Sickle Cell Disease Newborn Screening Follow-Up Program

Notice of Funding Opportunity
HRSA-21-036
Technical Assistance Webinar
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Genetic Services Branch
Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People

Housekeeping items

- **Download today's presentation**

- **Mute your phones**

- **Program website: https://www.hrsa.gov/grants/find-funding/hrsa-21-036**

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How to access the NOFO

- **Grants.gov**
  - **Search "HRSA-21-036" or "Sickle Cell"**
  - **Select Sickle Cell Disease Newborn Screening Follow-Up Program**
  - **Click on Package**
  - **Click on Preview**
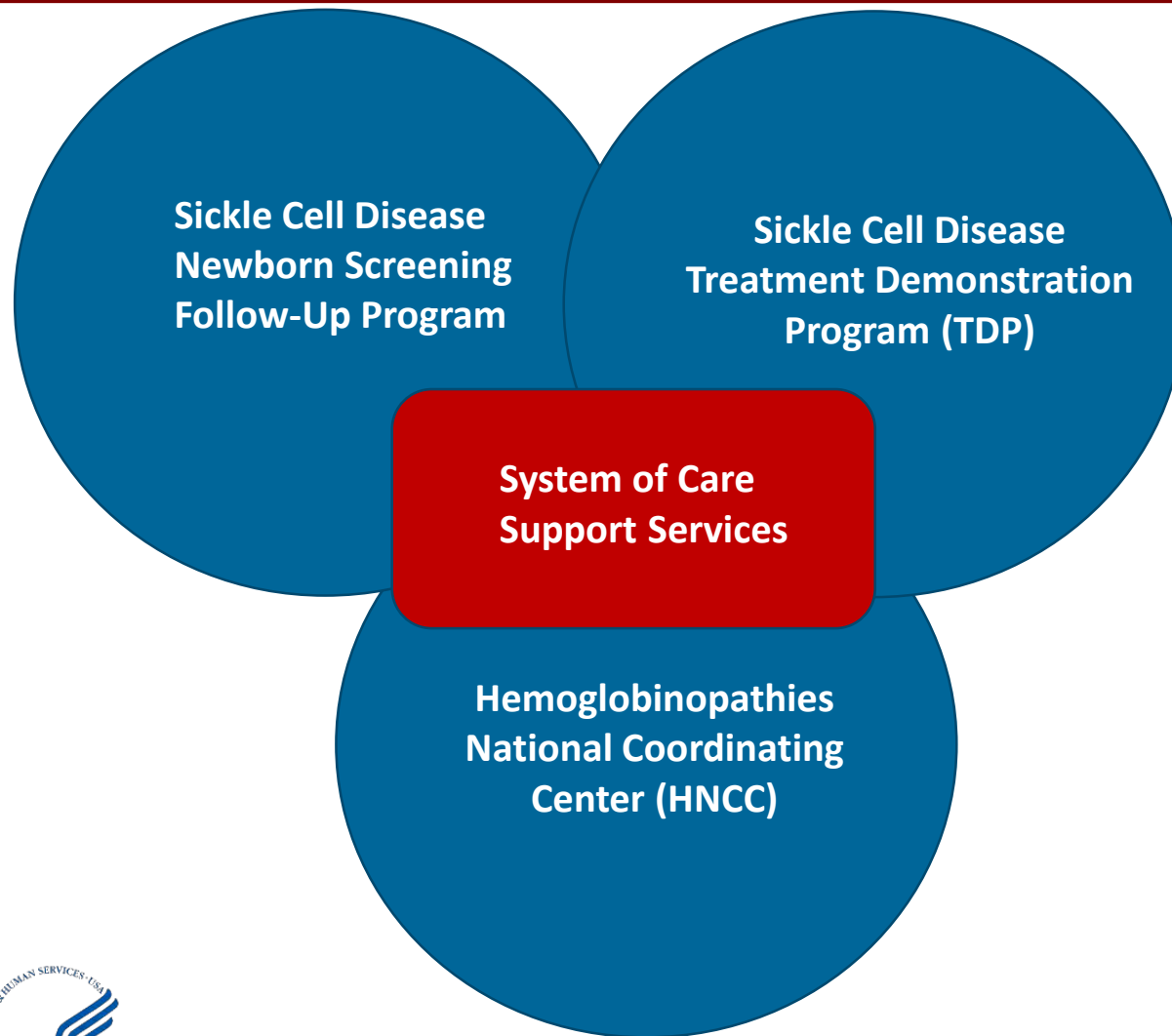 - **Download Instructions**

