the age of 50; and

WHEREAS, despite improvements in treatment, there is a need for more comprehensive and coordinated data collection efforts to better understand and quantify the scope and impact of sickle cell disease; and

WHEREAS, there is a need for states to ensure access to social and health care services and therapies that treat sickle cell disease, and particularly to ensure access to innovative therapies that have been approved in recent years to treat the underlying cause of the disease; and

WHEREAS, scientific and medical research advances need to be coupled with health care delivery and payment policies to ensure timely access to innovative pipeline products, particularly for Medicaid beneficiaries; and

WHEREAS, efforts should focus on the identification and the promotion of affordable interventions, including community education and training of health professionals; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study sickle cell disease in the Commonwealth.

In conducting its study, the Joint Commission on Health Care shall review the (i) availability of health care and support services for individuals with a diagnosis of sickle cell disease; (ii) medications, forms of treatment, and existing reimbursement frameworks and methodologies for sickle cell disease; (iii) current data available on individuals diagnosed with sickle cell disease, and whether additional reporting is needed to ensure comprehensive data collection; (iv) sickle cell disease educational efforts and materials available to health care providers and Virginians; (v) current state funding and programs focused on sickle cell disease; (vi) considerations of ancillary and co-occurring health challenges as result of sickle cell disease and its treatments, including reproductive health issues and iatrogenic infertility; and (vii) recommendations for improvements in the delivery of and access to health care services and treatment of individuals with diagnosis of sickle cell disease.

Technical assistance shall be provided to the Joint Commission on Health Care by the Department of Health and the Department of Medical Assistance Services; individuals with a diagnosis of sickle cell disease and caregivers for individuals with a diagnosis of sickle cell disease; community-based sickle cell disease organizations; health care providers who specialize in the treatment of individuals diagnosed with sickle cell disease; and comprehensive adult and pediatric sickle cell disease treatment centers and transplant institutions. All agencies of the Commonwealth shall provide assistance to the Joint Commission on Health Care for this study, upon request.

The Joint Commission on Health Care shall complete its meetings by November 30, 2024, and the chairman shall submit to the Division of Legislative Automated Systems an executive summary of its findings and recommendations no later than the first day of the 2025 Regular Session of the General Assembly. The executive summary shall state whether the Joint Commission on Health Care intends to submit to the General Assembly and the Governor a report of its findings and recommendations for publication as a House or Senate document. The executive summary and report shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.

Appendix 2: Types of sickle cell disease

Sickle cell disease (SCD) is an umbrella term for many types of sickle cell disorders. The type of sickle cell disease an individual has depends on the individual's genetic inheritance pattern and the specifics of how the hemoglobin has mutated. There are many types of abnormal hemoglobin, genetically coded as "S", "C", "D", "E", "O", and "beta thalassemia". Hemoglobin S is an abnormal form that causes red blood cells to sickle –all individuals with sickle cell disease inherit this gene from at least one parent. The most common types of sickle cell disease are:

- HbSS – individuals inherit hemoglobin S from both parents; this type is often called "sickle cell anemia"
- HbSC – individuals inherit hemoglobin S from one parent and hemoglobin C from the other parent
- HbS beta thalassemia – individuals inherit hemoglobin S from one parent and a gene for beta thalassemia from the other parent
    - HbS beta^0 (Beta thalassemia zero) – a type of beta thalassemia that typically causes a more severe form of SCD; this type is often called "sickle cell anemia"
    - HbS beta$^+$ (Beta thalassemia plus) – a type of beta thalassemia that typically causes a "milder" form of SCD
- HbSD, HbSE, and HbSO – rare subtypes in which individuals inherit hemoglobin S from one parent and hemoglobin D, E, or O from another parent

Individuals with sickle cell trait inherit the abnormal hemoglobin S gene from one parent, and a normal gene for hemoglobin from their other parent. They do not have sickle cell disease but may still have milder health problems and can still pass the abnormal hemoglobin S gene to their children.

