

2023

Indiana Department of Health
Division of Children's Special Health Care Services
Division of Maternal and Child Health

Lifelong Sickle Cell Collaborative Services Grant

Request for Applications



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EXECUTIVE SUMMARY

The Indiana Department of Health (IDOH) Maternal and Child Health (MCH) Division’s Genomics & Newborn Screening (GNBS) Program and Children with Special Healthcare Services (CSHCS) Division is accepting applications from nonprofit organizations, local health departments, and other health care entities within the State of Indiana to implement programs focused on addressing the needs of citizens impacted by sickle cell disease (SCD) or trait.

The applicant organization is responsible for complying with instructions included in section V of this Request for Applications (RFA).

Funding Opportunity Title:	Lifelong Sickle Cell Collaborative Services Grant		
Due Dates for Applications:	May 26, 2023 @ 5pm		
Anticipated Total Available Funding:	Funding Source	Component & Population Age	Total Available Funding (per fiscal year)
	GNBS Program	Component A: ages 0-1	\$300,000
	CSHSC Division	Component B: ages 1-21	\$490,000
	CSHSC Division	Component C: ages 21+	\$260,000
Maximum Request Award Amount:	Applicant budget cannot exceed \$1,050,000 per year. Max budget requests must address needs of all ages throughout the lifespan.		
Estimated Number of Awards:	One award encompassing statewide service collaborations; or multiple awards targeting specific populations to ensure statewide comprehensive services throughout the lifespan		
Estimated Award Amount:	Varied based on population(s) served		
Cost Sharing/Match Required	No		
Project Period:	7/1/2023 – 6/30/2025		
Eligible Applicants:	Nonprofit organizations, local health departments, and health care entities within the State of Indiana		

I. FUNDING OPPORTUNITY DESCRIPTION

Purpose

This notice solicits applications. The purpose of this opportunity is to provide comprehensive services including medical, social, and educational services for individuals with Sickle Cell Disease (SCD) and trait across the lifespan. IDOH acknowledges the need to improve the statewide system of coordinated specialized hematology care, address the high rate of lost to follow-up cases, improve transition services from pediatric to adult care, expand education to primary care and emergency room providers, and other unaddressed needs and gaps that exist among the Hoosier sickle cell community. IDOH is committed to combining state funds to address the gaps identified across the lifespan in an effort to ensure all individuals are able to access and receive the best services for them. Through this opportunity, IDOH encourages the planning and implementation of creative solutions to address all barriers and needs that currently impact follow-up services, treatment plan adherence, subsequent care, social and emotional support services, and other services that promote optimal well-being.

To meet the intention of this grant, all services provided must be data-driven and/or evidence-based and focused on improving health outcomes, healthcare delivery, and care coordination for individuals with SCD and sickle cell trait.

Applicants may request funding for services provided to any, or all, of the three population age group components below:

Component A: Funding for population age 0 to 1 year

Since 2017, an annual average of 1,628 cases (including sickle cell disease, sickle cell trait, and other hemoglobinopathies) have been referred from the state-funded newborn screening laboratory to the state-funded hemoglobinopathy NBS Care Coordination Partner for further follow-up, confirmatory testing and other support services to promote optimal health outcomes and reduce the lost to follow-up rate for the identified infants and their families. This funding exists to coordinate confirmatory testing (as applicable) and coordinate care for all infants referred from the newborn screening laboratory, and ultimately improve efforts to address factors that have led to Indiana's high lost to follow-up rate within this community. The applicant must clearly demonstrate the capacity and capability to plan and implement initiatives that are geared toward identifying current gaps in follow-up and working to reduce these gaps to ensure a reduction in lost to follow-up cases. Successful applicants will provide a clear understanding of current gaps within the population served and a comprehensive plan for implementing programs and resources to address all identified barriers and will be required to:

