

A Call to Action:

South Carolina Sickle Cell Disease State Plan

2019-2022



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**The South Carolina
Sickle Cell Disease
Advocacy Team**

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Executive Summary

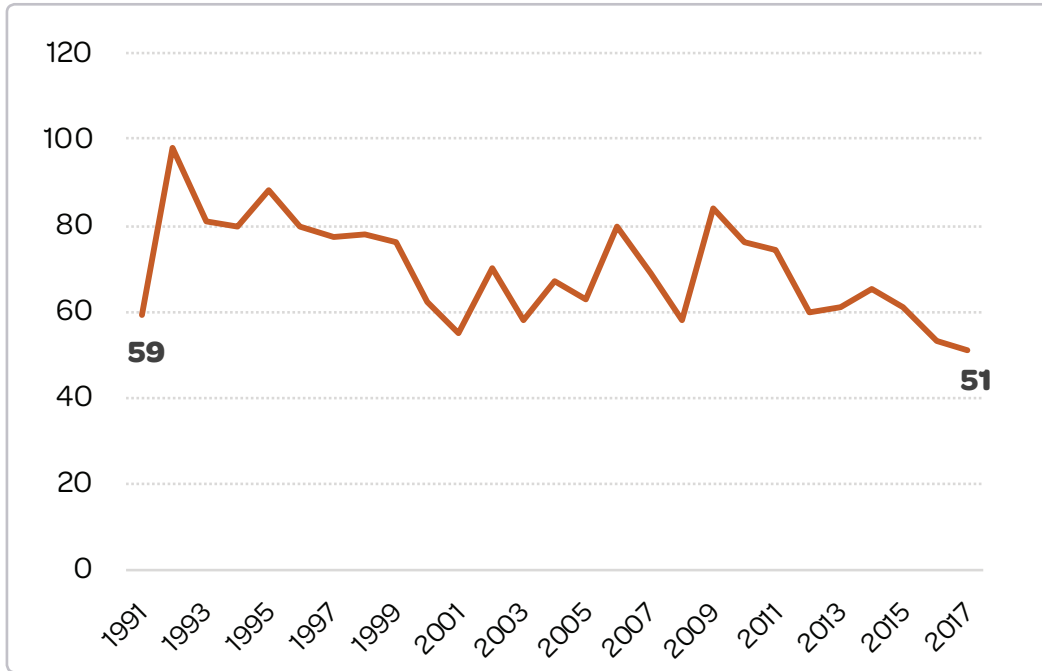
Sickle Cell Disease (SCD) is the most common inherited blood disorder in the United States (US)⁷. Despite improvements in treating children with sickle cell disease, it remains a life-limiting disease with multi-organ complications that reduces the quality of life of impacted individuals especially as the person ages⁷. SCD has suffered from decades of poor disease awareness and lack of funding compared to other inherited disorders⁸.

SCD affects 1 in 400 blacks and 1 in 19,000 Latinos and has a carrier rate of 1 in 12 and 1 in 100 for black and Latino populations in the US, respectively⁷. Many affected patients in the United States are of African descent, which highlights the genetic link of how a person acquires the disease. Data collected based on first-hand and personal experiences suggest that the increased health disparities affecting SCD are a result of both racial and disease specific stigmatization⁴. These health disparities have significantly limited improvements in disease management and discovery of new therapies or treatments³. The severity of SCD makes the impact of these health disparities more pronounced among populations that are disproportionately impacted. Due to the lack of a proficient coordinated system of care and limited number of providers for adults living with SCD throughout the US (and in South Carolina), there is an increase in emergency room and acute care utilization⁶. Additional concerns related to SCD are the significant lack of provider medical knowledge about the illness and socioeconomic determinants of health, which can limit access to quality care. Individuals living in poverty and living in underserved or rural areas have limited access to specialized medical treatment. The persistent challenges in the healthcare system and the lack of knowledge about SCD warrant the need for a state plan to coordinate efforts across state agencies and community organizations.

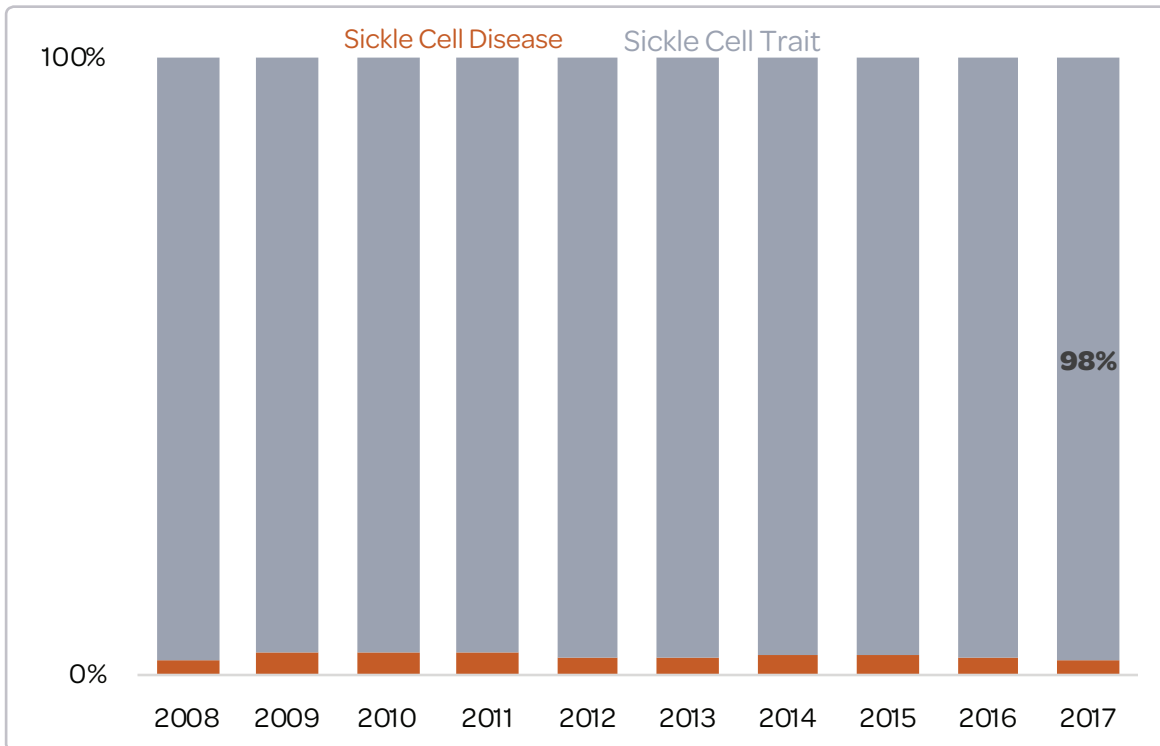
As of May 1, 2006, every state mandated that all children are tested for SCD at birth². Targeted newborn screening was initiated in South Carolina in the 1980s. According to South Carolina Department of Health and Environmental Control (DHEC) laboratory data, from 1991 to 2017 a total of 1,884 infants were born with sickle cell disease and a total of 56,607 infants were born with sickle cell trait (SCT). Graph 1 (on page 2) illustrates the confirmed number of sickle cell disease cases in SC from 1991 to 2017. Graph 2 (on page 2) illustrates the breakdown of SCD and SCT for all positive blood screens over the past 10 years.

