



**PRESS RELEASE  
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## **Congress Passes the Sickle Cell Treatment Act of 2018**

**BALTIMORE, MD** — On December 10, 2018, S.2465 – The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 – was passed by the Congress and now moves forward for the President to sign into law.

The bill represents a commitment by the government to continue much-needed research geared towards increasing the understanding of prevalence, distribution, outcomes, and therapies associated with sickle cell disease (SCD). It also reauthorizes SCD prevention and treatment grants awarded by the Health Resources and Service Administration (HRSA), and it authorizes the Centers for Disease Control and Prevention to award SCD surveillance grants to states, academic institutions and non-profit organizations.

“It is amazing what can happen when our collective voices sound together to affect positive change,” said SCDA President and CEO Beverley Francis-Gibson. “We are grateful for this legislative victory and to all of the individuals living with SCD and their families for their strength and for their efforts to be heard. The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 marks another step forward in our collective efforts to better understand the prevalence and outcomes of SCD through research and to address the complex needs of the sickle cell community.”

Sickle Cell Disease Association of America, Inc. thanks Senator Tim Scott (R-SC) and Senator Cory Booker (D-NJ) for their leadership and for introducing the bill on February 28, 2018, and we thank the bill’s co-sponsors Senator Doug Jones (D-AL), Senator Bill Cassidy (R-LA), Senator Debbie Stabenow (D-MI), and Senator Elizabeth Warren (D-MA).

SCDAA also thanks Congressman Danny Davis (D-IL), a long-time champion for the sickle cell community; Congressman Michael Burgess (R-TX); and Congressman G.K. Butterfield (D-NC) for supporting this bill in the U.S. House of Representatives. In addition, we are grateful to the members of the Sickle Cell Caucus and to our key partners such as the American Society of Hematology (ASH), Sick Cells, Sickle Cell 101, the SickleCellForum, #BoldLipsforSickleCell and the EveryLife Foundation.

### **About the Sickle Cell Disease Association of America, Inc.**

Sickle Cell Disease Association of America, Inc.’s mission is: To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. Visit: [www.sicklecelldisease.org](http://www.sicklecelldisease.org).

### **About Sickle Cell Disease**

Sickle cell disease, an inherited blood disease, causes red blood cells to have a sickle-shape. With their stiffness and unusual shape, blood flow is blocked to different tissues, ultimately damaging them. These red blood cells contain an abnormal type of hemoglobin, hemoglobin S, while normal red blood cells have hemoglobin A. Hemoglobin is important to the body because it helps the body carry oxygen throughout the body. There is currently no universal cure.

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