1. Provide resources and care coordination services to families of infants identified with sickle cell trait, sickle cell disease, and other hemoglobinopathies identified through newborn screening.
 - a. Work collaboratively with NBS follow-up staff to ensure rapid identification of infants at risk of having sickle cell disease or trait.
 - b. Ensure individuals identified with SCD are being seen by a hematologist.
 - c. Provide education to families about sickle cell trait and/or disease.
 - d. Connect families to social, financial, transportation and other resources (First Steps) required to address identified barriers within the SCD and trait community.
 - e. Work collaboratively with primary care physicians and pediatricians to ensure diagnostic testing is performed after newborn screening when appropriate and a treatment plan is established.
 - f. Ensure access to appropriate prophylactic medication and promote its use for SCD patients aged 2 months and older to prevent infections.
2. Document and analyze lost to follow-up case data.
 - a. Strategize efforts to target specific barriers to follow-up and continuity of care.
3. Report all required patient-level information to IDOH within the specified timeframes.
 - a. Work collaboratively with all/any other awardees receiving funding for components A, B, and/or C to respond to additional gaps that may be identified through the reported data.

Note: Applicants may elect to include multiple partners who provide follow-up services for specific geographic catchment areas throughout the state, rather than demonstrating statewide follow-up performed by one organization. This opportunity strongly encourages the expansion of current collaborations in a way that is meaningful to the populations served.

Component B: Funding for population age 1-21 years will focus on improving lifespan outcomes, care coordination, health equity, education to the public, outreach services and/or improving long-term data collection related to SCD or trait.

1. Providing wraparound/care coordination services for individuals and families ages 1 and older.
2. Establishing ongoing communication and outreach to those with SCD and trait
3. Providing services to ensure individuals return for follow-up visits:
 - a. Refer individuals to appropriate mental health services.
 - b. Assist the family in fully understanding their child's diagnosis.
 - c. Help the family know where to go for each identified need.

- d. Guide the family to set goals related to their child and family needs.
 - e. Provide services to ensure individuals return for follow-up visits.
 - f. Address social determinants of health that affect the family.
 - g. Provide or refer to appropriate social services to decrease unmet needs.
 - h. Provide or refer to services to help support success of the individual in all areas of life including but not limited to school, work, etc.
4. Increase education and awareness of SCD and trait among health care providers.
 5. Develop programming to build awareness in communities of need, which includes information, knowledge about status, and education about resources for SCD and trait.
 6. Improve emergency room education and awareness of SCD, especially regarding sickle cell crisis or other pain episode management.

Component C: Funding for population age 21 years and older will focus on improving lifespan outcomes, care coordination, health equity, education to the public, outreach services and/or improving long-term data collection related to SCD or trait.

1. Providing wraparound/care coordination services for individuals and families ages 1 and older.
2. Establishing ongoing communication and outreach to those with SCD and trait
3. Providing services to ensure individuals return for follow-up visits:
 - a. Refer individuals to appropriate mental health services.
 - b. Assist the family in fully understanding their individual's diagnosis.
 - c. Help the individual know where to go for each identified need.
 - d. Guide the family to set goals related to their child and family needs.
 - e. Provide services to ensure individuals return for follow-up visits.
 - f. Address social determinants of health that affect the family.
 - g. Provide or refer to appropriate social services to decrease unmet needs.
 - h. Provide or refer to services to help support success of the individual in all areas of life including but not limited to school, work, etc.
4. Increase education and awareness of SCD and trait among health care providers.
5. Develop programming to build awareness in communities of need, which includes information, knowledge about status, and education about resources for SCD and trait.
6. Improve emergency room education and awareness of SCD, especially regarding sickle cell crisis or other pain episode management.