Approximately 85% of individuals with SCD in SC have Medicaid and/or Medicare. There are currently several case management programs being developed and implemented by the managed care organizations and local community-based organizations¹⁰. The goal of these innovative programs is to connect affected individuals with SCD providers and to ensure improvements in the navigation of the health care system. In addition to the managed care organizations' approach, DHEC provides financial assistance and care coordination for eligible individuals through its Sickle Cell Program. Local partners across South Carolina are working with healthcare providers, families and individuals impacted by SCD to provide education, counseling and testing. Collectively, these agencies and organizations are working towards improved health management for individuals with SCD by identifying opportunities for better care transition from pediatric to adult care, care coordination, SCD awareness and expanded

Graph 1. Confirmed Number of Sickle Cell Disease Cases in SC, 1991–2017



Graph 2. Percent of Sickle Cell Disease and Sickle Cell Trait among All Cases in SC, 2008–2017

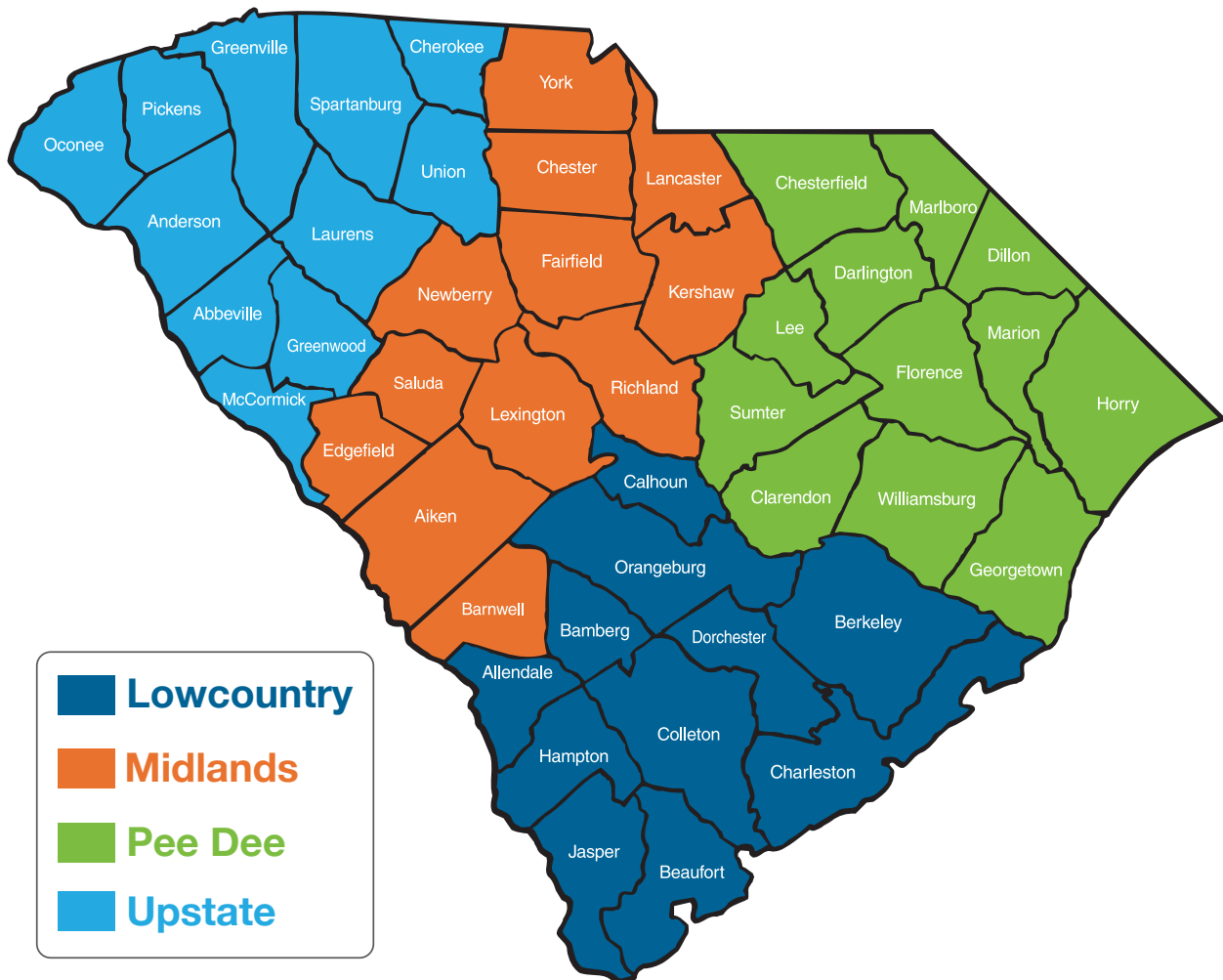


Source: DHEC Newborn Screening Follow-up

education for both patients and providers. Resources are needed to support a statewide, integrated and coordinated approach that includes both education and infrastructure to expand to a broader scope of services.

The overarching goal of the South Carolina Sickle Cell Disease State Plan is to provide a framework in developing systematic and coordinated strategies that address the lack of resources available to treat and care for patients with sickle cell disease. This plan is outlined for the next three years and is intended for the public, consumers, and health and human service professionals. Input has been provided by over 30 stakeholders from across the four different regions of South Carolina: Upstate, Midlands, Pee Dee and Lowcountry. By aligning resources and activities, the goal is to improve the lives of those affected by SCD across the state.

Figure 1. Map of South Carolina depicting the four different regions



Acknowledgements

Thank you to the following organizations and agencies for their dedication and commitment towards the development of the South Carolina Sickle Cell Disease State Plan.

The B Strong Group

Committee on Better Racial Assurance

Community Members

GLEAMNS Human Resources Commission, Inc.

Greenville Health Systems

James R. Clark Memorial Sickle Cell Foundation

Louvenia D. Barksdale Sickle Cell Anemia Foundation

Medical University of South Carolina

Molina Healthcare of South Carolina

Orangeburg Area Sickle Cell Anemia Foundation

Palmetto Health Children's Hospital

Select Health of South Carolina

South Carolina Department of Health and Environmental Control

South Carolina Department of Health and Human Services

Background on Sickle Cell Disease

According to the National Institutes of Health (NIH), sickle cell disease is a group of inherited red blood cell disorders in which affected individuals inherit the gene for an abnormal hemoglobin (hemoglobin S) or sickle hemoglobin¹¹. Hemoglobin (Hb) is the protein within the red blood cell responsible for carrying and delivering oxygen through the body.

People who have SCD inherit two abnormal Hb genes, one from each parent. In someone with SCD, the red blood cells become hard and sticky, which causes the cells to die early (resulting in anemia, a shortage of red blood cells) and clog blood vessels and block blood flow. People who inherit two copies of the HbS gene have the most common form of SCD, called HbSS or sickle cell anemia. People who inherit one HbS gene and one normal adult hemoglobin gene (called HbA) have sickle cell trait (SCT). While these individuals carry the trait, and can pass it to their children, they do not have the complications of SCD. However, other people who inherit one HbS and another abnormal hemoglobin (such as HbC, HbE, or a gene for β -thalassemia) still develop sickle cell disease. Figure 2 (to the right) depicts normal red blood cells and sickled red blood cells.



When red blood cells clog the blood vessels in SCD, oxygen cannot adequately reach the tissue, called vaso-occlusion. The most severe complication of vaso-occlusion in SCD is a stroke, which can occur at a young age.

The most well-known complication of SCD vaso-occlusion is a pain crisis. These pain attacks can occur without warning and a person may need to go to the hospital for evaluation and pain management. Most children with SCD are pain free between acute painful crisis or episodes; however, chronic daily pain develops in adolescents and adults due to repeated crises, which may cause death of bone tissue, nerve damage and organ deterioration. All parts of the body can be affected by SCD, including the person's spleen, brain, eyes, lungs, liver, heart, kidneys, penis, joints, bones, or skin¹¹. Complications of SCD can also result in potentially life-threatening complications – including infections, stroke, and organ damage – that require immediate emergency department (ED) care or inpatient hospitalization.

Normally, the body continuously makes new red blood cells to replace old cells; however, in SCD the body may have difficulty keeping up with how fast the cells are being destroyed. Anemia is a condition that arises when the number of red blood cells are lower than normal, which is an ongoing problem in SCD that can be worsened when affected individuals get certain infections.