Application Guide

HRSA SF-424 Application Guide

- **General information about the application process**

- **Registering in grants.gov and using Workspace**

- **Budget forms**

- **Formatting guidelines**

- **Website: HRSA SF-424 Application Guide**

HRSA Support for Sickle Cell Disease (SCD)

Sickle Cell Disease Newborn Screening Follow-Up Program

Sickle Cell Disease Treatment Demonstration Program (TDP)

System of Care Support Services

Hemoglobinopathies National Coordinating Center (HNCC)

Strengthen System of Care and Support:

- **Educating patients, families, and clinicians**
- **Linking individuals and families to evidence-based care**
- **Partnerships between clinicians, community organizations, and other stakeholders**

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Program Purpose

Purpose: Facilitate access to quality SCD care by:

1. Conducting outreach and working with individuals/families with SCD through diagnosis, treatment, and follow-up.

2. Educating families and providers

3. Disseminating resources

4. Collaborating with state newborn screening programs

5. Linking individuals/families to community resources, evidence-based care, and care coordination within the communities where they reside.

Program Goal

Goal: Improve health outcomes for individuals living with Sickle Cell Disease (SCD).

- Develop statewide and regional networks of SCD support services

- **Leverage the expertise of community-based organizations (CBOs) and community health workers (CHWs).**

Goal (Cont.)

Successful applicants:

- Provide health education and health promotion

- Develop partnerships with family organizations

- <u>Assist families with educational and social support services</u>

- Assist with transition services; and

- Help ensure individuals with SCD have access to services

Program Overview

- **Application due date:** **April 29, 2021**
- **Number of awards**
  - Fund up to 20 recipients in 20 different states
  - Provide up to 4 awards to support each of the 5 regions (See pg. 2 of the NOFO)
- **Funding per award**
  - Up to **$184,000 per year**
- **Total investment**
  - Approximately $3,680,000 per year
- **Period of Performance: September 1, 2021 through August 31, 2026 (5 years)**
- **Type of award: Grants**
- **Projected start date: September 1, 2021**

Program Objectives

August 2022: Partnership with SCD TDP recipients in state/region

2026: 90% of individuals/families served receive care through medical home and a knowledgeable SCD health care professional

2026: Increase by 20% from baseline the number of individuals receiving services from recipient

2026: Reduce by 30% the number of individuals/families served by recipient reporting unmet needs

Program Focus (NOFO, P. 4)

1. Strengthening SCD CBOs

2. Strengthening collaboration between SCD CBOs and other CBOs

3. Strengthening collaboration with state newborn screening/public health programs

4. Increasing collaboration with TDP recipients

5. Collaborating with the HNCC to reach patients

6. Utilizing CHWs to conduct outreach

7. Engaging Communities of Practice with other Follow-Up Program CBOs

Program Focus (continued)

Program Goal – Successful recipients (pg. 1):

- Understand the needs of SCD families
- Access and link families to community-based services
- Staffed with professionals with experience in SCD

Program Specific Requirements (pgs. 7-8)

- **Deliver high-quality community-based services and education to individuals living with SCD and their families.**
- Establish statewide infrastructure of community-based services
- Collaborate with TDP recipients to make community based services accessible in state
- Develop formal and informal partnerships with TDP sites, state newborn screening programs, hospitals, etc.

Program Focus (continued)

Program Narrative (pg. 9)

- **Methodology**
  - Describe how you will engage with individuals living with SCD and families in all aspects of the project including planning, implementation and monitoring. (pg. 9)
- *Organizational Information*
  - Describe the SCD population that you currently serve and what services are provided being sure to describe how you engage with the SCD community, and how you provide linkages to community services. (pg. 12)
  - Describe your expertise in SCD and how your organization's staff consists of professionals with knowledge and experience in SCD, including individuals with SCD or their families. (pg. 12)

Review Criterion 2: Response (pg. 18)

- **Methodology**
  - Delivering high-quality community-based services and education to individuals living with SCD and their families.

Review Criterion 5: Resources/Capabilities (pg. 19)

- **Organizational Information**
  - Demonstrates appropriate experience in providing SCD care including having appropriate experts including individuals with SCD with knowledge of SCD and discusses how families are linked to community-based services.

