



# GEORGIA STATE SENATE SENATE RESEARCH OFFICE

204 Coverdell Legislative Office Building | 404.656.0015  
18 Capitol Square SW  
Atlanta, GA 30334

ALEX AZARIAN  
ACTING DIRECTOR

## THE FINAL REPORT OF THE SENATE STUDY COMMITTEE ON SICKLE CELL ANEMIA

### COMMITTEE MEMBERS

**Senator Ed Harbison – Committee Chair**  
**District 15**

**Senator Tonya Anderson**  
**District 43**

**Senator Gloria Butler**  
**District 55**

**Senator Kim Jackson**  
**District 41**

**Senator Kay Kirkpatrick**  
**District 32**

## COMMITTEE FOCUS, CREATION, AND DUTIES

The Senate Study Committee on Sickle Cell Anemia was created by Senate Resolution 151 to determine the needs of Georgia residents with respect to prevention and treatment of sickle cell anemia and to identify sources of state and federal funding or private funding to address such needs.<sup>1</sup>

Senator Ed Harbison of the 15th served as the Committee Chair. The other Senate members included: Senator Tonya Anderson of the 43rd; Senator Gloria Butler of the 55th; Senator Kim Jackson of the 41st; and Senator Kay Kirkpatrick of the 32nd. The Committee held three meetings at the State Capitol on August 19th, November 1st, and December 10th, and heard testimony from the following organizations and individuals:

1. Children's Healthcare of Atlanta (CHOA)
  - Lakshmanan Krishnamurti, MD; Emory University; Professor Pediatrics; Attending Physician at CHOAS's Aflac Cancer and Blood Disorders Center
2. Georgia Research Alliance (GRA)
  - Susan Shows, President
  - Anu Kanthasamy
3. Association of Sickle Cell, Lower Chattahoochee Region
  - Ms. Louis Williams, Columbus, GA
4. National Marrow Donor Program/Be the Match
  - Jocelyn Thompson
5. Georgia Health Policy Center (GHPC), Georgia State University
  - Angela Snyder, PhD, MPH
6. Oncology and Sickle Cell Service Line of Grady Health System
  - Pooja Mishra; Vice President
7. Grady Health System
  - Nikita Barrett; Clinical Staff Manager
8. Emory University School of Medicine
  - Morgan McLemore, MD; Dept. of Hematology and Oncology
9. Global Blood Therapeutics
  - Dr. Kim Smith-Whitley; VP & Head of Research & Development
10. Sickle Cell Foundation of Georgia
  - Janette Nu'Man

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<sup>1</sup> [Senate Resolution 151 \(2021\)](#)

# COMMITTEE FINDINGS

## Background

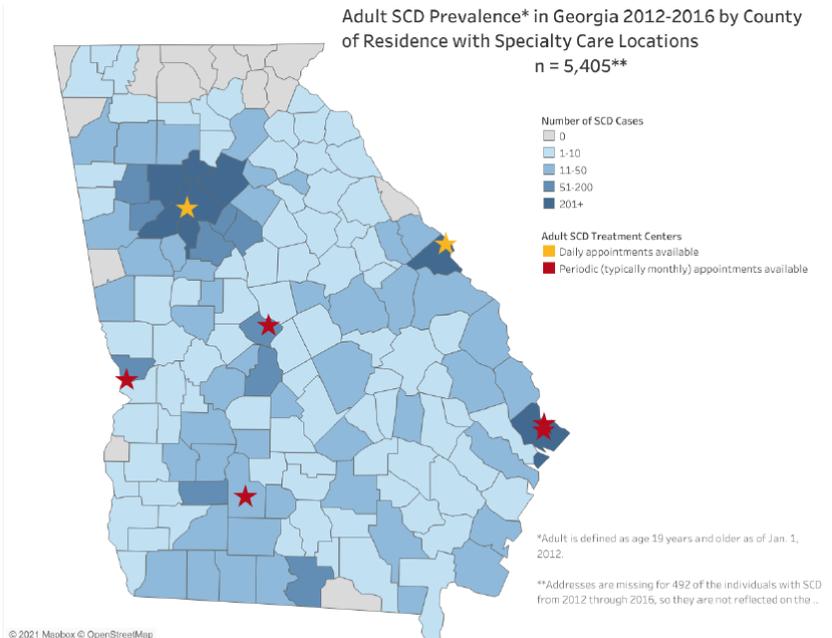
Sickle cell disease (SCD) is an inherited blood disorder that is marked by flawed hemoglobin and interferes with the delivery of oxygen to the tissues. While red blood cells with normal hemoglobin are smooth, disk-shaped, and flexible and move easily through blood vessels, cells with sickle cell hemoglobin are stiff and sticky. When they lose their oxygen, they form into the shape of a sickle or crescent. These cells stick together and cannot easily move through the blood vessels. This can block small blood vessels and the movement of healthy, normal oxygen-carrying blood. The blockage can cause pain.

