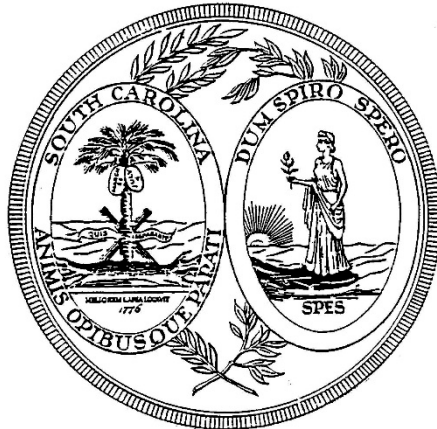


# **SICKLE CELL DISEASE STUDY COMMITTEE**

REPORT TO THE GENERAL ASSEMBLY



June 30, 2016

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## Enabling Legislation

The Sickle Cell Disease Study Committee was authorized by Proviso 117.126 of the 2015 - 2016 South Carolina Appropriation Act.

### **South Carolina General Assembly 121<sup>st</sup> Session, 2015-2016**

#### **Act 91**

AN ACT TO MAKE APPROPRIATIONS AND TO PROVIDE REVENUES TO MEET THE ORDINARY EXPENSES OF STATE GOVERNMENT FOR THE FISCAL YEAR BEGINNING JULY 1, 2015, TO REGULATE THE EXPENDITURE OF SUCH FUNDS, AND TO FURTHER PROVIDE FOR THE OPERATION OF STATE GOVERNMENT DURING THIS FISCAL YEAR AND FOR OTHER PURPOSES.

#### **Part 1B**

#### Operation of State Government

### **SECTION 117 - X90 - GENERAL PROVISIONS**

**117.126.** (GP: Sickle Cell Disease Study Committee) Of the funds authorized and appropriated to the Department of Health and Environmental Control, a Sickle Cell Disease Study Committee shall be created and charged with better serving adults with sickle cell disease (SCD), health care providers, and the public about State care and treatment. The committee is to examine existing services and resources available to children with the disease as well as adults with the disease. Additionally, the committee is to establish partnerships with institutions, and communities, a statewide network of service providers for adults with the disease; a comprehensive education and treatment program for adults, as well as establish standardized treatment and emergency room protocols.

Membership of the committee shall be comprised of thirteen members as follows:

- (1) one researcher or physician from the Medical University of South Carolina specializing in hematology;
- (2) one researcher or physician from the Children's Hospital Sickle Cell Clinic at the Medical University of South Carolina;
- (3) one citizen with Sickle Cell Disease;
- (4) one parent or caregiver of an individual with Sickle Cell Disease;
- (5) the Executive Director of the SC Hospital Association or their designee;
- (6) the President of the South Carolina Medical Association or their designee;
- (7) the Superintendent of Education or their designee;
- (8) the Director of the Department of Health and Environmental Control or their designee;

(9) the Director of the Department of Health and Human Services or their designee;

(10) two members of the House of Representatives appointed by the Speaker of the House, one of whom the Speaker shall designate as a co-chair of the Study Committee; and

(11) two members of the Senate appointed by the President Pro Tempore of the Senate, one of whom the President Pro Tempore shall designate as a co-chair of the Study Committee.

The study committee also may invite representatives of nonprofit entities with expertise regarding Sickle Cell Disease to participate in the Study Committee process.

The House of Representatives Medical, Military and Municipal Affairs Committee and the Senate Medical Affairs Committee shall designate staff to assist the Study Committee.

The study committee shall provide a report with findings and recommendations to the General Assembly and the Governor by June 30, 2016, at which time the Study Committee shall dissolve.