Successful applicants will demonstrate the following, and/or clearly define their partnerships with organizations who demonstrate the following:

- Be a nonprofit organization (as defined by the IRS Tax Determination), health department, hospital, or other health care related entity.
- Collaborate with traditional and non-traditional agencies or organizations.
- Serve the identified populations within Indiana.
- Have an established clinic, specialty clinic, or other healthcare facility that can provide care coordination for newborns with abnormal/presumptive positive newborn screen results.
- Have adequate staff capacity that can take on the workload of newborn screening patients and additional patients with sickle cell disease or trait not identified through Indiana newborn screening.
- Have a designated staff member as the primary contact for required patient reporting and communication with GNBS and CSHCS.
- Ensure a direct connection or collaboration with pediatric and/or adult hematologist to ensure successful care coordination.
- Establish and maintain a collaborative relationship with all awardees, CSHCS division, GNBS program, and the NBS lab.
- Comply with financial requirements as listed in the *Limit on Use of Funds* section.

Additional evaluation weight will be assigned to applicants demonstrating the ability to:

- Promote collaboration across multiple systems of care to enable statewide services throughout the lifespan.
- Provide services in resource-limited counties.
- Address the social determinants of health of citizens impacted by SCD or trait.

Background

Limit on Use of Funds

For purposes of this RFA,

Recipient expenditures necessary to perform the activities and achieve the goals of this grant could include:

- Salary/wages of staff-time dedicated to this program.
- Educational events and materials
- Travel spent for home visits or other clinic outreach visits.

Recipient expenditures may not include:

- Costs for in-hospital patient care
- Direct expenses for patient medical intervention/treatment, this funding is not intended as a supplemental coverage for medical care (exceptions may be made for approved prophylactic treatments with proven success of minimizing adverse

health implications that directly result from a condition on Indiana’s newborn screening panel).

- Construction of buildings, existing building renovations
- Contributions, gifts, donations
- Entertainment and/or food
- Automobile purchase
- Bad debts and/or interest
- Overhead costs such as internet, electric, utilities, etc.
- Fines and penalties
- Accounting expenses
- Contingency funds
- Executive expenses such as car rental and unrelated travel expenses
- Fundraising expenses
- Legal fees
- Legislative lobbying
- Equipment
- Dues to societies, organizations, or federations
- Incentives

Recipients must use reasonable efforts to ascertain expenditures in accordance with program activities and expectations, to document their findings in this regard, to invoice monthly through the established agency process, and to maintain records that demonstrate such expenses.

II. AWARD INFORMATION

Type of Application and Award

Type(s) of applications sought: New Grant Award

Summary of Funding

The Indiana Department of Health (IDOH) expects to award up to \$1,050,000 per fiscal year. Of this \$1,050,000, the GNBS program will provide \$300,000 and CSHCS division will provide \$750,000. The program period of performance is 7/1/2023-6/30/2025. Funding is dependent on exemplary recipient application. IDOH will communicate decision to fund via email.

III. ELIGIBILITY INFORMATION

Eligible Applicants

Eligible applicants include established genetic clinics, specialty clinics, or other healthcare facilities in Indiana.

IV. SUMMARY OF TIMELINE

Event:	Date:
Posting of Request for Applications	March 31, 2023
Deadline to Submit Written Questions	April 7, 2023 @ 5pm ET
Response to Written Questions	April 14, 2023
Optional Technical Assistance Call	April 19, 2023 @ 4pm
Application Due Date	May 26, 2023 @ 5pm ET
Award Announcements	June 2, 2023

V. APPLICATION AND SUBMISSION INFORMATION

Submission of Questions

To ensure fair and equitable consideration to all applicants, questions about the requirements or the application process must be submitted in writing via email.

SUBMIT QUESTIONS VIA EMAIL TO: Madeline Wilks at mwilks@health.in.gov

EMAIL SUBJECT LINE: Lifelong Sickle Cell Collaborative Services Grant RFA Question

Applicants are encouraged to submit questions by the designated due date of **5p.m. Eastern Time on April 7, 2023**. The questions will be compiled into a single document that will be posted online for all applicants and will provide answers to the proposed questions by April 14, 2023.