While SCD mostly affects people of African descent, it also affects individuals with heritage from the Mediterranean, Middle East, India, Central and South America, and the Caribbean. Dr. Krishnamurti explained that SCD is a global disease affecting over 300,000 births each year worldwide, including 4,000 births in the United States. Georgia is in the top 3 of states in the nation for SCD, with more than 10,000 individuals living with the disease in Georgia across almost every county. In the U.S., SCD affects roughly 100,000 Americans. It is estimated that about 1 in 3 African American babies is born with a sickle cell *trait*, and about 1 in 13 African Americans is born with SCD. People who have the trait inherit one sickle cell gene (“S”) from one parent and one normal gene (“A”) from the other parent. People with the sickle cell trait usually do not have any of the signs of the disease and live a normal life, but they can pass the trait on to their children. Additionally, there are a few, uncommon health problems that may potentially be related to sickle cell trait.

## State of Sickle Cell in Georgia

- Only two comprehensive sickle cell centers in the state
- No specialty services available outside of the two centers (Atlanta and Augusta)
- Periodic appointments available in some areas of the state provided by the Sickle Cell Foundation of Georgia and Augusta University
- Few non-specialty providers understand sickle cell disease or how to treat. Many reluctant to treat individuals with SCD
- Individuals forced to travel long distances to access care or chose to go without care increasing the risk of poor health outcomes and increased public burden

Source: Sickle Cell Foundation of Georgia



## Treatment Options

Dr. Krishnamurti explained that advances in care have provided patients with many treatment options. These include FDA approved medications such as Hydroxyurea, L-Glutamine, Voxelator and Crizanlizumab. Bone marrow transplantation and gene therapy are also treatment options that offer curative alternatives to certain patients. Dr. McLemore added that although gene editing and gene therapy are promising cures, recent trials have been placed on hold due to complications. He further explained that transplantation faces hurdles in finding matching donors.

Dr. Smith-Whitley also pointed out the 2019 FDA approval of Oxbryta in treating SCD. Oxbryta interferes in the sickling process resulting in the reduction in sickling and improving red blood cell health. With less red blood cell destruction, the developers anticipate an increase in hemoglobin to deliver oxygen to the body's tissues and organs. Dr. McLemore acknowledged that although Grady does use Oxbryta, it prefers

Hydroxyurea because it promotes the body's production of hemoglobin while also serving as an anti-inflammatory. He added that there is no evidence that Oxbryta reduces hospitalizations.

### **Barriers Identified**

- Access to care, especially for patients on Medicaid;
- Quality of care. This includes a lack of support for comprehensive case management, chronic pain, mental health, and complementary medicine. It also includes a lack of comprehensive and specialist care for adults;
- Lack of resources;
- Many providers are hesitant to prescribe opioid pain medications for fear of triggering the Georgia Prescription Drug Monitoring Program (PDMP) database<sup>2</sup>; and
- Lack of research funding.

The Committee learned that Grady Health System's Sickle Cell Clinic serves as a model for specifically addressing SCD and many of the above barriers. Established 37 years ago, the clinic is the world's first 24-hour acute care center for adult patients with sickle cell disease and is one of only two comprehensive sickle cell centers in Georgia. It provides comprehensive primary care by appointment and 24/7 acute care services for pain crisis management. The Committee discussed different approaches and hurdles to transporting patients from throughout the state to Grady, suggesting a hub-and-spoke network. This approach involves organizing routes as a series of spokes that connect outlying points to a central hub, which would be Grady.<sup>3</sup> Some members, however, felt that it might be more productive and efficient if local health agencies are trained to treat SCD and increase telehealth efforts, while leaving the hub-and-spoke network to annual or semi-annual visits.

### **Options for Ramping up Research Grant Funding**

The Georgia Research Alliance (GRA) provided background information on its role and options for grant funding and return on investment for Georgia businesses and universities. The idea for their SCD eminent scholar program came from Governor Deal's endorsement of Parkinson's disease research in honor of Senator Isakson. The key was getting the funding and support before approaching the Governor. The partnership reflects a collaboration between Morehouse School of Medicine, Emory, and CHOA and a \$15.85 million investment over 5 years (\$8.1M public via GRA; \$7.57M private).

