**SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC.**
**SICKLE CELL DISEASE NEWBORN SCREENING FOLLOW-UP PROGRAM**
Grant No.: SCDAA-NBS2020
REQUEST FOR PROPOSAL
Released: September 14, 2020
Application Deadline: October 9, 2020 11:59 pm (EDT)

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# I. PROGRAM FUNDING OPPORTUNITY DESCRIPTION
## 1. Purpose

This announcement solicits applications for the Sickle Cell Disease Newborn Screening Follow-Up Program (SCDNBSFP) to work with the Sickle Cell Disease Association of America, Inc. (SCDAA). Since 2018, SCDAA has collaborated with 16 community based organizations (CBOs) to improve care and reduce rates of individuals with sickle cell disease (SCD) who are "lost to follow-up". SCDAA serves as the National Coordinating Center to provide technical assistance to these CBOs. SCDAA seeks to provide funding to incoming CBOs or existing sub-grantees in order to achieve the goals of this program.

## 2. Program Goal

The goal of this program is to ensure that individuals diagnosed with SCD receive appropriate follow-up services including counseling, education, access to a medical home, and other services by supporting CBOs focused on SCD.

The primary population focus is families of individuals identified with SCD through newborn screening; however, all individuals with SCD will be included.

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Additional information about this program is available here:
https://sicklecelldisease.net/grant-project/

### 3. Award Details

Four awards are available; each award is $25,000. Funds must be spent by May 31, 2021.

### 4. Program Duration

CBOs selected through this funding opportunity will begin November 1, 2020. Funds must be spent by May 31, 2021. Program data should be reported to SCDAA by July 5, 2021.

## II. ELIGIBILITY INFORMATION

### 1. DEFINITIONS

A **Sickle Cell CBO** is a 501 (c) (3) non-medical community-based organization or a 501c3 nonprofit organization whose primary purpose is serving individuals with SCD and their families through providing direct, support, and advocacy services. A successful sickle cell CBO (1) provides health education and health promotion in a community setting using evidence-based information for SCD and related issues; (2) develops partnerships with families and related organizations to ensure that families are empowered as partners in their care; (3) assists families with obtaining educational and social support services; (4) assists with transition services; and (5) engages in activities that help ensure patients have access to services, including a medical home.

A **Community Health Worker (CHW)** is a lay health worker who is a trusted member of the community they serve and often belongs to the community served. This enables CHWs to serve as a link between health and social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. CHWs build individual and community capacity by increasing knowledge and self-sufficiency through outreach, community education, informal counseling, social support and advocacy.

In this program, a sickle cell CHW is an individual who has successfully completed a CHW training program and has completed additional training in SCD. Additionally, each CHW must meet the following criteria:

- o Must be 18 years or older,
- o Have a high school diploma, equivalent or higher,
- o Pass a health and drug test,
- o Pass a satisfactory background investigation
- o Have a valid driver's license and transportation and
- o Community advocate experience.

## 2. CBO ELIGIBILITY REQUIREMENTS

- o Organization must have corporate paperwork to include Letter of 501(c) (3) status from the Internal Revenue Service.
- o Must be in operation and providing services a minimum of five (5) years before submitting this application.
- o Organization must possess history of providing at least three (3) of the following service programs: 1. public or professional education, 2. health care screening, care coordination and/or counseling, referrals and follow-ups for screening and/or counseling, 3. client support services, referrals for client services, and 4. state advocacy and awareness of SCD health care and research.
- o Must demonstrate history of annual external financial audits or willingness to have baseline financial organizational audits to insure fiscal integrity.
- o Must be in compliance with all past SCDAA - HRSA financial policies and processes
- o Meet and adhere to national non-profit standards (*see CBO standards attachment*)
- o A physical office open to the public when COVID-19 restrictions are not in place for at least 30 hours per week. With existing COVID-19 restrictions, measures in place for prompt communication with the public for at least 30 hours per week
- o A physical office address and location to provide one on one service coordination
- o A telephone number dedicated to the organization, and listed in the telephone directory in all communities where services are offered and funds are solicited
- o Ability to communicate via the internet

## 3. PROGRAM REQUIREMENTS

CBOs will be expected to implement the following activities:

**Patient Recruitment & Assessment**
1. Recruit individuals living with sickle cell disease. A recruitment goal will be determined based on organizational capacity, state SCD population, and ability to create partnerships;
2. Identify and assess individuals living with SCD for a medical home and care coordination services and link them to care;
3. Increase the number of individuals with SCD in rural and other underserved areas who are provided care coordination by strategically providing outreach to those areas;
4. Implement non-traditional recruitment strategies and use community gate keepers and leaders to distribute and disseminate information on SCD to identify children and adults with SCD in need of services;
5. Document partnerships and patient recruitment data monthly in SCDAA's data capturing service, REDCap.