## Study Committee Membership

Two members of the House of Representatives appointed by the Speaker of the House:

Representative John Richard C. King - Co-Chair

Representative Robert L. Ridgeway, III, MD

Two members of the Senate appointed by the President Pro Tempore of the Senate:

Senator Darrell Jackson - Co-Chair

Senator Ronnie A. Sabb

Lorraine Bowman serving as a citizen with Sickle Cell Disease

Virgie Chambers

South Carolina Department of Education Deputy Superintendent for Operations and Support  
serving as the designee for the Superintendent of Education

Jessica Drennan

DHEC Program Manager, Children with Special Health Care Needs serving as the designee for  
the Director of the Department of Health and Environmental Control

Peggie Funny-Roane serving as a parent or caregiver of an individual with Sickle Cell Disease

Lorri Gibbons, RN

SCHA Vice President for Quality and Safety serving as the designee for the Executive Director  
of the South Carolina Hospital Association

Sherron Jackson, MD

MUSC Assistant Professor serving as the researcher or physician from the Children's Hospital  
Sickle Cell Clinic at the Medical University of South Carolina

Julie Kanter, MD

MUSC Assistant Professor serving as the researcher or physician from the Medical University of  
South Carolina specializing in hematology

Deirdra Singleton

DHHS Deputy Director of Health Programs serving as the designee for the Director of the  
Department of Health and Human Services

James Welsh, MD

SCMA Board of Trustees member serving as the designee for the President of the South Carolina  
Medical Association

## Findings

The Study Committee members are in agreement that medical and policy experts knowledgeable about Sickle Cell Disease and health care administration and funding must work together to develop legislative and programmatic changes for South Carolina. A review of programs and outcomes in other states will be a useful part of this process. Several specific significant issues and proposed recommendations were identified by the Study Committee.

- Need for greater public awareness about Sickle Cell Disease
  - Establish a state Sickle Cell Disease Awareness Day in South Carolina either in June to coincide with World Sickle Cell Awareness Day or in September which is Sickle Cell Awareness Month.
  - Promote community-based events that will educate the public about the disease and help raise funds for local initiatives.
  
- Need for more and better education about Sickle Cell Disease processes and medical best practices for health care providers, particularly for physicians and nurses who care for adults in primary and emergency department settings
  - Incorporate education about pediatric and adult Sickle Cell Disease treatment in physician residency training and nursing degree programs.
  - Promote participation in effective continuing medical education on Sickle Cell Disease by producing and making readily available webinars that incorporate patient testimonials in order to increase understanding and empathy by health care providers, particularly in regards to pain management for adults.
  - Increase support for and participation in Sickle Cell Disease continuing medical education by soliciting input and support from the South Carolina Hospital Association and the South Carolina chapter of the American College of Emergency Physicians.
  
- Need for more funding for Sickle Cell Disease programs to improve access to care in both urban and rural areas as well as better coordination between care providers at all levels
  - Implement a Sickle Cell Disease registry to improve data collection and potentially assist individual patients and health care providers by providing acute and chronic care coordination plans.
  - Ensure the South Carolina Reporting & Identification Prescription Tracking System, which is intended to improve the state's ability to identify and stop diversion of prescription drugs, does not impede the appropriate medical utilization of pain management for Sickle Cell Disease patients.
  - Incentivize hematologists and family practice physicians to accept both pediatric and adult Sickle Cell Disease patients.
  - Designate and fund Sickle Cell South Carolina Network (SC<sup>2</sup>) as the coordinating center for patients living with sickle cell disease under the Department of Health and Human Services (DHHS).
  - Seek Centers for Medicare and Medicaid Services authorization and associated state funding to qualify all individuals diagnosed with Sickle Cell Disease for Medicaid coverage and to authorize a Sickle Cell Disease community-based organization or SC<sup>2</sup>

to designate a case coordinator/manager for any patient with more than two emergency room visits per year.

- Expand access to sickle cell community-based organizations in underserved rural areas of the state.
- Foster effective collaboration among the organizations and agencies that work to assist people who have Sickle Cell Disease and their caregivers.
- Promote increased social and emotional support for Sickle Cell Disease patients and families.

## Meeting Summaries

The Sickle Cell Disease Study Committee met four times in the Gressette Building at the Capitol Complex.

### December 10, 2015

The organizational meeting of the Study Committee was held on December 10, 2015. The following members of the Study Committee were present: Lorraine Bowman, Virgie Chambers Jessica Drennan, Lorri Gibbons, Dr. Sherron Jackson, Dr. Julie Kanter, Representative John C. King, Peggie Funny-Roane, Representative Robert Ridgeway, Senator Ronnie Sabb, Deirdre Singleton, and Dr. James Welsh. Representative King called the meeting to order and led a discussion of the Study Committee's purpose and goals as established by the enabling budget proviso. The committee briefly reviewed the existing statutory and funding provisions for Sickle Cell Disease programs in South Carolina.