Eligible Applicants

- **Domestic public or private entities, including Indian tribes or tribal organizations (as those terms are defined at 25 U.S.C. § 450b) are eligible to apply. See 42 CFR § 51a.3(a).**

- **Domestic faith based and community-based organizations are eligible to apply.**

❖**Applications that exceed the ceiling amount will not be considered for funding.**

❖**Multiple applications from an organization are not allowable.**

Program-Specific Instructions

Utilize CHWs and other community-based leaders/experts to:

- Identify infants diagnosed with SCD and refer them to appropriate care
- Identify individuals living with SCD lost to follow-up and provide services
- Assess transition readiness and help develop/implement transition plan
- Utilize existing/develop new educational resources

Collaborate with TDP recipients

- Patient service referrals and education (patient, health professionals, community)

Collaborate with TDP recipients to increase access to community-based services

- MOUs/MOAs with CBOs in state/region
- Use telehealth to link individuals and families with education and follow-up support

Program-Specific Instructions (Cont).

Develop partnerships to support community-based services

- **TDP sites**

- **State newborn screening programs**

Participate in HNCC activities

- **National committees and regional workgroups**

- **Identify individuals with SCD to serve on steering committee and workgroups**

- **Participate in annual Follow-Up Program/TDP meeting**

Develop a sustainability plan for the program

Project Narrative – Methodology

Describe:

- Plan to create a statewide infrastructure of SCD CBO services

- Plan to utilize CHWs and other community-based experts

- Number of individuals with SCD that will be served through project

- Plan for project sustainability

- Plan to disseminate reports, products, and/or project outputs

Evaluation Measures

- Number of individuals with SCD/families served and the types of services provided
- Number of individuals with SCD/families referred to a knowledgeable SCD health care professional
- Number of individuals with a medical home
- Number of individuals reporting they are satisfied with services received from recipient
- Number of families reporting unmet needs
- Number of youth ages 12-26 that discussed transition plan with provider using nationally recognized best practices
- Number of informal and formal partnerships developed
- Number of virtual and in-person education sessions held
- Number of individuals or families recruited for steering committees, advisory boards, or workgroups

Evaluation Measures (Cont.)

Recipients will work with HNCC and TDP recipients on two measures:

- **By 2026:** Infants identified with possible SCD have a primary care medical home within two months of age.

- **By 2026:** Infants with confirmed diagnosis of SCD will have been seen by knowledgeable SCD provider within two months of age.

Discretionary Grant Information System (DGIS) Measures

- **Carefully review the listing of administrative forms and performance measures for this program at [DGIS Performance Measures](#)**
  - **Core**
    - **Grant Impact**
    - **Quality Improvement**
    - **Health Equity**
  - **Capacity Building**
    - **Technical Assistance**
    - **Impact Measurement**
    - **Sustainability**
    - **Products**
  - **Children and Youth with Special Health Care Needs**
    - **Family Engagement**
    - **Transition to Adult Health Care**

Budget

- See Section 4.1.iv of HRSA's SF-424 Application Guide.
  - A budget that follows the Application Guide will ensure that you will have a well-organized plan.
  - Salary Limitation: $199,300.
- Reminder: The Total Project or Program Costs are the total allowable costs (inclusive of direct and indirect costs) incurred by the recipient to carry out a HRSA-supported project or activity.
- Submit a budget for each year of the period of performance

Review Criteria

- **Need (15 points)**

- **Response (40 points)**
  - **Methodology - 20**
  - **Work plan and Logic Model - 10**
  - **Resolution of Challenges - 10**

- **Evaluative Measures (10 points)**

- **Impact (10 points)**

- **Resources/Capabilities (15 points)**

- **Support Requested (10 points)**

How to Apply

- **Register in three different systems**
- **SF-424 Application Guide, pages 10-12**

System	Purpose	Website
Obtain a Data Universal Number System (DUNS)	Unique 9-digit number that identifies an organization; adopted by the Federal Government to track how grant money is distributed	http://fedgov.dnb.com/webform/
Register with System for Award Management (SAM)	Central repository for organizations doing business with the Federal Government; designate E-Biz POC	https://www.sam.gov
Create a Grants.gov Account	Apply for grants online	http://www.grants.gov/

Application Planning

Where should you begin?