### **Education in Communities**

Ms. Williams of the Association of Sickle Cell, Lower Chattahoochee Region informed the committee of the efforts in the Columbus area made to help patients know their SCD status by helping with payment while also educating the community about the disease. Efforts also include a sickle cell clinic dedicated solely to address SCD in the community. The committee was urged that funding is needed to address the access to care issues in areas outside of Atlanta. Senator Kirkpatrick inquired about the role of public health in this and how efforts could be used to bring out quality of care through education. Senator Kirkpatrick mentioned that there may be a role in Graduate Medical Education (GME) to improve access and quality.

### **Georgia Hemoglobin Disorders Data Coordinating Center**

Operated by Georgia State University's Georgia Health Policy Center (GHPC) and funded through the CDC, the Georgia Hemoglobin Disorders Data Coordinating Center collects data on SCD. GHPC provided testimony focusing on the Sickle Cell Data Collection Program in particular. The goal of the Program is to improve the quality of life, life expectancy, and health of individuals with SCD by developing and disseminating scientific evidence to inform policies and practices. Its partners include: CDC Division of Blood Disorders; Department of Public Health (DPH); Department of Community Health (DCH); the Sickle Cell Foundation of Georgia; the Association of Sickle Cell, Lower Chattahoochee Region; CHOA; Grady; Augusta University; Memorial Hospital of Savannah's pediatric sickle cell program; and Georgia Southern University School of Public Health. While data was collected starting in 2010, the data set spans 2004-2019. GHPC explained that it has pediatric

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<sup>2</sup> The Georgia Prescription Drug Monitoring Program (PDMP) is an electronic database used to monitor the prescribing and dispensing of controlled substances. The PDMP provides prescribers and pharmacists with critical information regarding a patient's controlled substance prescription history. It can help eliminate duplicative prescribing and overprescribing of controlled substances and protect patients at risk of misuse.

<sup>3</sup> The hub-and-spoke network differs from the Point-to-Point network, which connects directly a set of locations without any interruption of services (e.g. pick up or drop off) even if the route itself may not be direct. As a network structure, hub-and-spoke allows for greater flexibility within a transportation system through a concentration of flows.

sickle cell data for the last 16 years, Medicaid data, some State Health Benefit Plan data, hospital and ED discharge information, and clinical subset information. Senator Kirkpatrick indicated that the all payer claims database (APCD) could be beneficial from a data sharing standpoint.<sup>4</sup>

**State Funding**

The Committee learned that the state currently appropriates \$850,000 in Fiscal Year 2022 for sickle cell programs. These funds are received by the Sickle Cell Foundation of Georgia through DPH.<sup>5</sup> Sickle cell disease programs have been funded intermittently since at least FY 2008. Additionally, SCD is one of the 35 inherited disorders that the DPH tests for with the Georgia Newborn Screening Program. In FY 2016, the service fee for newborn screening was raised from \$50 to \$75 per infant to assist with providing therapies for children with congenital disorders pursuant to O.C.G.A. § 31-12-6.