Appendix 3: Sickle cell disease ranks as a top diagnosis for hospital readmissions among Medicaid enrollees

In Virginia, the Department of Medical Assistance Services (DMAS) reports approximately 2,234 Medicaid enrollees with a diagnosis of sickle cell disease (SCD). A DMAS analysis of hospital readmissions between July 2020 and September 2023 found that SCD is the fourth most common diagnosis associated with hospital readmissions among Medicaid enrollees in Virginia (TABLE 6).

TABLE 6. Highest claim counts and their primary diagnoses associated with readmissions

Diagnosis	Claim Count	Total Payment
Alcohol related disorders	784	$ 1,149,280
Opioid related disorders	676	$ 300,165
Other sepsis	563	$ 6,156,272
Sickle-cell disorders	363	$ 1,897,464
Type 1 diabetes mellitus	352	$ 1,378,046

SOURCE: https://rga.lis.virginia.gov/Published/2024/RD266/PDF
NOTE: Data are from July 2020-September 2023

DMAS paid almost two million dollars between July 2020 and September 2023 for readmissions for individuals with SCD. The average payment for a SCD readmission, $5,227 per claim, was only exceeded by claims for sepsis, respiratory failure, and hypertensive heart and chronic kidney disease (TABLE 7).

TABLE 7. Highest total payments and their primary diagnoses associated with readmissions

Diagnosis	Claim Count	Total Payment	Average Payment per Claim
Other sepsis	563	$ 6,156,272	$ 10,935
Respiratory failure, not elsewhere classified	200	$ 2,299,205	$ 11,496
Hypertensive heart and chronic kidney disease	335	$ 2,190,478	$ 6,539
Sickle-cell disorders	363	$ 1,897,464	$ 5,227
Type 1 diabetes mellitus	352	$ 1,378,046	$ 3,915

SOURCE: https://rga.lis.virginia.gov/Published/2024/RD266/PDF
NOTE: Data are from July 2020-September 2023

Appendix 4: Newborn screening results for hemoglobinopathies

Dried blood spot testing, carried out as part of Virginia's newborn screening program, screens for all hemoglobinopathies - all disorders related to the hemoglobin molecule including sickle cell disease (SCD). Dried blood spot testing may identify hemoglobin abnormalities but screening results alone are not sufficient to diagnose SCD. Rather, screening results identify the presence of varying levels of different types of hemoglobin, including fetal hemoglobin (F), which babies have at birth (see TABLE 8 for most commonly reported results). For example, a screening result of "FSV" could indicate an infant has sickle cell disease, conditions identical to sickle cell trait, or a benign condition called sickle-cell hereditary presence of fetal hemoglobin. For all cases with a screening result indicating the possibility of SCD, confirmatory testing, disease education, and referral to a comprehensive pediatric sickle cell center are recommended. Because newborn screening results are not sufficient to diagnose SCD, screening results cannot be used to reliably count how many infants have SCD.

Table 8. Most commonly reported fetal sickle hemoglobin results

Result Code	Diagnostic Possibilities
FS Fetal hemoglobin and sickle hemoglobin	• HbSS (sickle cell anemia) • HbS beta^0 (sickle cell-Beta thalassemia zero) • HbS beta$^+$ (sickle cell-Beta thalassemia plus) • Sickle cell-hereditary persistence of fetal hemoglobin (a benign condition)
FSA Fetal hemoglobin, sickle hemoglobin, and small amount of adult hemoglobin	• HbS beta$^+$ (sickle cell-Beta thalassemia plus) • Sickle cell trait
FSC Fetal hemoglobin, sickle hemoglobin, and hemoglobin C	• HbSC
FSD Fetal hemoglobin, sickle hemoglobin, and hemoglobin D	• HbSD
FSV Fetal hemoglobin, sickle hemoglobin, and an unidentified hemoglobin variant	• HbSS (sickle cell anemia) • HbS beta^0 (sickle cell-Beta thalassemia zero) • Sickle cell-hereditary persistence of fetal hemoglobin (a benign condition) • HbSC Harlem

Result Code	Diagnostic Possibilities
	• HbSO Arab • Conditions phenotypically identical to sickle cell trait
FSE Fetal hemoglobin, sickle hemoglobin, and hemoglobin E	• HbSE disease

SOURCE: Quick Reference Guide to Results from Virginia Newborn Screening for Hemoglobinopathies.