Persons with SCT do not have any of the symptoms of SCD, but they can pass the trait on to their children. SCT cannot become SCD. SCD can only be inherited and is not contagious.

According to the Centers for Disease Control and Prevention (CDC), most people with SCT do not have any symptoms of SCD, although – in rare cases – people with SCT might experience complications¹². In their extreme form and in rare cases, the following conditions could be harmful for people with SCT:

- Increased pressure in the atmosphere (e.g., while scuba diving).
- Low oxygen levels in the air (e.g., when mountain climbing, exercising extremely hard in military boot camp, or training for an athletic competition). Due to this, the NCAA recommends that college athletics departments confirm the sickle cell trait status in all student-athletes.
- Dehydration (e.g., too little water in the body).
- High altitudes (e.g., flying, mountain climbing, or visiting a city at a high altitude)¹².

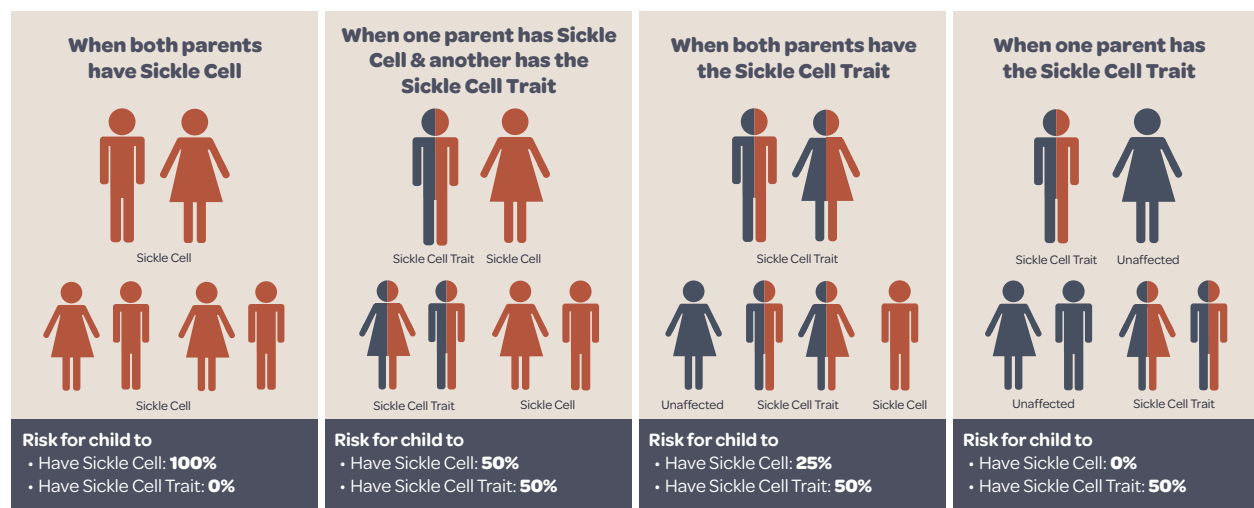
For someone who has SCT, the likelihood of having a child who has SCD or SCT depends on their partner’s family genetics.

If both parents have SCT, there is a:

- 50% chance the child will have SCT,
- 25% chance that child may have SCD, and
- 25% chance the child will not have SCD nor SCT but have normal red blood cells.

The figure below illustrates the likelihood of a child having SCD or SCT if a parent has SCD or SCT.

Figure 3. Depiction of parents having SCD, SCT or normal Hb and likelihood of having a child with normal Hb, SCT, or SCD



In the United States, approximately 100,000 people have sickle cell disease¹¹. Most of them are of African ancestry or identify themselves as black.

- About 1 in 13 African-American babies is born with SCT.
- About 1 million to 3 million Americans are affected by SCT.
- More than 100 million people worldwide have SCT.
- About 1 in every 365 black children is born with SCD.

There are also many people with this disease who come from Hispanic, southern European, Middle Eastern, southern Asia, or Asian Indian backgrounds¹¹.

Currently the only cure for SCD is a bone marrow or stem cell transplant⁷. There are several treatment options used by physicians to manage the complications or pain crisis caused by SCD. In the US, newborn screening has improved early diagnosis of affected individuals so that education can be provided to parents of babies with SCD. Educating the parents helps ensure they understand the potential severity of the disease. Because of newborn screening, through the use of antibiotics given to help prevent early infection, vaccines, and education, more than 98% of affected children are now surviving to 18 years of age and older in the US.

Challenges of Sickle Cell Disease

For many who have SCD, daily living from birth can consist of potential crises, chronic pain, trips to the local emergency rooms, stigma of disease, and an overall compromised quality of life. It is very important for affected individuals to have an identified, knowledgeable provider to ensure they receive appropriate preventive care and management. In addition to SCD, affected people remain at risk for other health conditions, such as diabetes, high blood pressure, high cholesterol, or arthritis, that can further worsen their SCD. Treating and caring for SCD and other health conditions can become costly, difficult and time-consuming. In addition to the physical complications of SCD, there are associated emotional and socioeconomic stressors¹.

Many individuals with SCD have full-time employment and require only intermittent care. However, others affected with SCD are profoundly debilitated. The disease can affect all aspects of a person’s life, including mental, emotional, social, physical well-being and the environments in which they live and work. Appropriately managing SCD encompasses much more than medical treatments alone.

Even though the physical complications for someone with SCD may remain constant regardless of age, psychological and social areas of a person’s life may be impacted differently as they get older. The table below illustrates the psychosocial challenges a person with SCD may face by age group.

Table 1. Psychosocial Challenges of SCD

Age Groups	Psychosocial Challenges
Infant (0–1 years)	<p>Parent(s) of infants with SCD:</p> <ul style="list-style-type: none"> • Feelings of guilt, anger, fear, helplessness, and heartbreak due to their child’s pain and fear • Sense of failure in trying to comfort their child • Stress from financial impact and impact on careers • Isolation due to fear of exposure to illness • Lack of understanding about the disease and treatment/management • Family/marriage conflict and stress
Child: Toddler, Preschool- and Elementary-aged (1–12 years)	<ul style="list-style-type: none"> • Poorer cognitive functioning (e.g., impaired intellect and attention) • Impaired academic achievement/decreased learning opportunities • Caregivers and teachers lack understanding about SCD and may label children as having “behavior problems” • Visio-motor (i.e., hand-eye coordination) impairment
Adolescent (13–19 years)	<ul style="list-style-type: none"> • Decreased executive functioning (e.g., difficulty organizing, difficulty in planning and initiation, inability to multi-task, difficulty with abstract concepts, mood swings, socially inappropriate behavior) • Poor body image, poor self-concept, low self-esteem • Increased anxiety (socially, academically, with relationships)

<p>Young adult (20-39 years)</p>	<ul style="list-style-type: none"> • Deal with health-related stigma transitioning from pediatric to adult care (e.g., burdened by providers' suspicions of being "drug seekers" and their lack of understanding about disease) • Difficulty forming and maintaining romantic relationships (impaired sexual functioning) • Anxiety of low employment rates and job retention
<p>Older adult (40+ years)</p>	<ul style="list-style-type: none"> • Anxiety/fear of body deterioration (fear of dying early) • Distress over employment/finances • Depressive symptoms (i.e., feelings of isolation, hopelessness, and despair)

In addition to the psychosocial factors that present everyday barriers, other issues impacting the lives of people with SCD are the closing of rural hospitals and urgent care centers, a lack of appropriate means of travel, the inability to maintain full-time employment and the lack of insurance.

In SC many rural hospitals and urgent care centers have closed, which causes many people to travel farther to receive medical care. For those with SCD, traveling can be particularly difficult and can trigger pain episodes. In addition, SC is faced with profound socioeconomic disparities. South Carolina has a higher average of uninsured individuals of 15% under the age of 65 versus the national average of 12%⁵. Of the total population in South Carolina, 15% of uninsured individuals are between the ages of 18 and 65⁵.