Submission of Applications

To be considered for this competitive funding, a completed application must be received by IDOH **NO LATER THAN May 26, 2023, at 5pm Eastern**.

SUBMIT APPLICATIONS VIA EMAIL TO: NewbornScreening@health.in.gov

EMAIL SUBJECT LINE: Lifelong Sickle Cell Collaborative Services Grant Application

Application Page Format and Limitations

The application narrative may not exceed 25 pages. All application documents should be formatted with **one-inch margins, single spaced, 12-point font, including page numbers, submitted as a single PDF document.** Applications that exceed the page limit will be considered non-responsive and will not be entered into the review process. The budget will be a separate Excel file and all other required documents should be contained within a single PDF. Any budget exceeding the maximum requested award amount of \$1,050,000 will not be entered into the review process. The work plan, budget and **other required documents are not included in the 25-page limit.** All required section headings are listed below. Please do not alter the format of the document.

Applications must be complete, within the specified page limit, and submitted prior to the deadline to be considered under this notice.

Application Cover Page

Information requested on the cover page includes:

- Funding request
- Organization's name, address, phone, fax, and email
- AOS Vendor ID
- IDOA Bidder ID
- Tax ID/EIN of the organization
- DUNS Number
- Additional clinic site information
- Program Contact name, title, address, email, phone, fax, and signature (electronic is acceptable)
- Signatory name, title, email, phone, signature (electronic is acceptable)

A template Application Cover Page is provided.

Application Narrative

The application narrative provides a comprehensive description of the organization's program and approach. It should be succinct, self-explanatory, and well organized so that reviewers can understand your organization's ability and means to fulfill the program goals.

Successful applications will contain all sections, section headers and bulleted requirements below.

Section 1: INTRODUCTION & SUMMARY OF REQUEST

In this section:

1. Briefly describe the purpose of the requested funding, which populations will be served (components A, B and/or C) and how it will serve the identified population(s).
2. Provide a high-level description of population-specific needs, proposed solutions and total requested funding amount.

Section 2: STATEMENT OF NEED

In this section:

1. Describe population-specific challenges that reduce the ability of Hoosiers with SCD and trait to reach their health potential. Identified challenges must include social determinants of health, health disparities and/or promotion of health equity.
2. Describe the specific problem(s) or need(s) for each specific age group that will be addressed by the project. Evidence may include current data, research, local surveys, reports from the local Health Department or United Way, and must include data available from the IDOH website.
3. All problems identified should:
 - Clearly relate to the purpose of the applicant agency.
 - Include only those problems that the applicant can impact.
 - Be supported by data available on the IDOH website and/or from local sources (this evidence must show that the problem(s) or need(s) exist(s) in the community you are proposing to impact.
 - Describe the target population(s) and numbers to be served within each age group.
 - Describe the system of care and how successfully the project fits into the system.
 - Describe barriers to access to care and how those barriers will be addressed.
 - Address disparities if the county has significant minority populations and how the disparities will be addressed.

Section 3: METHODS AND APPROACH

1. In this section, the following must be included by all applicants, regardless of components requested:
 - Propose solutions to the problems identified in the *Section 2: Statement of Need*.
 - Describe the methods and/or programs through which the applicant will implement the proposed solutions.
 - Explain how the methods and programs provide services tailored to each population age group.