- **Check registrations in DUNS, SAM, and grants.gov!**

- **Have you read the NOFO carefully and completely?**

- **Is your organization eligible to apply?**

- **Does your organization have the technical expertise, the personnel, and the financial capacity to implement the project?**

- **Are your stakeholders supportive?**

- **Is your organization prepared to implement the project within the proposed budget?**

https://www.hrsa.gov/grants/apply-for-a-grant/prepare-your-application

Tips for Writing a Strong Application

- **Goals and objectives**
  - **Define them clearly**
  - **Be specific**

- **Need**
  - **The need for the service or activity that the grant will support**
  - **Your organization's track record in fulfilling that need**

- **Response and impact**
  - **Show how you plan to achieve the program's purpose**
  - **Include supporting data whenever possible**

- **Resources and capabilities**
  - **Elaborate on your organization's knowledge, staffing, and fiscal stability**
  - **Explain how these items ensure you can carry out your proposal and meet the goals of the grant program**

- **Budget**
  - **A realistic plan that matches your goals and objectives**
  - **Include a narrative that justifies the costs**
  - **Must align with work plan**

Top Tips for Applying

1. Start preparing the application early.
2. Follow the instructions in the NOFO carefully.
3. Keep your audience in mind.
4. Be brief, concise, and clear.
5. Be organized and logical.
6. Show evidence of fiscal stability and sound fiscal management.
7. Attend to technical details.
8. Be careful when using attachments.
9. Proofread and review the application to ensure accuracy and completion.
10. Submit all information at the same time.

Submit Application in Grants.gov

SF-424 Application Guide, pages 12-15

Create, Complete, and Submit a Workspace Package in grants.gov
- **Sign and Submit**
- **Grants.gov Tracking Number**

❖ **HRSA suggests submitting applications to Grants.gov at least <u>three</u> calendar days before the deadline to allow for any unforeseen circumstances!**

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Questions and Answers

- **Use the chat box for questions**

- **Q+A's posted:**

https://www.hrsa.gov/grants/find-funding/hrsa-21-036

Questions and Answers

Q: What is the Hemoglobinopathies National Coordinating Center (HNCC)?

A: The HNCC will provide support to both the TDP and Follow-up recipients. It will be chosen through a contract.

Q: If my organization currently participates in CHW training, would I still have to participate in CHW training conducted by the HNCC.

A: Yes, the Follow-Up Program recipients are required to collaborate with the HNCC. Please see pgs. 7-12 of the NOFO for these required activities.

Questions and Answers

Q: Is an international non-profit organization working on tribal maternal and child projects related to sickle cell eligible to apply?

A: HRSA will only consider eligible applicants for this funding opportunity. As stated on the bottom of page i. and 5 of the Notice of Funding Opportunity (NOFO), eligible applicants include any domestic public or private entity, including an Indian tribe or tribal organization (as those terms are defined at 25 U.S.C. § 450b). See 42 CFR § 51a.3(a). Domestic faith based and community based organizations are eligible to apply.

Q: I am a clinician, can I apply for this program?

A: For the Follow-up program, we do not require that a clinician lead the project. As stated earlier, this program focuses on families and providing community based services. We welcome applications from any organization that believes they can implement the goals and purpose of the program. Specifically, see page 1 of the NOFO where the goal is described as well as a description of a successful recipient for this program. In addition, please see pgs. 7-12 for a description of activities that each recipient will be responsible for implementing and describing in their application.

If you are a clinician with expertise in SCD, you may be interested in the TDP Program. The TDP focuses on supporting clinicians. https://www.hrsa.gov/grants/find-funding/hrsa-21-032

Questions and Answers

Q: Will HRSA award 4 recipients in states across the 5 SCD TDP regions (ie. one in the Northeast, one in the Southeast, one in the Midwest, and one in the Pacific) and leave leave 16 awards remaining of the 20 that could be geographically dispersed among all TDP regions?

OR

Will HRSA award 4 recipients in states from all of the 5 SCD TDP regions (ie. four in the Northeast, four in the Southeast, four in the Midwest, four in the Heartland and Southwest, and four in the Pacific)?

A: HRSA intends to geographically disperse all of the awards for up to twenty recipients in this opportunity. That will include up to four recipients from four unique states per region, in all five of the SCD TDP regions. That means up to 4 recipients from unique states in Northeast, up to 4 recipients from unique states in Southeast, up to 4 recipients from unique states in Midwest, up to 4 recipients from unique states in Heartland and Southwest, and up to 4 recipients from unique states in the Pacific. This approach will help evenly distribute our funds throughout the regions.

Contact Information

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