The committee discussed the need to identify ways to work with the regional sickle cell community-based organizations, the medical community, hospitals, state agencies, the public school system, and those directly affected by Sickle Cell Disease that would:

- Better educate the medical community and the public about the disease
- Foster effective collaboration among the organizations and agencies that work to assist people who have Sickle Cell Disease and their caregivers
- Educate the General Assembly about the importance of the problem and spur them to action in order to address unmet needs

Representative King asked the committee members to come to the next meeting prepared to discuss current services, programs, grants and other funding opportunities for addressing Sickle Cell Disease. He urged the members to identify strategies for improving collaboration and education. He also noted that two pharmaceutical companies have approached him with an interest in working with the committee to break down barriers to participation in clinical trials that could lead to better treatment.

### January 28, 2016

The second Study Committee meeting was held to receive reports from committee members. The following members of the Study Committee were present: Lorraine Bowman, Virgie Chambers Jessica Drennan, Lorri Gibbons, Dr. Julie Kanter, Representative John C. King, Peggie Funny-Roane, Representative Robert Ridgeway, Deirdre Singleton, and Dr. James Welsh.

Representative David J. Mack, III, House District 109, thanked the members of the committee for their interest in improving health care for those affected by Sickle Cell Disease. He stressed the need to improve access to care and how that ultimately will reduce the cost of care while improving health outcomes.

The first speaker was Melodie Hunnicutt, Executive Director of the James R. Clark Memorial Sickle Cell Foundation. She provided the committee with an overview of the four sickle cell



community-based organizations in South Carolina. Those organizations are the L. D. Barksdale Sickle Cell Anemia Foundation in Spartanburg, the Orangeburg Area Sickle Cell Anemia Foundation in Orangeburg, the James R. Clark Memorial Sickle Cell Foundation in Columbia, and COBRA Human Services Agency Sickle Cell Program in Charleston.

Ms. Hunnicutt touched on the services offered by each of the four organizations. Those services include:

- Genetic testing and counseling to reduce incidence of Sickle Cell Disease
- Patient, professional, and community education
- Patient advocacy
- Patient assistance
- Nurse case management

Ms. Hunnicutt presented the following priority needs and concerns for Study Committee's consideration:

- Lack of national and state data on sickle cell patients (number, location, disease trajectory)
- Too few hematologists and family practice physicians accepting Sickle Cell Disease patients which leads to scarcity of medical homes
- Inconsistent access to and referrals for nurse case management services
- Inconsistent use of National Institutes of Health approved Sickle Cell Disease treatment protocols by primary care physicians
- Need statewide comprehensive sickle cell service array
- Need greater care coordination among service providers
- Need standard plan of care for all Sickle Cell Disease patients
- Need individualized patient pain plans in hospital emergency departments
- Need ongoing training for physicians and other medical personnel, including community and hospital-based providers
- Need increased social and emotional support for patients and families
- Return to having sickle cell treatment referrals made directly to the four community-based organizations

The second presenter, Dr. Julie Kanter, led a discussion about problems sickle cell patients face in the health care system. She noted that Sickle Cell Disease is highly prevalent in South Carolina and said recent studies estimate there are up to 4500 persons with Sickle Cell Disease in our state. Despite the prevalence of the disease, the majority of primary care and emergency department physicians have not received education in Sickle Cell Disease management, particularly for adult patients. In addition, there are very few health care providers who are willing and able to treat patients over the age of eighteen who have Sickle Cell Disease.

Dr. Kanter stated there is a lack of care coordination and follow-up for all patients with Sickle Cell Disease, particularly in rural areas, regardless of age. Care coordinators and case managers often do not work together and likely are underutilized. Pharmaceutical services are poorly coordinated and often fail to support physicians in improving patient care. The lack of statewide protocols and quality improvement processes in Sickle Cell Disease care are major problems that need to be addressed.