Sickle Cell Disease Patients and their Hospital Encounters in South Carolina, 2016

As mentioned previously, those living with SCD often require acute care, including frequent visits to the emergency room. DHEC staff in the Bureau of Health Improvement and Equity analyzed uniform billing data for emergency department (ED) and inpatient hospitalization discharges in the state, excluding data from the military health system, for all primary and secondary SCD encounters according to ICD-10 diagnostic codes for 2016.

The ED and hospitalization datasets were combined, and descriptive analyses were conducted to examine patient characteristics such as age, race, gender, payer type, and region of residence and to further explore ED visits and hospitalizations for SCD. The final dataset consisted of 1,977 patients with a total of 11,896 hospital encounters. Characteristics of individuals with SCD and their hospital encounters are shown in the table below.

In 2016, there were a total number of 11,869 hospital encounters; 73.1% were ED visits (n=8,679), and 3,217 (27.0%) were inpatient hospitalizations. Most patients with a hospital encounter based on 2016 discharges were less than 18 years of age (33.6%) and aged 30-44 (23.2%). Almost 99% of patients were African American, and just under half of all patients had Medicaid as the payer (48.0%). Most patients with a hospital encounter in 2016 lived in the Upstate region (34.0%), followed by the Midlands (26.7%), Pee Dee (23.7%), and Lowcountry (15.5%) regions. Out of the 1,977 patients with a hospital encounter, 1,599 (80.9%) had an ED visit, and 1,163 (58.8%) were hospitalized.

Table 2. Characteristics of SCD patients and hospital encounters in SC

Patient characteristics	Number (percent)
Total number of patients	1,977 (100.0)
Age (in years)	
0-9	396 (20.0)
10-17	269 (13.6)
18-24	315 (15.9)
25-29	300 (15.2)
30-44	459 (23.2)
45-64	215 (10.9)
65+	23 (1.2)
Gender	
Male	1,077 (54.5)
Female	899 (45.5)
Race	
African American	1,952 (98.7)
White	7 (0.4)
Other	21 (1.1)
Expected payer	
Medicaid	948 (48.0)
Medicare	449 (22.7)
Private	388 (19.6)
Self-pay/uninsured	192 (9.7)
Region of residence	
Lowcountry	307 (15.5)
Midlands	528 (26.7)
Pee Dee	469 (23.7)
Upstate	673 (34.0)
Type of hospital encounter^b	
Patients with ED visit	1,599 (80.9)
Patients with inpatient hospitalization	1,163 (58.8)
Encounter characteristics	Number (percent ^a)
Total number of hospital encounters	11,896 (100.0)
Type of hospital encounter	
Number of ED visits	8,679 (73.1)
Number of inpatient hospitalizations	3,217 (27.0)

^a Percentages may not total 100 due to missing or rounding.

^b These categories are not mutually exclusive.

Source: SC Revenue and Fiscal Affairs (RFA) Inpatient Discharges and ED Visits

Further examination of 2016 ED discharge data showed:

- 1,599 patients with SCD had 8,679 visits to the ED in South Carolina
- Average number of ED encounters per patient for SCD was 5.42
- Majority of ED patients were 45 years of age or younger (89.7%)
 - × Based on the age ranges above, out of all ED visits due to SCD, the majority were among 25-30-year olds (30.5%), followed by 31-45-year-olds (29.1%)
- Almost 99% of the patients with at least one ED visit in 2016 were African American (n=1,580)
- ED visits by source of payment showed most patients were covered by Medicaid (47.1%) or Medicare (22.3%)
- Although females represented 54% (n=861) of the 1,599 patients, they represented only 43% (n=3,724) of the total number of visits, indicating men had more ED visits
- 34.9% of the ED patients were from the Lowcountry, 26.9% from the Midlands, 23.3% from the Pee Dee, and 15% were from the Upstate
- Total ED charges for SCD in 2016 were \$32.2 million, with an average charge of \$3,705 per encounter

Further examination of 2016 inpatient hospital discharge data showed:

- 1,163 patients with SCD had a total of 3,217 inpatient hospitalizations
- Average number of inpatient encounters for SCD in 2016 was 2.76, with a minimum of 1 and a maximum of 31 visits
- Majority of the inpatient hospitalizations were for the 31-45 age group (27.5%)
- Inpatient hospitalizations by source of payment showed the majority of encounters were paid by Medicare (31.4%) or Medicaid (53.6%)
- Majority of hospitalizations were African American (98.8%), female (57.7%), and residents of the Lowcountry Public Health Region (35.8%)
- Total healthcare charges pertaining to inpatient hospitalizations for SCD was \$93.4 million, with an average hospitalization charge of \$29,041

The data above demonstrates the extraordinary burden of SCD on the affected individual as well as the caregivers and the medical system. This state plan is designed to highlight some of the barriers faced by those affected by SCD in order to develop strategies to overcome those barriers. These barriers were identified by a large group of stakeholders, including patients, providers, families and communities caring for those living with SCD.

In order to optimally manage SCD, a multi-dimensional approach is required. This state plan identifies current gaps in the management of SCD in South Carolina:

- Lack of providers
- Lack of education for providers
- Insufficient financial sustainability
- Need for public awareness
- Limited access to care
- Limited statewide data surveillance system

South Carolina needs a supported, multi-dimensional treatment system across the lifespan that meets the needs of patients and families affected with SCD.

History of Sickle Cell Disease Programs and Services in South Carolina

Community-Based Organizations and Funding

Initiated in phases in 1971 and 1972, both the Charleston County Comprehensive Health Planning Board and the Committee on Better Racial Assurance Agency (COBRA) received funding to initiate a sickle cell disease program with DHEC. These supportive services consisted of educating the public about SCD, providing testing and counseling to individuals and families with SCD, and providing patient support.

In the 1980s South Carolina received block grant funding; a portion was set aside to support three community-based organizations (CBOs) that were providing access to genetic testing, counseling, patient support services, and public awareness about SCD. The COBRA Sickle Cell Program, James R. Clark Memorial Sickle Cell Foundation and Louvenia D. Barksdale Sickle Cell Anemia Foundation located in Charleston, Columbia and Spartanburg respectively, received contracts from DHEC. Upon the state receiving additional funding for SCD, Orangeburg Area Sickle Cell Anemia Foundation began covering six of the 16 counties that COBRA previously served.

Newborn Screening in South Carolina

From 1985 to 1987, COBRA initiated a Newborn Screening Pilot Project. Dr. Charles Darby, the Medical University of South Carolina (MUSC) Pediatrics Department Chair, and Dr. Shashidhar Pai, pediatric geneticist, led MUSC's involvement in the project. During this time infants were tested at birth, DHEC laboratories provided analysis, and MUSC confirmed the analysis. In 1985, the prophylactic penicillin (PROPS) study demonstrated that early initiation of penicillin prophylaxis in children with SCD would dramatically decrease blood infections in at-risk infants. As a result of the pilot project, sickle cell was included on the newborn screening panel. Testing began statewide in 1987 per recommendations from COBRA and Dr. James Eckman with the Emory University Department of Medicine and director of the Comprehensive Sickle Cell Center at Grady Health Systems in Atlanta, and with support from the other CBO directors and representatives.

Prior to 1995, the infrastructure to support the identification and treatment of SCD in South Carolina was not defined. With data from the pilot programs and the PROPS study as background, Proviso 30.13 was enacted by the South Carolina Legislature and provided funding for CBOs. Proviso funding continues to support activities performed by the sickle cell CBOs to provide access to genetic testing, prevention programs, education programs, and counseling for families with infants identified with SCT from newborn screening results. Additionally, a portion of the funds are used to support DHEC's Sickle Cell Program.