<b>Budget Items Referencing Sickle Cell</b>					
<b>Fiscal Year</b>	<b>Bill No.</b>	<b>Language</b>	<b>Recurring Funds</b>	<b>One-time Funds</b>	
FY2008 (General)	HB95	Increase funds for a specially equipped bus to perform sickle cell anemia testing throughout the state.	\$300,000		
FY2008 (Amended)	HB989	Transfer funds to the Infant and Child Essential Health Treatment Services program for a sickle cell bus			(\$300,000)
FY2008 (Amended)	HB989	Transfer funds from the Epidemiology program for a sickle cell bus.			\$300,000
FY2009 (General)	HB990	Provide funds for a new, specially equipped bus to perform sickle cell anemia testing throughout the state.	\$300,000		
FY2009 (Amended)	HB118	Reduce funds for sickle cell services provided by the Fulton-DeKalb Hospital Authority.			(\$88,796)
FY2010 (General)	HB119	Reduce funds received in HB990 (FY09G) for a second sickle cell bus.			(\$300,000)
FY2010 (General)	HB119	Reduce funds from sickle cell services provided through the Fulton-DeKalb Hospital Authority contract.			(\$88,796)
FY2013 (Amended)	HB105	Reduce funds for programmatic grant-in-aid for the genetics and sickle cell testing program. (S and CC:Reduce funds for programmatic grant-in-aid for genetics testing and recognize an alternative delivery mechanism for sickle cell testing program)			(\$525,172)
FY2014 (General)	HB106	Reduce funds for programmatic grant-in-aid for the genetics and sickle cell testing program. (S and CC:Reduce funds for programmatic grant-in-aid for genetics testing and recognize an alternative delivery mechanism for the sickle cell testing program)			(\$525,172)
FY2014 (General)	HB106	Increase funds for the sickle cell disease treatment contract.	\$150,000		
FY2016 (General)	HB76	Increase funds for the Georgia Comprehensive Sickle Cell Center.	\$50,000		
FY2017 (General)	HB751	Eliminate one-time funds for the Georgia Comprehensive Sickle Cell Center. (CC:No)	\$0		
FY2017 (General)	HB751	Increase funds for the Medical College of Georgia Sickle Cell Center at Augusta University.	\$117,178		
FY2017 (General)	HB751	[Medical Assistance Program CFDA93.778]	\$246,842		
FY2018 (General)	HB44	Increase funds for developing telehealth sickle cell mobile units. (CC:Increase funds to upgrade telehealth sickle cell mobile units)	\$50,000		
FY2019 (General)	HB684	Provide funds for the Sickle Cell Foundation of Georgia for sickle cell outreach offices to improve access to care and reduce unnecessary emergency room costs.	\$150,000		
FY2020 (General)	HB31	Increase funds for the Sickle Cell Foundation of Georgia for sickle cell outreach offices to improve access to care, reduce unnecessary emergency room costs, and expand physician training and community education in underserved areas.	\$150,000		
FY2020 (Amended)	HB792	Reduce funds for the Sickle Cell Foundation of Georgia.			(\$115,000)
FY2021 (General)	HB793	Reduce funds for the Sickle Cell Foundation of Georgia.			(\$115,000)
FY2022 (General)	HB81	Increase funds for the Sickle Cell Foundation of Georgia.	\$365,000		
<b>Current Appropriation Level</b>			<b>\$850,052</b>		

Source: Senate Budget and Evaluation Office

<sup>4</sup> All-payer claims databases (APCDs) are large state databases that include medical claims, pharmacy claims, dental claims, and eligibility and provider files collected from private and public payers. APCD data are reported directly by insurers to states.

<sup>5</sup> The Sickle Cell Foundation of Georgia’s mission is to reduce the incidence of sickle cell disease, to monitor the prevalence of sickle cell, and to help improve the quality of life for persons afflicted with the disease. It works closely with the State of Georgia, medical facilities and personnel, Sickle Cell Support Groups, physicians, nurses, clinics, social workers, volunteers, and other organizations to deliver and to help facilitate client services.

## COMMITTEE RECOMMENDATIONS

The Committee submits the following recommendations:

1. Leverage existing resources such as Federally Qualified Health Centers (FQHCs) and county health departments to improve treatment around the state by connecting them with sickle cell experts for consultation.
2. Work with Georgia medical schools and primary care residency programs to improve sickle cell material in their curriculum. Additionally, incentivize hospitals, emergency centers, and non-specialty providers to take advantage of available training and increased SCD training availability.
3. Establish an intercity shuttle bus system or a sub-system to an existing transit system in each medium size metro area to serve sickle cell patients in the state. In particular, utilize mobile units to transport Grady specialists from Metro Atlanta to underserved rural and medium size metro areas on a quarterly basis and establish mechanisms that will facilitate such resource sharing.
4. Establish a clearinghouse to coordinate between Atlanta and medium cities along with additional funding for those areas. This will help utilize and maximize Grady Memorial Hospital's resources and knowledge to assist for those smaller cities. Additionally, establish mechanisms to allow data sharing between funded community-based organizations and clinical organizations to reduce the number of individuals lost to follow-up through the provision of community health worker services.
5. Expand access to medical care and support programs that aim to create meaningful and sustainable change for sickle cell patients. This should involve scaling up existing programs and services to expand access to care to additional areas of the state, including:
  - Funding for additional mobile units and additional hematologists to expand coverage areas; and
  - Funding to sustain current community health workers and place additional workers in the most underserved and southernmost parts of the state.
6. Create a pathway for extending Medicaid benefits to Georgians 18 to 25 years of age living with SCD regardless of SSI/Disability status.

Respectfully Submitted,

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SICKLE CELL ANEMIA**

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**Senator Ed Harbison – Committee Chair  
District 15**