Dr. Kanter gave a brief overview of a National Maternal and Child Health Workforce Development Grant for which she and Jessica Drennan are co-leads. The goals of the grant are to:

- Improve access to care
- Use quality improvement tools to drive health transformation
- Foster systems integration and harmonization within public health and across organizational boundaries
- Further effective change management, collective action and individual leadership skills that will lead to health improvement of specific populations

Dr. Kanter also reviewed the Duke Endowment funded South Carolina Sickle Cell Disease Access to Care Pilot Program (SC<sup>2</sup>). The SC<sup>2</sup> program is designed to increase access to care for all persons with Sickle Cell Disease in South Carolina. It includes both specialty and primary care and uses a hub-and-spokes care delivery model using a collective impact approach. Both in-person clinics and telehealth clinics are to be utilized in the pilot. The program will develop a statewide treatment protocol based on the Sickle Cell Disease care guidelines from the National Institutes of Health Heart, Lung, and Blood Institute. It will require working with Centers for Medicare and Medicaid Services partners to obtain approval for the protocol.

The plan for SC<sup>2</sup> is to improve and coordinate a case management program; build a shared savings program; and develop/utilize a Sickle Cell Disease registry for individualized care plans for patients seeking acute care. Dr. Kanter reviewed the resources and methods that will be required to meet these goals and the timeline for implementation. The measurable outcomes will include:

- Enhanced access to disease modifying medications. Currently, Hydroxyurea is the only FDA-approved disease-modifying drug for Sickle Cell Disease. Appropriate use of the drug should result in a \$6,000 annual decrease in health care cost per patient who takes the medication.
- Reduced inappropriate transfusion utilization for stroke prevention in those at-risk with Sickle Cell Disease or for acute treatment of severe organ dysfunction. Each unit not transfused saves up to \$500 per event and decreases the risk of blood exposure complications.
- Decreased rates of hospitalizations and emergency department visits.
- Improved quality of care and quality of life for individuals living with Sickle Cell Disease.

The committee discussed potential legislative initiatives to support the sustainability of SC<sup>2</sup>. Funding will be a critical component. Dr. Kanter raised the possibility of ultimately operating SC<sup>2</sup> independently from the Medical University of South Carolina (MUSC) with its own organization and funding. She has plans to develop a sustainable, reimbursable model for Sickle Cell Disease care and utilize the current payment structure to demonstrate that the SC<sup>2</sup> clinical program will generate sufficient revenue at individual outreach clinic locations to support the program while at the same time saving on urgent care and hospitalization costs.

The committee also discussed the need to incentivize physicians and nurses to become better educated and trained to handle Sickle Cell Disease patients. Dr. Kanter noted that improved health care provider reimbursement rates would aid in getting physicians, advanced practice providers, and nurses to provide needed care. One idea offered is to create a one year hematology fellowship

specializing in Sickle Cell Disease. Dr. Kanter and other colleagues are advocating for this type of fellowship at the national level.

Representative Joseph H. Neal, House District 70, brought up a significant problem Sickle Cell Disease patients face with prescription pre-authorization requirements under the state Medicaid plan. He told the committee about a constituent who died while waiting for approval for an expensive medication. Deirdra Singleton reviewed the DHHS policies used in contracts with managed care organizations to ensure their prior authorization policies are not overly restrictive.

#### April 7, 2016

The third committee meeting was held as a listening session to hear concerns and receive information from citizens who are affected by Sickle Cell Disease, their families and caregivers, and their health care providers. Members of the public were invited to attend and address the committee. The following members of the Study Committee were present: Lorraine Bowman, Dr. Julie Kanter, Representative John C. King, Peggie Funny-Roane, Representative Robert Ridgeway, Senator Ronnie Sabb, Deirdre Singleton, Kathy Tomashitis attending in place of Jessica Drennan, and Dr. James Welsh.

Lorraine Bowman spoke as a representative of the Adult Sickle Cell Support Group. She provided a handout with information about Sickle Cell Disease, the Support Group, Dr. James R. Clark's legacy, and adult patient priorities. The most significant Support Group priority is to work for better care for adults with Sickle Cell Disease. The Support Group advocates for better public awareness and for medical staff education about Sickle Cell Disease. Ms. Bowman expressed concern about the lack of care and assistance for adults with the disease. She noted that many patients are not taken seriously when seeking care during a crisis and often are treated as drug seekers.