In 2004, the Sickle Cell Treatment Act (SCTA) was included as part of the American Jobs Creation Act. This was the first major legislative move on the national level in more than 30 years that focused on SCD¹³. The SCTA brought national attention to this devastating illness and demonstrated the need for an increase in SCD funding and awareness. The law furthermore provided funding for genetic counseling, community outreach and education, and the establishment of 40 SCD treatment programs. Offering the opportunity to improve health outcomes for individuals with SCD, the SCTA of 2004 increased the emphasis of equity and quality. These newly established clinics were funded for five years.

In 2006, newborn screening for SCD became federal law. Through newborn screening, infants with SCD are referred to a hematologist within the first month of life for initiation of penicillin therapy, counseling and education. In South Carolina, children born with SCT continue to be referred to one of the four sickle cell CBOs.

Department of Health and Environmental Control and SCD

In 1995, the first statewide SCD plan was initiated by DHEC and CBO representatives. The goal of this plan was to increase sustainable funding to support SCD-related services and hire a statewide director of SCD within DHEC.

In addition to the services above, additional allocation was provided to DHEC starting in 2014 to provide educational training on SCD for physicians, nurses and hospital staff. To enhance SCD awareness and education, each CBO received additional funds to host an annual symposium in their respective region. Over the last four years, attendance at these conferences and follow-up evaluations have shown that attendees found the training opportunities to be useful, appreciated and anticipated.

DHEC continues to allocate resources to the Sickle Cell Program, which provides care coordination and payment services for qualified individuals who have sickle cell. Starting in September 2016, Children and Youth with Special Health Care Needs (CYSHCN) and Newborn Screening Follow-Up (NBS) within DHEC collaborated to ensure infants with an abnormal result indicating SCD via NBS test results are receiving proper care and treatment and have a medical home. In December 2017, DHEC partnered with Patient Services, Incorporated (PSI) to pilot a premium assistance program for eligible clients enrolled under the DHEC program to assist with health insurance coverage.

Current Events: SCD in South Carolina

Success in the identification and treatment of children with SCD over the past 20 years has led to a much larger affected adult population. With the increased patient population, there is an increased need for medical providers, resources and treatment for persons living with SCD in South Carolina. Thus, as part of the 2015-2016 South Carolina General Assembly's 121st Session, the Sickle Cell Disease Study Committee was authorized by Proviso 117.126 of the 2015-2016 South Carolina Appropriation Act. This committee was charged with examining existing services and resources available to children and adults living with SCD. In addition, the committee was to establish partnerships with institutions, communities and a statewide network of providers for adults with the disease. The committee also was to establish a comprehensive education and treatment program for adults, as well as standardized treatment and emergency room protocols.

The study committee's recommendations were released at the end of the legislative session in June 2016. The findings illustrated that medical and policy experts, health care administrators, and funding sources must work together to develop legislative and programmatic changes for the residents of South Carolina with sickle cell disease⁹. A recommendation of the Sickle Cell Disease Study Committee also included the need for a Sickle Cell State Plan.⁹

Other findings from the study committee report included:

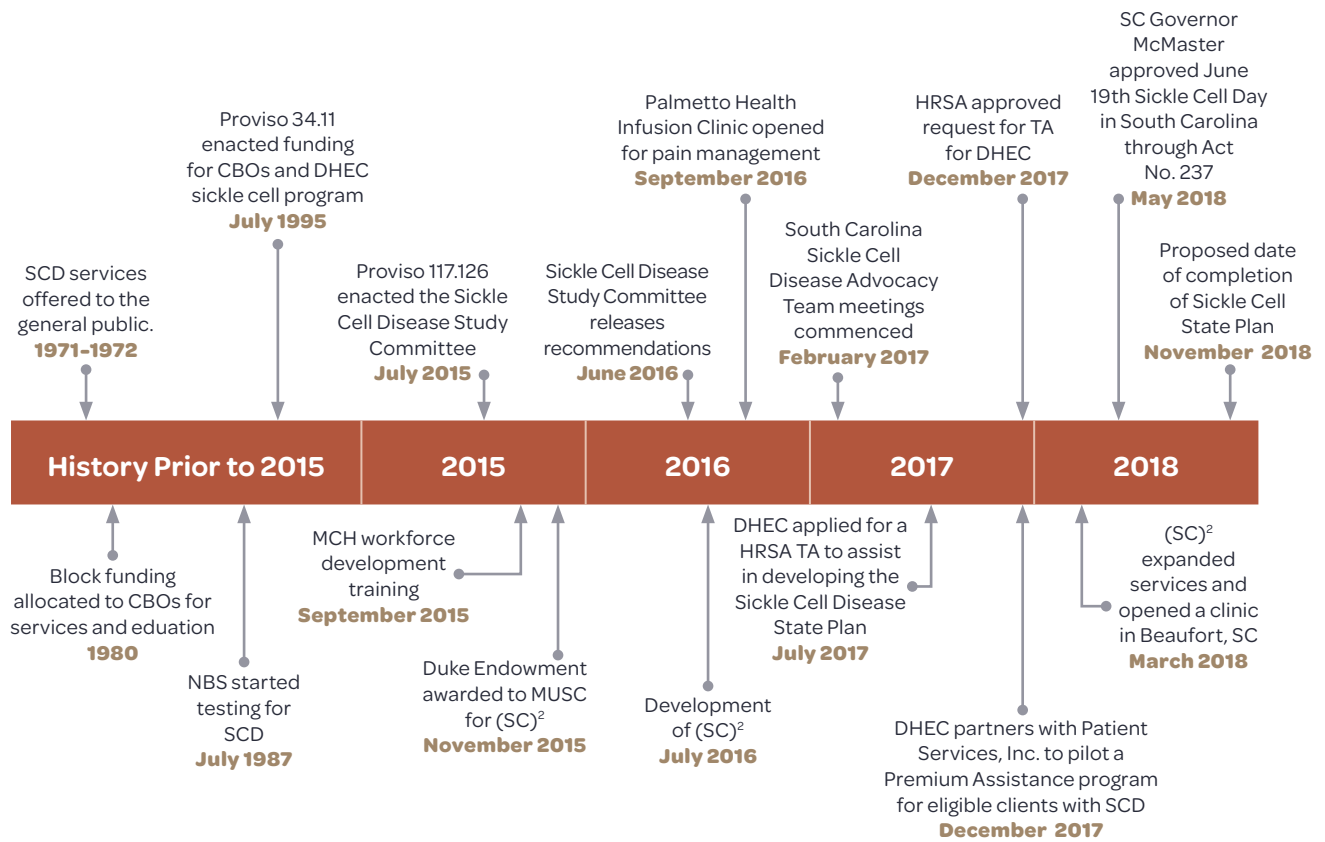
- a. The need for greater public awareness about SCD
- b. The need for more and better education about the SCD processes, including best medical practices for health care providers (HCPs), especially for physicians and nurses who care for adults in primary care and emergency departments
- c. The need for more funding for sickle cell disease programs to improve access to health care in both urban and rural regions of the state as well as better care coordination among providers at all levels

During the same year, Dr. Julie Kanter with the Medical University of South Carolina (MUSC) in Charleston, SC, established the South Carolina Sickle Cell Network (SC)2 with funding provided by the Duke Endowment. (SC)2 is a sickle cell disease network aimed at ensuring all affected individuals living in SC have access to both a primary care physician and a SCD specialist. The goals of the network are to enhance access to care for affected individuals, educate local providers to develop knowledge and self-efficacy in treating and managing SCD, and improve cost of care through increased quality of care. In addition, by using a hub-and-spokes model of care and harnessing the resources of the state, including telemedicine and community hospitals, (SC)2 is working to maintain SCD care clinics in these hospitals to keep local care as "local" as possible. A state-based voluntary registry has also been initiated as part of (SC)2 to allow individuals with SCD to receive their individualized-care plans when needing acute care and to better characterize SCD within the state.

