

Georgia "Gold Standard" for Sickle Cell Disease



Updates and Accomplishments 2017-2020



Sickle Cell Foundation of Georgia, Inc.

The mission of the Sickle Cell Foundation of Georgia, Inc. is to engage, educate, and energize the community to improve the quality of life for people affected by sickle cell disease. "Living Well with Sickle Cell"

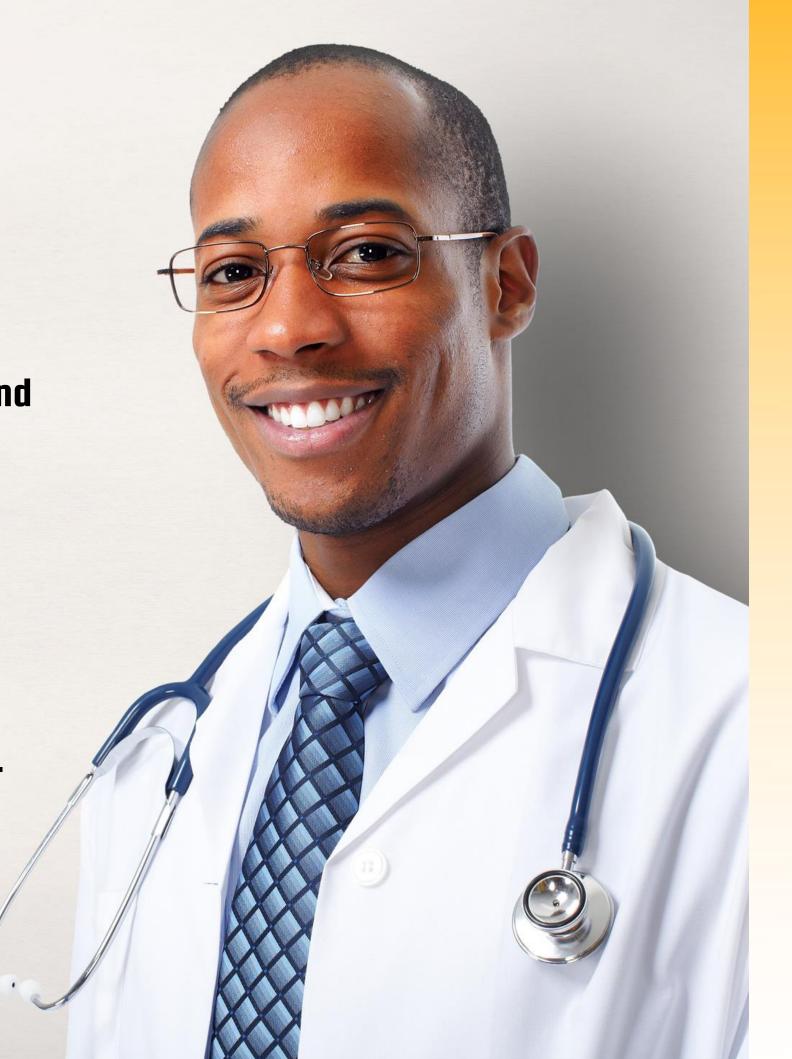
Purpose and Goals

Improve health outcomes of individuals living with sickle cell disease

 Reduce reliance on and utilization of emergency departments and urgent care centers

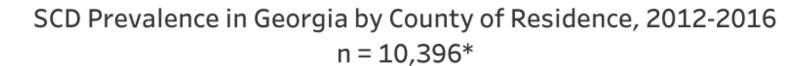
 Improve access to knowledgeable care and treatment of sickle cell disease with a focus on underserved areas of the state