- Include concrete ideas for collaboration among all awardees and other organizations or programs to enable lifelong coordination of care and health promotion.
 - Specifically state how efforts will lead to a decrease in the unmet needs within the population served.
2. Additionally, applicants must also describe the follow for each component for which funding is requested. If funding is only requested for one or two components, only include the applicable components:
- **Component A: POPULATION AGE 0-1**
 - Describe the organization's strategies and process to refer and coordinate any newborn within the state to appropriate services following identification through newborn screening.
 - Provide a flow chart demonstrating the proposed follow-up process; include all steps and methods within the process, from initial referral by NBS laboratory, to contact to family and PCP, diagnostic testing, continued care, additional services to families, and data collection, evaluation, and reporting.
 - Note: Awardees will be required to collaborate with the newborn screening lab and the GNBS program to finalize the referral and care coordination process per condition.
 - **Component B: POPULATION AGE 1-21**
 - Describe the organization's strategies and process to increase to ensure families receive education about their child's diagnosis and goal setting, are referred for mental health services, social services, academic and workforce assistance, as well as follow-up clinical appointments.
 - **Component C: POPULATION AGE 21+**
 - Describe the organization's strategies and process to ensure adults receive education about effective management of their condition and prevention of acute pain crises, are referred for mental health services, social services, academic and workforce assistance, as well as follow-up clinical appointments.
 - Develop programming to build awareness in communities of need, which includes information, knowledge about status, and education about resources for SCD and trait.
 - Explain how emergency room education and awareness of SCD, especially regarding sickle cell crisis or other pain episode management, will be implemented.

Section 4: GOALS, OBJECTIVES, & ACTIVITIES

In this section, include each component for which funding is requested. If funding is only requested for one or two components, only include the applicable components:

- Component A: POPULATION AGE 0-1

Goals and Objectives should encompass the following:

- Activities that promote successful and timely coordination of families to the appropriate clinical, educational, social interventions based upon referral type (disease or trait).
 - Examples of these interventions and services include professional and public education efforts, initiatives to reduce families' barriers to care, newborn screening care coordination activities such as providing condition-specific and sickle cell disease and trait education to families, follow-up of infants identified through screening, arrangement of confirmatory testing and reporting of SCD and trait patient information to the department.
- Assessment of other current needs within the served population and implementation of creative solutions to bridge the identified gaps.
- Patient data collection and reporting to the department to improve the evaluation of continuity of services throughout the lifespan.

- Component B: POPULATION AGE 1-21

Goals and Objectives should encompass the following:

- Activities that promote successful and timely coordination of families to the appropriate clinical, educational, social interventions based upon referral type (disease or trait).
 - Examples of these interventions and services include professional and public education efforts, initiatives to reduce families' barriers to care, follow-up, and collaborations to increase awareness.
- Assessment of other current needs within the served population and implementation of creative solutions to bridge the identified gaps.
- Patient data collection and reporting to the department to improve the evaluation of continuity of services throughout the lifespan.

- Component C: POPULATION AGES 21+

- **Goals and Objectives should encompass the following:**
 - Activities that promote successful and timely coordination of families to the appropriate clinical, educational, social interventions based upon referral type (disease or trait).
 - Examples of these interventions and services include professional and public education efforts, initiatives to reduce families' barriers to care, follow-up, and collaborations to increase awareness.
 - Assessment of other current needs within the served population and implementation of creative solutions to bridge the identified gaps.
 - Patient data collection and reporting to the department to improve the evaluation of continuity of services throughout the lifespan.
- Identify at minimum four (4) goals per year, per component. Each goal should include at least one (1) objective and one (1) activity necessary to meet the goal. Additional objectives and/or activities may be necessary to meet the goal.
- For each goal, there must be at least one (1) performance metric defined that clearly measures the success of the goal. Explain how the performance metric data will be tracked and reported to IDOH.

Please ensure these are SMARTIE (Specific, Measurable, Achievable, Relevant, Time-bound, Inclusive, and Equitable) goals. For additional information on SMARTIE goals please visit <https://www.managementcenter.org/resources/smartie-goals-worksheet/>

Applicants will be required to collaborate with the GNBS program and CSHCS division to edit or finalize goals, objectives, and activities upon award.

Section 5: ORGANIZATIONAL INFORMATION & STAFFING PLAN

In this section:

4. Include a brief history of the organization.
5. Describe how the organization's mission, structure, history of partnerships, and current activities contribute to the ability to meet program goals outlined in the purpose of this solicitation.
 - Identify any additional clinics or organizations that will collaborate with you to achieve the program goals.
6. Describe the current staff and any additional positions that need filled to accomplish the program goals. Provide a timeline for the completion of filling any positions.