**Utilization of Community Health Workers and Educator Counselors**

1. Employ and utilize a minimum of two community health workers who must be

HIPAA-certified and trained through an approved CHW training program that includes both academic skills and field instruction;
2. Sustain CHWs to assist individuals and families with SCD with access to programs and services, health education, patient and family-centered medical home, and health care transition;
3. Describe and maintain general and SCD-specific care coordinator services of your CHW;
4. Use CHWs to plan and implement patient education program to support patient compliance and management and conduct SCD public awareness events (including virtual events).

**Community Based Services & Care Coordination**
1. Increase the number of health care visits and compliance with care guidelines among patients with SCD;
2. Connect and expand the number of adolescents and young adults seen by an adult SCD care team within a year of transitioning;
3. Provide access to programs for patients and families to include linking and supporting SCD patients and their families when engaging the education system and social support systems;
4. Promote individuals reached and served as partners in care and empower patients to become advocates of their own health;
5. Identify transition-aged individuals in need of this program to participate in a peer-to-peer mentor program.

**Education and Dissemination**
1. Provide education to families of newly diagnosed individuals with SCD identified through universal newborn screening programs;
2. When possible, work with the HRSA-17-078 Sickle Cell Disease Treatment Demonstration Program recipients to develop and disseminate educational information;
3. Utilize the national patient adherence, education & follow up program for newly identified patients entitled: "Care Coordination: Empowering Families"; once training has been provided;
4. Implement workshops, education sessions, and other programs to enhance awareness in the SCD community about the effectiveness of hydroxyurea;
5. Utilize a toolkit which includes a pre-test/post-test for hydroxyurea education sessions.

**Partnership Building**
*Due to the ongoing COVID-19 pandemic, sub-grantees will be required to meet 2 of the following requirements:*
1. Attempt to build and/or engage a minimum of 2 new partnerships per month while maintaining relationships with previous contacts to advance SCD patients' provider network;
2. Build partnerships with hospitals and health systems to facilitate referrals and access to family-centered medical homes;

3. Build partnerships with family organizations to support family leadership trainings, including partnerships with MCHB funded programs such as the Family-to-Family Health Information Centers;
4. Build partnerships with state government agencies, such as the State Newborn Screening Program and State Medicaid agencies to help facilitate and sustain activities;
5. Create and sustain new partnerships and maintain current partnerships with local and state public health departments, state newborn screening programs, community health centers, clinics and other institutions.

**Data Collection**
1. Implement data collection strategy to collect, track and analyze data to measure process and  impact/outcomes;
2. Ensure that accurate and honest collection remains consistent and measurable;
3. Report data outcomes as a component of project reporting;
4. Adhere to data reporting schedule as determined by Project Director;
5. Inform SCDAA of factors that may have affected data collection or reporting.


## III.  APPLICATION AND SUBMISSION INFORMATION
### 1.  Application Content
#### i.  Project Abstract

Provide a summary of the application. The project abstract must be single-spaced and limited to one page in length. Place the following at the top of the abstract:
o  Project Title
o  Applicant Organization Name
o  Address
o  Project Director's Name
o  Contact Phone Numbers (Voice, Fax)
o  Email Address
o  Website Address, if applicable

#### ii.  Project Narrative

Include the following section headers for the Narrative:

o  **Needs Assessment**
   Outline the needs of the sickle cell community in your state.  Briefly include:
   o  Population of newborns and children with sickle cell disease and sickle cell  trait identified through newborn screening
   o  Unmet health needs regarding  community-based follow-up services available across the lifespan. You should also  describe the extent to which patients have access to coordinated, integrated care  in the context of a medical home model.
   o  Disparities based on race, ethnicity, gender identity, sexual  orientation, geography, socioeconomic status, disability status, primary language,

health literacy, and other relevant dimensions should be considered.
- o Relevant discussions of people with disabilities; non-English speaking populations; lesbian, gay, bisexual, and transgender populations; people with limited health literacy; or populations that may otherwise be overlooked when identifying the target population.

Please discuss any relevant barriers in the service area that the project hopes to overcome.

- o **Organizational Information**
Provide information on the CBO's mission, structure, and scope of activities and describe how these contribute to the ability of the CBO to conduct the program requirements and meet program expectations. Provide information on the program's resources and capabilities to support provision of culturally and linguistically competent health literacy services. Describe how the unique needs of target populations of the communities served are routinely assessed and improved.

Provide a description of the organizational structure, the decision-making process and approaches that will be employed to work cooperatively with the CBOs and other partners and stakeholders.

- o **Methodology**
Propose methods that will be used to address the stated activities. Be sure to describe:
  - Activities used to achieve each project requirement
  - Development of effective tools and strategies for ongoing staff training, outreach, collaborations, clear communication, and information sharing/dissemination with efforts to involve patients, families and communities of culturally, linguistically, socio-economically and geographically diverse backgrounds if applicable.