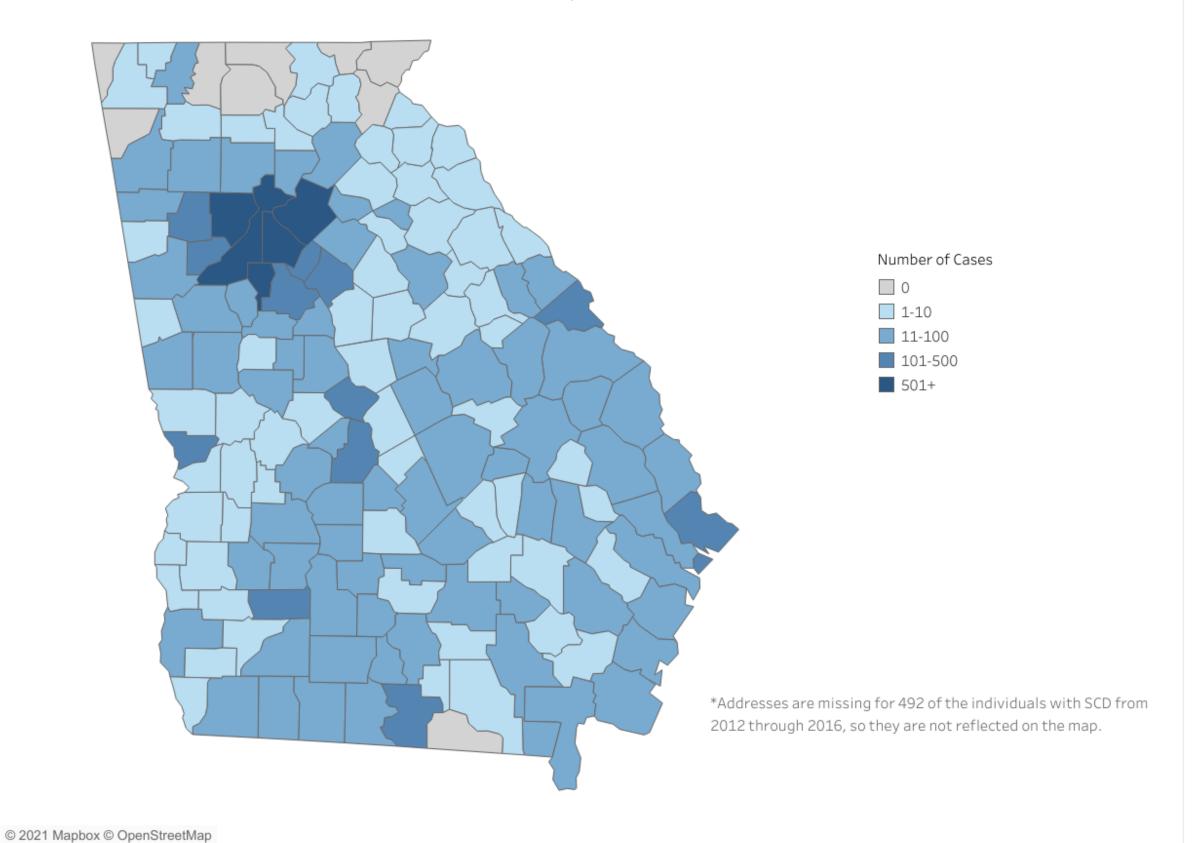
 Promote awareness among the general public and disease self management among individuals living with sickle cell disease