The next speaker to address the Study Committee was Tyrone Davis, an adult with Sickle Cell Disease. He noted that health care facilities in the central part of South Carolina are much better prepared to deal with pediatric sickle cell cases than adult cases. He said that adults often are underserved and sometimes mistreated because they are misunderstood to be drug seekers. Mr. Davis said there is a real need for better pain control measures for adults with Sickle Cell Disease.

Vernell Graham from Williamsburg County addressed the committee as a representative of the Sickle Cell Anemia Disease Society of Williamsburg County. She provided a written handout with information about the Society and a report to the Study Committee. Ms. Graham agreed with Mr. Davis that many medical professionals do not take the pain suffered by adults with Sickle Cell Disease seriously. Ms. Graham asked the Study Committee for assistance with establishing a sickle cell community-based organization in Williamsburg County.

Representative David J. Mack, III, House District 109, attended the meeting as a representative of COBRA Human Services Agency Sickle Cell Program in Charleston. He talked to the Study Committee about work he and this agency have done to raise public awareness about Sickle Cell Disease and the need for more access to care in rural areas of South Carolina.

Earlene Washington, an older adult with Sickle Cell disease, told the Study Committee about her brother who died with the disease. She expressed concern about the prohibitive cost of sickle cell drugs and the need for affordable health insurance coverage.

Next, the Study Committee heard from Jacque Jackson and Samantha McCrea. Both women are adult Sickle Cell Disease patients who have experienced many of the same problems in the health care system with poorly trained medical staff and a lack of access to care in Williamsburg County. Both expressed the need for a sickle cell community-based organization in Williamsburg County.

The last speaker, Peggie Funny-Roane, addressed the Study Committee as a parent of a Sickle Cell Disease patient. Ms. Funny-Roane agreed with the other speakers about the poor treatment many patients experience when they are in need of pain management. She told the Study Committee about how her daughter has had to endure long waits and dismissive, disrespectful treatment in hospitals when she is experiencing a sickle cell crisis. Ms. Funny-Roane stated more needs to be done to improve public awareness of Sickle Cell Disease and noted that September is National Sickle Cell Awareness Month.

#### May 19, 2016

The Study Committee met to review the information received at previous meetings and formulate its report to the General Assembly. The following members of the Study Committee were present: Lorraine Bowman, Jessica Drennan, Lorri Gibbons, Dr. Sherron Jackson, Representative John C. King, Peggie Funny-Roane, Representative Robert Ridgeway, Senator Ronnie Sabb, Jenny Stirling attending in place of Deirdre Singleton, and Dr. James Welsh.

Representative King called the meeting to order and thanked Study Committee members for their service on the committee and for their ongoing efforts to improve the health care status of citizens with Sickle Cell Disease. He stated that while it is evident from the information and testimony received that there is a lot of work to be done, he is encouraged by the level of interest and commitment to improving patient care expressed during the committee meetings. He, Senator Sabb, and Representative Ridgeway assured the members that their commitment to making positive changes for sickle cell patients in South Carolina will not end when the Study Committee dissolves at the end of June. Following a recapitulation of the previous meetings, Representative King noted three initiatives he wanted the Study Committee to consider in its recommendations:

- Increase funding for DHEC's sickle cell programs and their regional partner programs
- Establish a state Sickle Cell Disease Awareness Day in South Carolina
- Create a registry or data base of sickle cell patients to help them avoid being treated as drug seekers and ensure timely and medically appropriate pain management

Representative Ridgeway suggested that the Study Committee could urge the professional licensure boards to require every other licensure cycle that physicians, physician assistants, and nurses complete continuing medical education (CME) courses on current best practices in Sickle Cell Disease treatment. Other members expressed concern that there could be push-back from an additional mandatory CME requirement. Jessica Drennan informed the committee that an existing budget proviso directs DHEC to provide funds for prevention and educational programs as well as testing, counseling, and newborn screening. The Sickle Cell Disease community-based organizations in South Carolina offer some CME's but they are not mandatory.

Representative Ridgeway took over as chair when Representative King left the meeting because of a previous commitment.

