

PRESS RELEASE For Immediate Release December 18, 2018 Contact: Carole Bernard Director of Communications and Marketing <u>cbernard@sicklecelldisease.org</u> (410) 528-1555 (o) (443) 538-1565 (c)

The President Signs the Sickle Cell Treatment Act of 2018

Advocacy Efforts Create Legislative Victory

BALTIMORE, MD — On December 18, 2018, S.2465 – The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 – was signed into law by the President. <u>Click here to read more!</u>

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 has been a long journey for the sickle cell community in getting the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 signed into law, but we did it" said SCDAA President and CEO Beverley Francis-Gibson. "We thank the President and the Congress for listening to the voices within the sickle cell community. Today, we proudly stand together knowing that this new law will benefit individuals and their families living with sickle cell disease, help us to better understand the prevalence and outcomes of SCD through research and to address the complex and diverse 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 this year, and we thank the bill's cosponsors 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 longtime 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.

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: <u>www.sicklecelldisease.org</u>.

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.