In response to the Sickle Cell Disease Study Committee report, DHEC convened a group of stakeholders from multi-disciplinary agencies to develop the South Carolina Sickle Cell Disease State Plan in A Call to Action. This group of stakeholders, known as the South Carolina Sickle Cell Disease Advocacy Team (SCSCDAT), includes physicians, hematologists, nurses, care coordinators, government agencies, non-profit organizations, Medicaid managed care organizations, and families and individuals living with SCD. The state plan is divided to address the following section areas:

- Public Awareness and Education
- Health Care Provider Education (including students and trainees)
- Improving Access to Health Care
- Sustained and Increased Funding

To assist in the development of the state plan, DHEC received funding from Health Resources and Services Administration (HRSA) to secure a public health consultant to provide technical assistance (TA).



Key Highlights:

- **1971-1972** - Sickle Cell Services offered to the public.
- **July 1987** - SCD added to the newborn screening testing panel statewide.
- **November 2015** - MUSC received Duke Endowment funding to start the South Carolina Sickle Cell Network (SC)² led by Dr. Julie Kanter.
- **June 2016** - Sickle Cell Disease Study Committee releases recommendations for addressing SCD in South Carolina, including the need for a state plan.
- **February 2017** - DHEC held first stakeholders meeting to develop a state plan addressing gaps and critical issues impacting persons living with SCD in South Carolina.
- **May 2018** – SC Governor McMaster approved June 19th “Sickle Cell Day in South Carolina.”
- **November 2018** – Proposed completion of the Sickle Cell State Plan.

State Plan Partners

The South Carolina Sickle Cell Disease Advocacy Team will collaborate to implement strategies and activities outlined in the state plan. Partnerships are vital in coordinating efforts among partnering organizations and agencies. These partnerships have been identified by the team and will help maximize resources to achieve successful implementation of identified strategies across South Carolina.

The current state plan partners include:

Academic Medical Centers: The academic and research hospitals consist of the Medical University of South Carolina, Palmetto Health/University of South Carolina School of Medicine, and Greenville Health Systems. These hospitals continue to support the clinical care of individuals with sickle cell disease.

First Choice by Select Health of South Carolina (First Choice): Select Health of South Carolina is one of South Carolina's Medicaid managed care organizations providing access to healthcare.

Molina Healthcare (Molina): Molina Healthcare is a multi-state health care organization that arranges for the delivery of health care services and offers health information management solutions to nearly 5 million individuals and families who receive their care through Medicaid, Medicare and other government-funded programs in 15 states.

SC Association of School Nurses (SCASN): The South Carolina Association of School Nurses promotes the delivery of quality health programs to the school population and school community by strengthening the growth of professional school health nurses and advancing the practice of school nursing.

SC Commission for Minority Affairs (CMA): The South Carolina Commission for Minority Affairs was created to provide the citizens of the state with a single point of contact for information regarding the state's minority population. The primary focus of the commission is to provide statistical data and technical assistance for research and planning, to disseminate statistically significant data and its impact on the minority community, publish a statewide statistical abstract, establish advisory committees representative of the minority population, seek funding to implement programs for minority groups, and promote regulations.

SC Department of Education (DOE): The South Carolina Department of Education oversees public K-12 education in South Carolina. The mission of the DOE is to provide leadership and support so that all public education students graduate prepared for success.

SC Department of Health and Environmental Control (DHEC): The South Carolina Department of Health and Environmental Control (DHEC) is the state regulatory agency charged with promoting and protecting the state's public health and its land, air, and water quality as authorized by federal and state law. These bureaus and departments will provide support to implement identified activities: Camp Burnt Gin, Bureau of Chronic Disease and Injury Prevention, Newborn Screening Follow-Up, Bureau of Laboratories, and Bureau of Maternal and Child Health.

SC Department of Health and Human Services (DHHS): The South Carolina Department of Health and Human Services is the state agency responsible for administering the state Medicaid program.

SC Department of Mental Health (DMH): The South Carolina Department of Mental Health is committed to providing quality mental health services to residents of South Carolina.

SC Hospital Association (SCHA): The South Carolina Hospital Association is a private, not-for-profit organization made up of some 100-member hospitals and health systems and about 900 personal members associated with their institutional members. The South Carolina Hospital Association serves as the collective voice of the state's hospital community.

SC Medical Association (SCMA): SCMA's purpose is to promote the highest quality of medical care through advocacy on the behalf of physicians and patients, continuing medical education, and the promotion of medical and practice management best practices.

SC Primary Health Care Association (SCPHCA): The South Carolina Primary Health Care Association is the unifying organization for Community Health Centers (CHCs) in South Carolina. CHCs are community-based, non-profit organizations that provide comprehensive, high-quality, patient-focused health care services in a culturally appropriate manner. The goals of the SCPHCA include meeting the needs of low-income, uninsured, isolated, vulnerable, and special needs populations and to reduce health disparities across the state by strengthening the CHCs.

SC State School Nurse Consultant (SNC): The South Carolina Department of Health and Environmental Control (DHEC) and the state Department of Education (DOE) jointly employ a State School Nurse Consultant. The State School Nurse Consultant provides guidance regarding school health and school nursing services to school districts and other entities upon request.

School Social Workers Association of SC (SSWA): The School Social Workers Association of South Carolina is dedicated to improving the quality of life and education for children and families through advocacy, professional development and providing access to information.

Sickle Cell Community-Based Organizations (CBOs):

- **Committee On Better Racial Assurance (COBRA):** The goal of COBRA's Sickle Cell program is to help patients and citizens make informed life-time choices regarding Sickle Cell disorders and their clinically significant variants. COBRA's mission is to serve the citizens of South Carolina's Lowcountry to help them become aware, informed, educated, tested by consent, counseled, supported and assisted to the extent of available resources.
- **James R. Clark Memorial Sickle Cell Foundation:** Founded in 1972, the foundation provides a wide range of services to individuals who have sickle cell trait and sickle cell disease and their families. Services include genetic screening and counseling; nurse and community health worker case management; patient, professional, and community education; patient advocacy services; and emergency client assistance.

- **Louvenia D. Barksdale Sickle Cell Foundation:** The L.D. Barksdale Sickle Cell Anemia Foundation was organized in 1974 by Mrs. L.D. Barksdale, a Spartanburg educator who saw a need and became an advocate for individuals with sickle cell anemia in Spartanburg County. The mission of the L.D. Barksdale Sickle Cell Anemia Foundation is to optimize the quality of health care and the quality of life for individuals and families impacted by the presence of the sickle cell disease in the upstate region of South Carolina.
- **Orangeburg Area Sickle Cell Anemia Foundation:** Orangeburg Area Sickle Cell Anemia Foundation is a nonprofit organization serving six counties in the lower region of South Carolina. This organization offers several different services to families and individuals who have sickle cell trait and sickle cell disease. Services include genetic screening and counseling, community education via health fairs and fundraising walks, and support groups.

South Carolina Sickle Cell Disease State Plan

Goal 1: Public Awareness and Education – Develop statewide multi-level messaging and communication to increase awareness and public engagement in Sickle Cell Disease.

An often-recurring discussion surrounding SCD has been the need to increase the community's knowledge about the disease and trait. Even though SCD remains the most common inherited blood disorder, a lack of general knowledge remains. A major component of the plan is to address messaging and how it is disseminated across the state to increase public awareness and educate the community.

Information and awareness-related activities is an important component to reducing the morbidity and mortality due to complications of SCD. Awareness activities through community-based organizations, support groups and advocacy organizations provide effective avenues to reach people with SCD. Other methods for delivering information can include direct counseling, development and distribution of information materials, and referral to agencies that screen and serve individuals for and with SCD.

Strategy: Increase availability of resources for residents and persons who live in or move to SC regarding SCD.