The State of Sickle Cell in Georgia

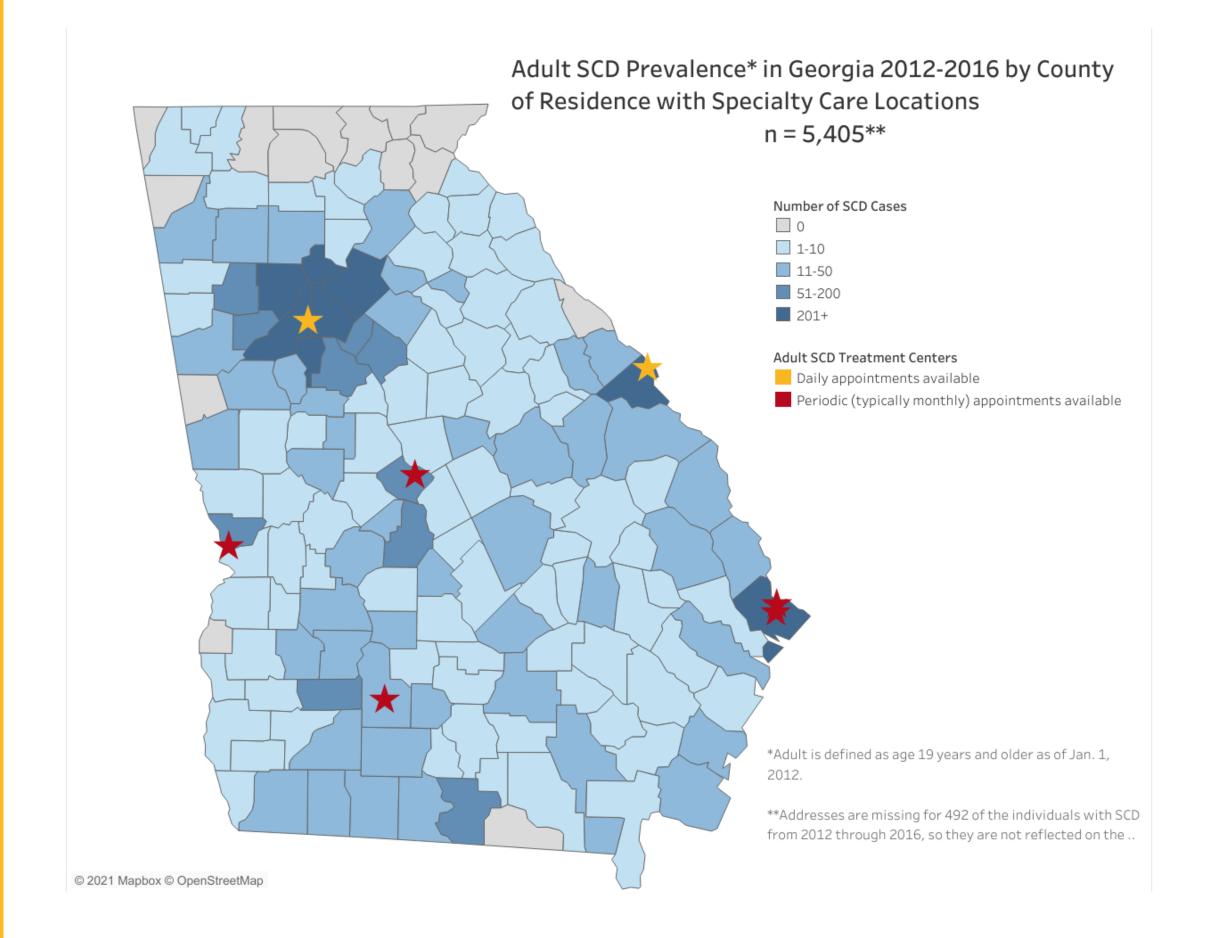
- Over 10,000 individuals living with sickle cell disease in 147 counties 4th largest population in the nation
- 155 babies born each year with sickle cell disease, &,000 born with an abnormal hemoglobin, 4,300 have sickle cell trait
- 87% (I4I) of counties are medically underserved, among highest rates of medically underserved in the nation
- 69% of counties are rural
- 67.7% of individuals living with sickle cell disease reside in counties that are designated as medically underserved or rural or both





State of Sickle Cell in Georgia

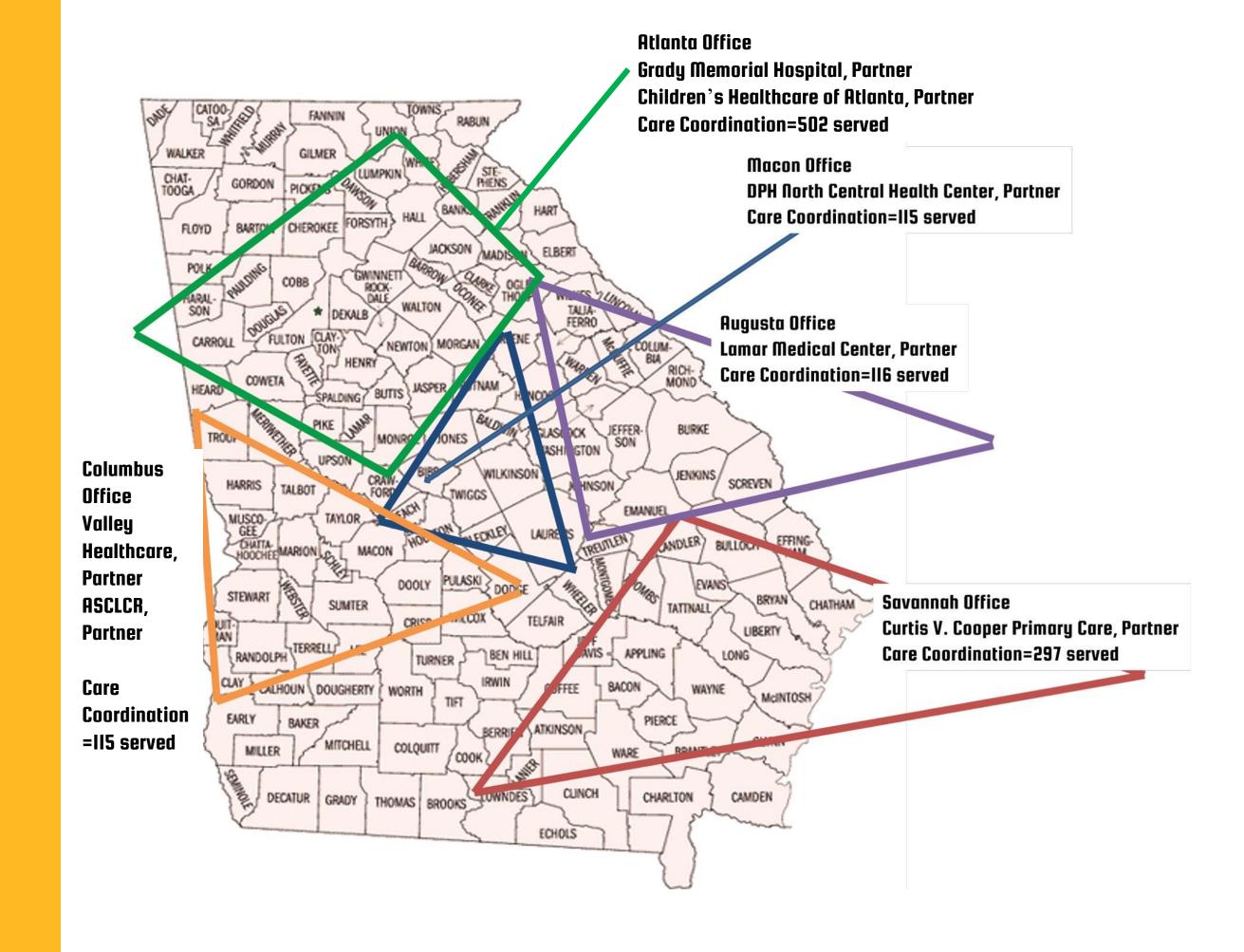
- Only two comprehensive sickle cell centers in the state
- No specialty services available outside of the two centers (Atlanta and Augusta)
- Periodic appointments available in some areas of the state provided by the Sickle Cell Foundation of Georgia and Augusta University
- Few non-specialty providers 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