Appendix 5: Statewide Sickle Cell Chapters of Virginia funding, Fiscal Years 2008-2026

Statewide Sickle Cell Chapters of Virginia (SSCCV) annual reports show that in most years, General Assembly appropriations are distributed to three or four member organizations (TABLE 9). The chapters primarily use their funding for sickle cell disease (SCD), health educational materials and multimedia advertising.

TABLE 9. SSCCV has distributed funding to local chapters since 2008

Fiscal Year	Pediatric	Percent of SSCCV members supported	Number of SSCCV members supported
2008	$100,000	37.5%	3/8
2009	$95,000	37.5%	3/8
2010	$90,000	37.5%	3/8
2011	$90,000	63.5%	5/8
2012	$90,000	63.5%	5/8
2013	$88,200	63.5%	5/8
2014	$105,000	66.7%	6/9
2015	$105,000	66.7%	6/9
2016	$105,000	66.7%	6/9
2017	$105,000	44.4%	4/9
2018	$105,000	44.4%	4/9
2019	$105,000	44.4%	4/9
2020	$105,000	44.4%	4/9
2021	$105,000	44.4%	4/9
2022	$105,000	44.4%	4/9
2023	$105,000	33.3%	3/9
2024	$105,000	TBD	TBD
2025	$105,000	TBD	TBD
2026	$105,000	TBD	TBD

SOURCE: SSCCV annual reports to the House Appropriations and Senate Finance Committees.

Appendix 6: History of funding for Comprehensive Sickle Cell Clinic Networks

The General Assembly has appropriated state general funds for the Pediatric Comprehensive Sickle Cell Clinic Network since Fiscal Year (FY) 2008 (TABLE 10). Total annual appropriations have remained relatively steady over the years, with two increases – to $305,000 in FY 2016, and then again to $450,000 for FY 2025.

Funding for the Adult Comprehensive Sickle Cell Clinic Network began in FY 2021. The Adult Comprehensive Sickle Cell Clinic Network initially received the same amount as the Pediatric Comprehensive Sickle Cell Clinic Network – $305,000 in FY 2021 – but saw a substantial increase to $805,000 in FY 2022. The General Assembly allocated an additional $75,000 to the Adult Comprehensive Sickle Cell Clinic Network, beginning in FY 2025, to provide additional support to services for adults with sickle cell disease in Eastern Virginia.

Table 10. Funding for Pediatric and Adult Comprehensive Sickle Cell Clinic Networks, FY08-FY26.

Fiscal Year	Pediatric Comprehensive Sickle Cell Clinic Network	Adult Comprehensive Sickle Cell Clinic Network
2008	$200,000	
2009	$200,000	
2010	$200,000	
2011	$200,000	
2012	$200,000	
2013	$200,000	
2014	$200,000	
2015	$200,000	
2016	$305,000	
2017	$305,000	
2018	$305,000	
2019	$305,000	
2020	$305,000	
2021	$305,000	$305,000
2022	$305,000	$805,000
2023	$305,000	$805,000
2024	$305,000	$805,000
2025	$450,000	$880,000

Fiscal Year	Pediatric Comprehensive Sickle Cell Clinic Network	Adult Comprehensive Sickle Cell Clinic Network
2026	$450,000	$880,000

SOURCE: Virginia final state budget for FY08-FY26.

The Virginia Sickle Cell Awareness Program distributes funding regionally via Requests for Proposals (RFPs) or direct contracts with state institutions, such as VCU Health and UVA Health. Whenever the General Assembly provides increased state funding, VDH works with each treatment center to distribute the additional funds. While there is no formula for calculating how much each treatment center receives, larger institutions with bigger patient caseloads generally receive a larger share. The notable exception is Carilion Clinic, which receives additional funding, even with their lower patient volume, to help them build the infrastructure to start a clinic.

JOINT COMMISSION ON HEALTH CARE

411 EAST FRANKLIN STREET, SUITE 505

RICHMOND, VIRGINIA 23219

804-786-5445

http://jchc.virginia.gov