Key Partners	Activities	Year Completed
Academic Medical Centers	<ul style="list-style-type: none"> Maintain the (SC)2 website with statewide resources, calendar of events, sickle cell treating hospitals, sickle cell. CBO events and activities, and other organizations events and activities related to SCD. 	Current and ongoing
Sickle Cell CBOs, DHEC, Academic Medical Centers	<ul style="list-style-type: none"> Increase advertisement of health fairs and events held throughout the state via social media, radio, TV, and newspaper. 	Current and ongoing
DHEC, DOE, SCASN	<ul style="list-style-type: none"> Create a blog and/or press release re: NCAA requirements for sickle cell test results and publish twice a year blogs/press releases. Disseminate CDC handout on "Tips for Supporting Students with Sickle Cell Disease" to SC schools. 	Year 1 and ongoing
DHEC, Sickle Cell CBOs	<ul style="list-style-type: none"> Publicize the blood disorders weekly session at Camp Burnt Gin. Publicize other camps geared toward children and youth with sickle cell. 	Current and ongoing

Strategy: Implement sickle cell awareness day and month activities for South Carolina.

Key Partners	Activities	Year Completed
Sickle Cell CBOs, Academic Medical Centers, SCSCDAT	<ul style="list-style-type: none"> Implement the “#SC Sickle Strong” campaign statewide for Sickle Cell Awareness Day and month. Create and distribute information materials and multimedia. 	Year 1 and ongoing
DHEC, Sickle Cell CBOs, SCSCDAT	<ul style="list-style-type: none"> Utilize social media and email blasts to disperse consistent educational messaging about SCD and SCT. Develop press releases to increase local awareness 	Year 2 and ongoing
Sickle Cell CBOs	<ul style="list-style-type: none"> Host Sickle Cell Day at the Capitol. 	Year 2
Sickle Cell CBOs	<ul style="list-style-type: none"> Establish Sickle Cell Sunday statewide with local faith-based organizations. 	Current and ongoing

Strategy: Increase activities with public and private agencies and/or organizations to increase awareness about SCD and SCT.

Key Partners	Activities	Year Completed
DHEC	<ul style="list-style-type: none"> Collaborate with DHEC departments to implement sickle cell information into their program when working with consumers. 	Year 1 and ongoing
DHEC	<ul style="list-style-type: none"> Continue working with Chronic Disease and Injury Prevention to implement a sickle cell track at the Annual Chronic Disease Symposium. 	Ongoing
SCASN	<ul style="list-style-type: none"> Include sickle cell as a clinical focus at the SCASN Professional Development Summer Conference. Add sickle cell on clinical focus day for SCASN Orientation. School Nurse Program Advisory Committee to develop sample IHP template for students with SCD to be included with an EAP and shared with non-clinical care school providers. 	Year 2
SCHA, DHEC, Sickle Cell CBOs	<ul style="list-style-type: none"> Create an educational webinar geared toward medical professionals that can be viewed for credit live and via recording. 	Year 2
SCSCDAT	<ul style="list-style-type: none"> Host a statewide SCD fair or symposium annually to educate the state on SCD and SCT and increase visibility of the CBOs and SCSCDAT. 	Year 3
Sickle Cell CBOs	<ul style="list-style-type: none"> Continue regional educational symposiums for physicians and HCPs. 	Current and ongoing
DHEC, Sickle Cell CBOs, Academic Medical Centers	<ul style="list-style-type: none"> Update current flyers about SCD and SCT and translate to other languages. Disseminate flyers to doctor’s offices, churches, hospitals, and treatment centers. 	Year 1
DHEC, Sickle Cell CBOs, Academic Medical Centers, Molina, First Choice, CMA, SCMA	<ul style="list-style-type: none"> Partner with other organizations to have vendor tables at their community events and health fairs. 	Year 1 and ongoing

Goal 2: Health Care Provider Education: Student and Postgraduate – To increase educational awareness of medical professionals with an emphasis on primary care and emergency department physicians, nurses, medical and nursing students.

For people living with SCD and the parents of children with SCD, knowledge related to prevention and health maintenance is imperative. Even more critical is the knowledge that health care providers have who treat and care for persons with SCD. Stigmas associated with having the disease are concerns for persons with SCD, but continuing education and training for health care providers and nurses may help reduce these stigmas. Establishing proficient education for health care providers about SCD and SCT is another major component of the state plan.

This includes information related to the prevention of dehydration; avoiding exposure to severe cold and heat; preventing infections; maintaining appropriate nutrition, recognizing and getting early medical follow-up for symptoms such as fever; and implementing pain evaluation and management. Additionally, it is important to provide SCD-related genetic counseling and information about the health risk and options to those who are affected.

Strategy: To develop and implement strategies to improve healthcare provider participation in the care of SCD clients in SC.

Key Partners	Activities	Year Completed
SCSCDAT, Sickle Cell CBOs, Academic Medical Centers	<ul style="list-style-type: none"> Submit a letter of support to the Sickle Cell Disease Coalition and American Society of Hematology for sickle cell fellowships and to establish scholarships for primary care residencies and nursing students with emphasis on medical care for SCD patients in rural areas. 	Year 2
SCHA, Academic Medical Centers	<ul style="list-style-type: none"> Conduct Grand Rounds sessions for the medical community in SC addressing issues regarding SCD. 	Year 3 and ongoing

Strategy: To improve the SCD content and care skills taught to all physicians and nurses during their training at educational institutions in SC.

Key Partners	Activities	Year Completed
SCHA, SCMA, Academic Medical Centers	<ul style="list-style-type: none"> Develop a task force between organizations to explore what educational opportunities can be developed. Evaluate other states' response to increases provider education. 	Year 3
Academic Medical Centers	<ul style="list-style-type: none"> SCD educators and SCD treatment center MDs collaborate with Physician Residency and Nursing Schools (via web or onsite learning) to offer partnership between SCD treatment centers for a clinical rotation. 	Year 3 and ongoing

Strategy: Increase primary care providers’ basic knowledge of evidence-based sickle cell care.

Key Partners	Activities	Year Completed
Sickle Cell CBOs, Academic Medical Centers	<ul style="list-style-type: none"> • Create a YouTube and iTunes podcast channel using a “Ted Talk” model (10-minute talk), covering an endless number of topics from basic to advance using creditable information and developed educational materials. • Encourage medical associations in the state to promote the Southeastern Regional Sickle Cell Tele-Mentoring ECHO Program to their members. Record the ECHO Sessions and allow access via the YouTube and iTunes channels. 	Year 3
Sickle Cell CBOs, Academic Medical Centers	<ul style="list-style-type: none"> • Form partnerships between the SCD education organizations, SCD treatment center education teams, and Nursing and MD Educational institutions to ensure that SCD CEU’s, webinars, presentations are a part of professional conferences throughout the state. • Advocate to include sickle cell in booklet for nursing CEUs. 	Year 3 and ongoing
Sickle Cell CBOs, SCHA, SCPHCA	<ul style="list-style-type: none"> • Partner with SCD organizations to provide patient-centered focus presentations and seminars as part of professional conferences. • Implement guidelines developed by medical experts in collaboration with patients and caregivers. 	Year 3 and ongoing

Strategy: Increase incentives for Primary Care Providers to focus on SCD.

Key Partners	Activities	Year Completed
Academic Medical Centers	<ul style="list-style-type: none"> • Investigate opportunities for scholarships related to physicians serving the SCD community. • Review loan repayment opportunities for physicians and nurses who serve in a rural area. 	Year 3

Goal 3: Improving Access to Care – To increase access to holistic care for persons with SCD across the state.

There are multiple types of complications faced by those with SCD. Many of these problems make obtaining proper treatment and care difficult for a person with SCD. Such factors may be a lack of transportation, lack of insurance, no hospital or urgent care center within a reasonable driving distance, or a shortage of providers who will treat adults with sickle cell. A comprehensive approach to care that targets the “whole person” may help improve biological functions, quality of life, and the perceived health, and functional status of the patient and family.

Improving the system of care to ensure all persons with SCD have sufficient access to health care will be addressed as part of the state plan.

