

**Project Title:** The Sickle Cell Disease Association of America, Newborn Screening Follow-up Program (SCDAA-SCDNBSFP).

**Applicant Organization Name:** Sickle Cell Disease Association of America, Inc. (SCDAA)

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**Grant Program Funds Requested:** \$2,904,400

**Overview:** As the premier SCD advocacy organization and current grantee for HRSA's Sickle Cell Disease Newborn Screening Program, SCDAA is well positioned to successfully implement the Newborn Screening Follow up Program and ensure access to care for individuals with sickle cell disease (SCD). **Needs to be addressed:** SCD is a complex inherited multisystem medical condition with devastating and debilitating consequences leading to impairment of quality of life and a shortened lifespan. This proposal will ensure individuals with SCD identified through newborn screening will receive appropriate follow-up services including counseling, education and access to a medical home. **Proposed services:** SCDAA is a national organization founded in 1971 comprised of 42 community-based member organizations working to increase SCD awareness, lead disease-related advocacy initiatives, and provide education, counseling and other support services to individuals with SCD in their communities. Under the proposed program, SCDAA will competitively select and equip community based organizations (CBOs) in at least **15 states** to implement project activities. These organizations, working in collaboration with SCDAA will build a wide network of CBOs, state screening programs, local public health departments, primary health care providers, federally qualified health centers, family organizations to ensure that persons diagnosed with SCD are linked to care and remain attached to a medical home. SCDAA will recruit, and train at least 150 community health workers (CHW) to provide care coordination and follow up services to persons living with SCD. SCDAA will work CBOs to develop and disseminate best practices and maintain a resource repository with national reach. SCDAA's approach also will include the following innovations: 1. Peer to peer mentoring using the InquisitHealth Mentor 1to1 model, a successful model that has worked well with other patients living with chronic diseases. The program will pair patients and families that are struggling to stay in care or have never been linked to care with a patient/family that has been successful in care; 2. Excellence in patient engagement. Through a PCORI-sponsored project and other projects, SCDAA engages patients and their families in research, advocacy and encourages them to be partners in care; 3. Public-Private partnerships that will include collaborations with the pharmaceutical industry and other private organizations in the served communities. SCDAA is pleased to announce that Pfizer already has committed \$250,000 to supplement CHW salaries. SCDAA also already has partnerships with a total of 12 pharma companies; 4. Ongoing tele-mentoring of CHWs that will eliminate isolation and ensure that they are supported throughout and beyond the duration of this grant. **Population to be served:** This proposal will serve at least 15,000 individuals with SCD across the country, with special focus on individuals identified via newborn screening, young adults transitioning to adult care, and individuals in underserved communities. Additionally, we will work with at least 1 CBO in each of the HRSA Sickle Cell Disease Treatment and Demonstration Project regions (TBD).