PRESS RELEASE
For Immediate Release
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Re-Authorization of the Sickle Cell Treatment Act Passes Through the House of Representatives
~Sickle Cell Disease Association of America, Inc. Celebrates Legislative Victory~

BALTIMORE, MD (February 28, 2018) – On Monday, February 26, 2018, the U.S. House of Representatives considered and passed H.R. 2410, the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act, which was introduced on May 11, 2017, by Rep. Danny Davis (D-IL).

H.R. 2410 would authorize the Secretary of Health and Human Services to conduct surveillance and collect data on the prevalence of sickle cell disease (SCD). In addition, the bill would authorize the Secretary to develop public health initiatives that support community-based organizations in education activities and to support regional and state health departments in testing to identify SCD.

"This is a major victory for the sickle cell community," said Sonja L. Banks, Sickle Cell Disease Association of America, Inc. (SCDAA) President. "It has been a long journey to get to this momentous occasion. SCDAA has worked tirelessly on the Treatment Act. We are so grateful for the ongoing support from Congressman Danny Davis and Congressman Michael Burgess (R-TX) for co-sponsoring this important legislation in the U.S. House of Representatives. We also want to thank the Congressional Sickle Cell Caucus for standing alongside the sickle cell community."

As the leading advocacy organization working on a national level to resolve issues surrounding SCD and sickle cell trait, SCDAA led a grassroots, community-driven effort over the past five years on the Sickle Cell Treatment Re-Authorization Act. This effort began with a community town hall of more than 230 members of the sickle cell community, including patients, parents, caregivers, and providers, providing feedback to enhance expired Treatment Act legislation. As a result, SCDAA incorporated the sickle cell community's input and worked to finalize a bill that incorporated new aspects to include: Young Adult Transition, programs that cover the life span of patients, and a line item for the Centers for Disease Control (CDC). SCDAA also worked to help form and serve as host organization for the Congressional Sickle Cell Caucus, and SCDAA President Sonja Banks testified in front of the U.S. House of Representatives Health Subcommittee in 2016 about the enhanced services that would be provided to the sickle cell community through the bill. Last year, the Sickle Cell Treatment Re-Authorization Act was reintroduced in the U.S. House of Representatives as H.R. 2410 and moved to mark-up.

H.R. 2410 allows states to receive federal funding for patient counseling, educational initiatives and community outreach programs. It also supports the continuance of a National Coordinating and Evaluation Center and community-based sites that provide SCD follow-up and other services to support comprehensive care for newborns diagnosed with SCD. In addition, the bill improves upon the HRSA demonstration program. The treatment and prevention component of the reauthorization sets a more realistic number of eligible entities which can be funded. It also places a duty on all entities to "expand, coordinate, and implement transition services for adolescents with sickle cell disease making the transition to adult-focused health care."

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Additionally, H.R. 2410 establishes surveillance grants for states, wherein grants would be authorized to states representing a majority of the sickle cell disease patient population. The data, which would be accumulated under this grant program covers associated health outcomes, complications and treatments, and would result in public health initiatives and strategies which would improve current estimates about the incidence and prevalence of the disease. It would identify health disparities, assess the utilization of therapies and strategies to prevent complications from the disease, and evaluate the impact of genetic, environmental, behavioral and other risk factors that may impact health outcomes.

About Sickle Cell Disease
Sickle cell disease, an inherited rare 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 blood carry oxygen throughout the body. There is currently no universal cure.

About the Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America, Inc. serves as the nation's only advocacy organization working full time on a national level to resolve issues surrounding SCD and trait. Our mission is: To advocate for and enhance our membership's ability to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all in the world with sickle cell disease. Visit: www.sicklecelldisease.org.

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