Dr. Welsh stated that a traditional CME course likely will not raise health care practitioner sensitivity to the needs of Sickle Cell Disease patients. Members of the committee discussed ways to put together a team approach for providing more personal testimonials from patients and their care-givers. Lorri Gibbons suggested that this provider education could be done through webinars that could be updated periodically and offered through DHEC or the South Carolina Hospital Association web sites. Dr. Welsh noted the webinars will be more effective with good video production that presents patients and their experiences in a way that can touch the hearts of health care providers. Senator Sabb said that hospitals could do a lot to promote these webinars to their emergency department personnel. Representative Ridgeway agreed and said that hospital staff meetings could provide a good mechanism for broaden provider participation.

Dr. Jackson shared with the committee MUSC's recent experience in educating health care providers about Sickle Cell Disease. She said that the three symposia MUSC held to educate physicians and nurses about how to treat adult sickle cell patients were poorly attended. She agreed that webinars and videos are a good approach but that hospital support and a buy-in on the concept from the physicians and other emergency department providers for the effort will be required for it to be successful. Jessica Drennan noted that incorporating education about Sickle Cell Disease when medical students are doing their residency training could be effective. Representative Ridgeway agreed. Lorri Gibbons stated that a good way to get support from the physicians is to bring the South Carolina chapter of the American College of Emergency Physicians (ACEP) to the table and get their support for education about treating adult sickle cell patients. Senator Sabb suggested and Representative Ridgeway agreed that it would be a good idea to set up a legislative meeting with a representative of ACEP to let them know about the Study Committee's concerns about medical management of the adult Sickle Cell Disease population.

Lorraine Bowman agreed that there is a need for better health care provider education pertaining to treating adults with Sickle Cell Disease. She noted that changes need to be made to promote better care and pain management, particularly for patients in crisis.

Peggie Funny-Roane expressed support for the ideas that had been discussed thus far and stated that she feels it is important to educate the public as well as health care professionals. She said a Sickle Cell Awareness Day should be used to foster greater public awareness and noted that public events like sickle cell awareness walks have proven useful for educating the public and for raising funds for Sickle Cell Disease patient scholarships. Senator Sabb agreed and shared with the committee that they have had good success with sickle cell awareness walks in Williamsburg County.

The Study Committee reviewed three written proposals submitted by Dr. Kanter who was unable to attend the meeting due to a previous commitment to attend a conference.

1. I propose that all individuals born in South Carolina or establishing valid residence in South Carolina receive Medicaid (lifetime) starting at birth due to the diagnosis of Sickle Cell

Disease (SCD). This designation would not require patients to also be on a disability status or to receive SSI but would encourage and allow individuals affected by SCD to work and lead productive lives without fear of losing insurance coverage.

The legislative members discussed the process involved with amending the state Medicaid plan and agreed that funding could be a significant issue for implementing this recommendation.

2. I propose that the Sickle Cell South Carolina Network (SC2) receive annual (line item) infrastructural funding as the coordinating center for patients living with sickle cell disease under DHHS. The responsibility of SC2 will be to assemble and receive approval for a state wide sickle cell plan (ongoing) and to demonstrate improvements in care quality, patient-reported outcomes, and cost for individuals living with Sickle Cell Disease.

The Study Committee agreed there is a lot of promise in this program and it will be good to look at this proposal towards the end of the pilot to evaluate which elements of the project are most beneficial for patient outcomes and work out the best way for the state to support it.

3. I propose that all individuals with Sickle Cell Disease be given a designated case coordinator/manager if they have required more than two emergency room visits per year that is covered by Medicaid to enhance disease self-management and self-care in order to decrease unnecessary acute care utilization.

Representative Ridgeway stated that, like with the first of Dr. Kanter's recommendations, identifying a state funding source will be key to moving forward. However, he noted that this proposal deserves serious consideration because of the potential cost savings and improved long term health outcomes for patients with better disease management.

Representative Ridgeway expressed his gratitude to the members of the Study Committee, the representatives of Sickle Cell Disease organizations, and members of the public who participated in the Study Committee meetings. He and Senator Sabb pledged their long term commitment to putting forward legislation that will improve the quality of health care for sickle cell patients. They noted that some initiatives will require a multi-year effort.