- Access to appropriate health care is a major need
- I.4 million Georgians are uninsured and many more are at risk for losing coverage (13.4%, fourth highest in the country)
- No more than 50% of adults with SCD have > I SCD visit per year with a knowledgeable provider
- Only 39% have had a visit with a hematologist
- Access to health care is limited to emergency departments for 21% of uninsured adults with SCD
- Disparities in access to health care exacerbated by the pandemic and the new surge

Sickle Cell Offices



Access to Care: Care Coordination.

Care coordination services provided to 1,523 individuals in 124 counties

- 172 individuals linked to medical homes (primary care) for routine medical care and reduce use of emergency departments and urgent care centers
- 230 individuals linked to hematologists or comprehensive sickle cell centers for specialty care or other specialty providers
- 435 individuals provided with supportive services (food assistance, housing assistance, other practical needs)

Access to Care: Provider Training

- 500 non-specialty health care providers received in-person or remote training
 - Augusta
 - Columbus
 - Macon
 - Swainsboro
 - Georgia Academy of Pediatrics
 - Georgia State Medical Association
- 80% reported increased comfort treating individuals with SCD



Access to Care: Visiting Hematologist

57 individuals with sickle cell disease received specialty care in partnership with Federally Qualified Health Centers or use of Mobile Clinic





Support to Community Based Organizations

- Tapestry Connections, Hinesville
 - **-\$1,125**
 - Patient assistance gift cards
- Sickle Cell Association of Savannah
 - **-\$3,150**
 - Patient transportation
 - COVID-I9 safety supplies
 - Go Bags (Emergency Bags) for emerging adults

Support to Community Based Organizations

- Huisman Sickle Cell Foundation of Augusta
 - -\$3,400
 - Gas cards
 - COVID-19 safety supplies
 - Go Bags
- Association for Sickle Cell, Lower Chattahoochee Region, Columbus
 - **-\$19,250**
 - CHW salary and administrative overhead
 - **-\$3,150**
 - Patient supplies
 - Go Bags
 - **-\$5,000 (2017)**
 - CHW support
 - **\$35,075 (Total Support)**





- Sustain community health workers in current location and expand to counties in the southern part of the state
- Expand use of mobile clinic to provide hematology services to additional underserved areas of the state
- Videotape non-specialty provider training for on-demand access to expand availability of providers knowledgeable of evidence-based practices for treatment and maintenance of sickle cell disease
- Leverage resources to support and build capacity of community organizations across the state to provide services

State Level Issues

- Access to resources to pay for care
- Increased collaborations between clinical and community-based organizations including data sharing to facilitate care and support
- Engagement of medical training facilities to encourage and prepare nonspecialty providers to provide evidence-based care
- Incentives for non-specialty providers to treat individuals with sickle cell disease in areas of the state with limited access to specialty care
- Continued and enhanced involvement of community-based organizations in sickle cell research

Contact Us

Reach out to us for inquiries or comments.



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