  [Current sub-grantees: Describe how additional funding will enhance or change your current methods]

- o **Data Collection Capacity**
This project utilizes REDCap, an online data collection platform, to capture client-level data and CBO-level progress towards meeting objectives.

Describe how your organization has collected, analyzed, and tracked data in the past, including data on providing services to individual clients. Describe current experience, skills, and knowledge in data entry and tracking. If selected, CBOs will report on services included but not limited to:

  - o Number of people served through care coordination
  - o Number of people provided supportive services
  - o Types of services provided
  - o Number and types of partnerships

Data will be collected continuously and should be provided to SCDAA monthly.

[Current sub-grantees: Describe process for collecting, analyzing, and tracking program data. Include any changes you will make with additional funding.]

- o **Resolution of Challenges**
  Discuss challenges you are likely to encounter in designing and implementing activities and approaches that will be used to resolve challenges.

- o **Sustainability Plan**
  Describe how key program elements which have been effective will be sustained after federal funding ends.

iii. **Budget**
Please use the SCDAA budget template that was shared with this RFP. The project budget should include the total allowable costs (inclusive of direct **and** indirect costs) incurred by the recipient to carry out this project or activity from November 1, 2020 to May 31, 2021. Include sufficient detail in this budget so that SCDAA can understand the expense.

[Current sub-grantees: Submit a revised Year 4 budget that shows how an additional funds will be allocated.]

iv. **Work Plan**
Use the SCDAA work plan template to outline the activities you will undertake to meet the stated objectives. Each of the program requirements listed above is included in the work plan. For each requirement, list between 1 to 4 activities that will be undertaken. Include a short description of the activity, the time period for the activity, the outcome, and the people who will be responsible.

In addition to the activities, please include a SMART objective for each of the 6 topic areas. A SMART objective is Specific, Measurable, Achievable, Realistic, and Time-phased. Additional information is provided in the "Instructions" tab of the work plan template.

[Current sub-grantees: Submit a revised Year 4 work plan that shows how additional funds will impact planned activities.]

v. **Attachments**

Attachment 1: Staffing Plan
Include the role, responsibilities, and qualifications of proposed project staff.

Attachment 2: Project Organizational Chart
Provide a one-page figure that depicts the organizational structure of the project.

Other Relevant Documents
Include any relevant documents, including letters of support. Letters of support must be dated and specifically indicate a commitment to the project/program (in-

kind services, dollars, staff, space,  equipment, etc.).

2.  **Dun and Bradstreet Data Universal Numbering System (DUNS) Number and  System for Award Management**

    You must obtain a valid DUNS number, also known as the Unique Entity Identifier, for  your organization/agency and provide that number in the application.  You must also  register with the System for Award Management (SAM) and continue to maintain active  SAM registration with current information at all times during an active federal award or  an application or plan under consideration by an agency (unless you are an individual or  federal agency that is exempted from those requirements under 2 CFR § 25.110(b) or  (c), or has an exception approved by the agency under 2 CFR § 25.110(d))**. Applicants that fail to allow ample time to complete registration with SAM will not be eligible for a deadline extension or waiver of the electronic  submission requirement.**

3. **Application Due Date**
   The due date for applications under this RFP is *October 9, 2020 at 11:59 P.M. Eastern Standard Time.* Applications submitted after this deadline will not be considered.

   Each completed application should be emailed to Ashley Clark at aclark@sicklecelldisease.org  with four document attachments. These attachments should be titled:  Narrative, Budget, Work Plan, and Attachments.

6.  **Technical Assistance Call**
    A technical assistance webinar will be held Friday, September 18, 2020 at 2:00 pm (EDT). Email Arielle Juberg at ajuberg@sicklecelldisease.org to receive a link to the Zoom webinar.

    For more information or questions, please contact Ashley Clark at aclark@sicklecelldisease.org

7.  **Narrative and Attachment Formatting Guidelines**

    i.   **Font**
         Please use an easily readable font, such as Times Roman, Arial, Courier, or CG Times. The text and table portions of the application must be single-spaced and submitted in 12-point font. Applications not adhering to 12-point font requirements may be deemed non-responsive and returned. For charts, graphs, footnotes, and budget tables, you may use a different point or size font but not less than 10 point or size font. It is vital that the charts are legible when scanned or reproduced.

    ii.  **Paper Size and Margins**

For duplication and scanning purposes, ensure that the application can be printed on 8½" x 11" white paper. Margins must be at least one inch at the top, bottom, left and right of the paper. Left-align text.

**iii. Page Limit**
Completed applications shall be *no more* than 15 pages. Applications can be fewer than 15 pages. The Budget, Work Plan, and Attachments will not be counted in this limit.

