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Contact: Carole Bernard  
Marketing and Communications Manager  
Email: cbernard@sicklecelldisease.org  
Phone: 410-528-1555 (office) / 443-538-1565 (cell)



**Sickle Cell Disease Association of America, Inc. Awards Community Based Organizations with \$2,033,080 for Newborn Screening Follow-up Program**

**BALTIMORE, MD – February 20, 2018** – The Sickle Cell Disease Association of America, Inc. (SCDAA) was awarded \$2.9 million annually for the next four years from the Health Resources & Services Administration (HRSA) for the Sickle Cell Disease Newborn Screening Follow-up Program in June 2017. With these funds, SCDAA is continuing its efforts to establish the national infrastructure to ensure that individuals diagnosed with sickle cell disease (SCD) receive appropriate care coordination and follow-up services including counseling, education materials and access to a medical home.

SCDAA has identified 16 community based organizations (CBOs) in fifteen states, to receive \$2,033,080, 70% of its 2017 HRSA grant award, to support them with the capacity to identify, educate and link patients to care in 15 states across America.

<b>COMMUNITY BASED ORGANIZATION GRANTEES</b>
<b>AL - SCDAA-Mobile Chapter</b>
<b>CA - Sickle Cell Disease Foundation of California</b>
<b>CA - Cayenne Wellness Center</b>
<b>GA – Sickle Cell Foundation of Georgia</b>
<b>IL – Sickle Cell Disease Association of Illinois</b>
<b>IN – Martin Center Sickle Cell Initiative</b>
<b>LA – Baton Rouge Sickle Cell Anemia Foundation</b>
<b>MI – Sickle Cell Disease Association of America, Michigan Chapter</b>
<b>NC – Piedmont Health Services and Sickle Cell Agency</b>
<b>NJ – The Sickle Cell Association of New Jersey</b>
<b>NY – Sickle Cell Thalassemia Patient Network</b>
<b>OH – Ohio Sickle Cell Health Association</b>
<b>OK – Supporters of Families with Sickle Cell Disease</b>
<b>PA – Children’s Sickle Cell Foundation</b>
<b>SC – James R. Clark Memorial Sickle Cell Foundation</b>
<b>TX – Sickle Cell Association of Texas-Marc Thomas Foundation</b>

SCDAA will achieve the following key objectives:

- Work with state CBO partners to provide care coordination, medical home assistance, education and other services to at least 15,000 non-active patients
- Recruit, train and retain at least 150 Community Health Workers (CHWs) via a proprietary curriculum developed by SCDAA
- Provide technical assistance to CBOs to conduct outreach to individuals with SCD
- Develop partnerships with providers and share resources to promote individuals and families as partners in care

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- Develop, disseminate and ensure application of core competencies for CHWs in SCD
- Establish and maintain a publicly available online repository of sickle cell-related evidence based materials, articles and other resources for use by children and adults with SCD, families and the SCD community
- Develop partnerships with stakeholders from the public and private sectors to address emerging issues related to sickle cell disease and sickle cell trait

“As the nation’s largest and oldest member-based sickle cell advocacy organization, SCDAA is well-positioned to execute the Sickle Cell Disease Newborn Screening Follow-up Program, and we are so grateful for the opportunity to continue to support CBOs across the country in increasing access to care while building a larger community of informed, active and motivated patients,” said SCDAA President Sonja L. Banks.

As a current grantee and the lead organization for HRSA’s Sickle Cell Disease Newborn Screening Program, SCDAA has served as the National Backbone Organization for HRSA, working with CBOs across the country to implement a strengthened approach to access quality care, quality care improvement and strategic activities within the sickle cell community. Over the past 2 years, SCDAA accomplished the following:

- Enhanced the capacity of 26 member and non-member CBOs, covering 19 states by providing administrative and infrastructure support
- Launched its National SCD Community Health Workers Training Program (based on a proprietary curriculum) and trained more than 85 CHWs that have reached more than 13,000 patients and assessed over 8,000 individuals in need of either a medical home or Hydroxyurea education
- Developed and launched a Shared Management System to collect and analyze patient data for HRSA and to report data outcome measures

#### **About the Health Resources and Services Administration**

The Health Resources and Services Administration (HRSA) is part of the U.S. Department of Health and Human Services. HRSA is the primary Federal agency responsible for improving access to health care services for people who are uninsured, isolated, or medically vulnerable. For more information about HRSA and its programs, visit [www.hrsa.gov](http://www.hrsa.gov).

#### **About Sickle Cell Disease Association of America**

SCDAA is a national nonprofit with the mission 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 people in the world with sickle cell disease. SCDAA serves as the nation’s only nonprofit organization working full-time on a national level to resolve issues surrounding sickle cell disease and trait. For more information about SCDAA, please visit [www.sicklecelldisease.org](http://www.sicklecelldisease.org).