Strategy: Provide case managers for patients who have more than 2 ED annual visits.

Key Partners	Activities	Year Completed
Academic Medical Centers	<ul style="list-style-type: none"> Increase outpatient MD/Hematology visits to address members’ needs to see a decrease in preventable ED visits and inpatient admissions. 	Year 2 and ongoing
Molina, First Choice, DHHS, Sickle Cell CBOs	<ul style="list-style-type: none"> Compile a statewide directory of sickle cell case management providers with descriptions regarding services (what is available, how is it delivered, and the area served). 	Year 2
Molina, First Choice, DHHS, Sickle Cell CBOs	<ul style="list-style-type: none"> Schedule case management providers to present to relevant county/regional/state agencies. Provide overview of services and referral procedures. 	Year 1 and ongoing

Strategy: Improve access to mental health professionals.

Key Partners	Activities	Year Completed
DMH, DHHS	<ul style="list-style-type: none"> Implement statewide standard protocols for mental health services covered by managed care organizations (MCOs) addressing psychosocial issues. Institute mental health teams within the MCOs. 	Year 3

Strategy: Improve the experience when patients living with SCD age out of pediatric care and transition to adult services.

Key Partners	Activities	Year Completed
DOE, Academic Medical Centers, SCHA, SCMA	<ul style="list-style-type: none"> Create transition education opportunities to foster relationships between pediatric and adult providers. Create training activities around transition opportunities. Disseminate transition education to the medical community. 	Year 2 and ongoing
Academic Medical Centers	<ul style="list-style-type: none"> Initiate transition activities starting at 13 years to address needs and barriers. 	Year 2 and ongoing

Goal 4: Increased and Sustained Funding – To establish sustainable funding for sickle cell disease treatment and management.

Gaps existing in funding to support SCD programs, research, and clinical advances, suggest that policy can assist in the efforts to improve the health of all individuals affected by this disease. In order to implement new activities and provide a better coordinated and integrated system of care, additional funding is essential.

SCD organizations have the opportunity to actively highlight and present testimony to support additional funding needs. Additionally, SCD organizations can make contributions to other organizations, agencies, and companies. Educating the community about the impact and gaps in addressing SCD in South Carolina will be key to achieving this goal and establishing a sustainable stream of funding to support sickle cell activities and research efforts across the state.

Strategy: Collaborate with policymakers to highlight the need for additional sickle cell disease funding at the state level.

Key Partners	Activities	Year Completed
Sickle Cell CBOs, SCSCDAT, Academic Medical Centers	<ul style="list-style-type: none"> Identify local and national partners to support sustainable funding for South Carolina sickle cell services. Create a policy brief on SCD in South Carolina. 	Year 2
Sickle Cell CBOs	<ul style="list-style-type: none"> Secure sustainable private funding in the form of grants and/or donations to support sickle cell services. 	Year 2
Sickle Cell CBOs, Academic Medical Centers	<ul style="list-style-type: none"> Identify funding sources and potential grants to support physician residency and nursing programs to include hands-on sickle cell training in sickle cell treatment centers. 	Year 2

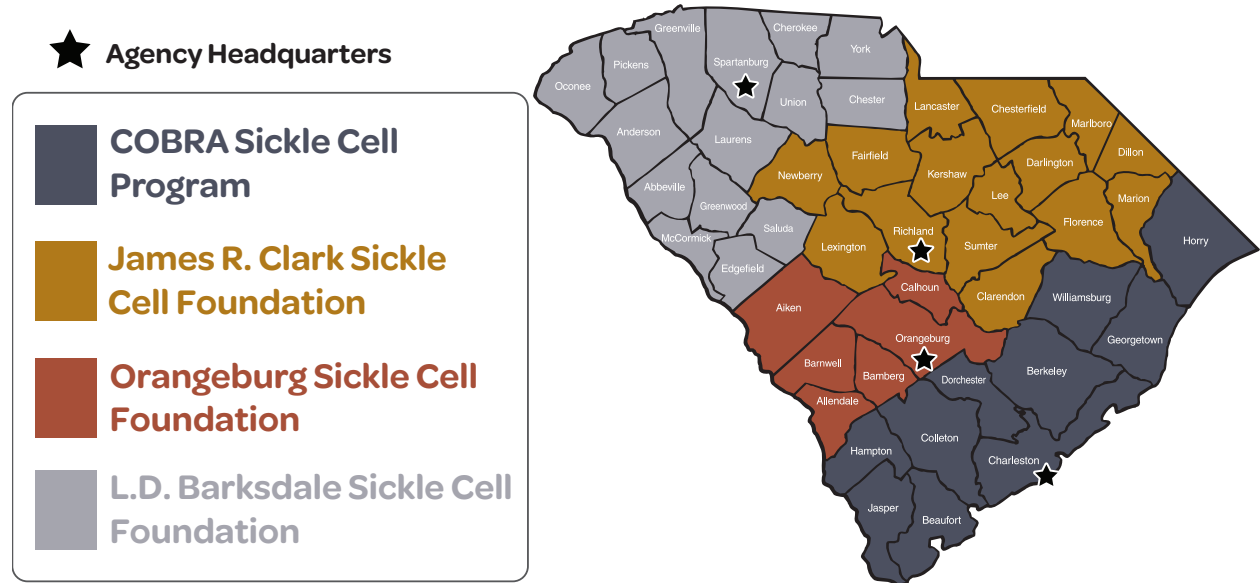
Moving Forward: Steps to Implementation

This plan reflects a Call to Action to address the gaps and barriers facing persons affected by SCD in South Carolina. The intent of the action items identified in this plan is to improve the quality of life of the individual as well as the caregivers of people with SCD. The plan reflects the knowledge, skills, expertise and desire of action-driven individuals from various backgrounds across the state who want to make a difference in the lives of people with SCD. The South Carolina Sickle Cell Disease Advocacy Team will lead implementation of this plan with participation and collaboration from the identified key partners.

In Year 1, the SCSCDAT will develop an evaluation plan to assess progress of the activities. As activities are completed, the plan will be reviewed after the three-year period to assess new activities upon which the stakeholders agree. Many aspects of this plan are already being implemented. As South Carolina's SCD initiatives move forward, the state is poised to deliver enhanced services and support to those with SCD and/or their families through existing programs.

Appendix

Map of CBO Coverage Areas



Acronyms

Camp Burnt Gin
CBG

Centers for Disease Control and Prevention
CDC

Chronic Disease and Injury Prevention
CDIP

Emergency Department
ED

Children & Youth with Special Health Care Needs
CYSHCN

Health Care Providers
HCP

Health Resources Administration
HRSA

Hemoglobin
Hb

Managed Care Organizations
MCOs

Maternal and Child Health
MCH

National Institutes of Health
NIH

Newborn Screening Follow-Up
NBS

Red Blood Cells
RBC

Sickle Cell Disease
SCD

Sickle Cell Trait
SCT

South Carolina
SC

South Carolina Department of Education
DOE

South Carolina Department of Health & Environmental Control
DHEC

South Carolina Department of Health & Human Services
DHHS

South Carolina Hospital Association
SCHA

South Carolina Primary Health Care Association
SCPHCA

South Carolina Association of School Nurses
SCASN

South Carolina Sickle Cell Disease Advocacy Team
SCSCDAT

South Carolina Medical Association
SCMA

South Carolina Sickle Cell Network
(SC)2

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Many individuals, agencies, and organizations from across the state combined to produce the SC Sickle Cell Disease State Plan. A special Thank You to everyone who gave of their time to participate in this huge endeavor. This resulted in creation of a plan to address the care and treatment of persons living with SCD across the lifespan in South Carolina. Members of the South Carolina Sickle Cell Disease Advocacy Team (SCSCDAT) include physicians, hematologists, government agencies, non-profit organizations, healthcare management organizations, and individuals living with SCD and their family members. Members of the SCSCDAT are as follows:

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