**iv. Names**
Include the name of the applicant and 12-digit grant number on each page as a footer.  All attachments should be labeled (in footer) as attachment name given in RFP.

**v. Section Headings**
Put all section headings flush left in bold type.

**vi. Page Numbering**
Please include page numbers in the Project Narrative and Attachments. Do not number any standard SCDAA designated forms (Budget & Work Plan). Number each attachment page sequentially. Reset the numbering for each attachment. (Treat each attachment/document as a separate section.)

**vii. Allowable Attachment or Document Types**
Unless otherwise noted, please do not submit organizational brochures or other promotional materials, slides, films, clips, etc. The attachment types listed below are supported by SCDAA.   Files with unrecognizable extensions may not be accepted or may be corrupted, and will not be considered as part of the application. When the application is printed by SCDAA, documents should print as you have formatted them. If using Excel or other spreadsheet documents, be aware that reviewers will only see information that is set in the "Print Area" of the document.

File Attachment Types (acceptable by SCDAA):
  o  .PDF - Adobe Portable Document Format
  o  .XLS/.XLSX - Microsoft Excel

Each completed application should be emailed with four document attachments. These attachments should be titled:  Narrative, Budget, Work Plan, and Attachments.

All attachments should be numbered as directed in formatting guidelines and scanned as one PDF document.  You may attach these files as Zip files should there be a need to compress due to file size.

| Document Title | Include in designated file | Count in 15-page limit | Must be numbered |
|---|---|---|---|
|  |  |  |  |
| Abstract | Narrative | Yes | No |
| Narrative | Narrative | Yes | Yes |
| Budget | Budget | No | No |
| Work Plan | Work Plan | No | No |
| Attachments | Attachments | No | Yes |

## IV. **APPLICATION REVIEW INFORMATION**

Applications will be scored according to the following criteria:

- **Clarity of plan** (0-5 points)
  Does the applicant have a clearly articulated plan? Is the plan reasonable?

- **Demonstrated need** (0-10 points)
  Does the applicant's community have a significant burden or risk factors associated with the SCDAA focus areas? Or are there disparities within the community or specific subpopulations at greater risk? Is there a gap in services or messaging?

- **Data Collection Capacity** (0-10 points)
  Does the applicant describe their experience with data entry and tracking? Does the applicant describe how they will comply with data collection and reporting requirements?

- **Work Plan** (0-10 points)
  Did the applicant include a clear and concise work plan? Does this document describe how the applicant will carry out activities and meet objectives for the project period?

- **Budget** (0-5 points)
  The reasonableness of the proposed budget in relation to the objectives, the complexity of the research activities, and the anticipated results. The extent to which costs, as outlined in the budget and required resources sections, are reasonable given the scope of work. The extent to which key personnel have adequate time devoted to the project to achieve project objectives

- o **Potential impact** (0-5 points)
  What is the potential impact or local significance of this project? Does the applicant clearly articulate what outcomes will be achieved? Will the project affect a substantial or influential portion of the community? Will it help to influence or catalyze the development of policy, partnerships, funding, or services?

- o **Innovative Approach** (0-5 points)
  Does the applicant's project innovatively capture the intended audience? Does the program uniquely tackle SCD disparities that remain sustainable beyond grant funding?

The four applicants with the highest cumulative scores will be awarded funds.


## V.   Frequently Asked Questions

Q: What is the schedule for reviewing applications?
A: Applications must be submitted by October 9, 2020. SCDAA will review applications based on the criteria above and decide by the week of October 25. Funding will begin on November 1, 2020. Newly-funded CBOs who are selected should plan to have onboarding calls and webinars the week of November 1, 2020.

Q: What will happen after federal funding ends?
A: This federal grant will continue until May 31, 2021. A new iteration of the Sickle Cell Disease Newborn Screening Follow-Up Program was recently announced by the Health Resources and Services Administration (HRSA). The funding forecast is available here:
https://www.grants.gov/web/grants/view-opportunity.html?oppId=328460
SCDAA does not have any more information than what is included in the forecast. SCDAA has been sharing resources to assist CBOs in sustaining successful grant activities. Newly-funded CBOs would also receive these resources.

Q: Do I need to be an SCDAA member organizations?
A: No, CBOs are not required to be an SCDAA member organization.

Q: If I am already funded as part of the SCD Newborn Screening Follow-Up Program, can I apply for additional funding?
A: Yes. Current sub-grantees can apply to be considered for additional funding. Please refer to specific instructions for current sub-grantees in the Application and Submission Information section.

Q: How will CBOs receive funding?
A: Funding is provided on a reimbursement basis. CBOs will spend funds on allowable costs and be reimbursed by the 15th of the following month. Receiving reimbursement is contingent on submitting documentation of expenses each month.