7. Designate the organization's point of contact for the GNBS program and the CSHCS division.
 - A contact person is required for nights, weekends, and holidays for newborn screening coordination activities.
8. Describe the facilities that will house project services. In this section you must address the following and demonstrate that:
 - Facilities are adequate to house the proposed program.
 - Facilities are accessible for individuals with disabilities in accordance with the Americans with Disabilities Act of 1990.
 - Facilities will always be smoke-free.
 - Hours of operation are posted and visible from outside the facility. (Include evening and weekend hours to increase service accessibility and indicate hours of operation at each site on Form B-2.

Section 6: BUDGET NARRATIVE

In this section:

- Include the specific dollar amount requested and how it will be distributed to each budget item per population age group.
- Explain how your program will utilize awarded funds to fulfill the proposed activities and approach.
- Clearly demonstrate how the funding is related to reaching goals and promoting health equity.

Section 7: SUSTAINABILITY PLAN

It is imperative to demonstrate the ability to sustain vital program activities without state funding to ensure continuity of services. In this section:

- Explain how your program would sustain all program activities if state funding was not available.

Work Plan

The work plan will supplement the goals, objectives, and activities proposed by the applicant within [Section 4](#) of the application narrative. The work plan must be completed using the provided SCD RFA Work Plan Template.

Budget Worksheet

The budget worksheet should be completed in the provided Microsoft Excel document. Do **NOT** substitute a different format. Create a budget for each fiscal year. Fiscal year 2024 starts on 7/1/2023 and ends 6/30/2024. Fiscal year 2025 starts on 7/1/2024 and ends 6/30/2025. The budget is an estimate of what the project will cost. The budget

estimate cannot exceed \$1,050,000. The budget should be broken down by age population as follows:

Funded by:	Component & Population Age	Available Funding per year
GNBS Program	Component A: ages 0-1	\$300,000
CSHSC Division	Component B: ages 1-21	\$490,000
CSHSC Division	Component C: 21+	\$260,000

Each budget item must also be clearly described in the *Budget Narrative* section.

Additional Required Documents

Please also include the following documents in a single PDF file:

- An organizational chart
- Resumes/CVs of Staff
- Letters of Support/MOUs (maximum of 5)
- Grant application checklist

VI. EVALUATION CRITERIA

Review Process

Applications will be reviewed for completeness and funds will be awarded based upon the organization's ability to achieve the program goals. Awards will vary based on population served and prevalence of newborn screening conditions. Applications will be evaluated by various MCH/CSHCS division staff.

The following point breakdowns will be used for each part of the application, totaling 100 points:

- **Applicant Narrative – 75 points**
 - Section 1: Introduction and Summary of Request – 5 points
 - Section 2: Statement of Need – 5 points
 - Section 3: Methods and Approach – 20 points
 - Section 4: Goals, Objectives, and Activities – 20 points
 - Section 5: Organizational Information and Staffing Plan – 10 points
 - Section 6: Budget Narrative – 10 points
 - Section 7: Sustainability Plan – 5 points
- **Additional Required Documents- 25 points in total**
 - Applicant Cover Page – 1 point
 - Work Plan – 10 points
 - Budget Worksheet – 10 points

- Organizational Chart – 1 point
- Resumes/CVs of Staff – 1 point
- Letters of Support MOUs – 1 point
- Grant Application Checklist – 1 point

VII. REQUIRED COMMUNICATION WITH IDOH

Information Sharing

Recipients will be required to electronically report patient data on *Patient Status Forms* to the GNBS Program and the newborn screening laboratory within five (5) business days of a qualifying event. Qualifying events include a confirmed diagnosis, a ruled-out diagnosis, lost-to-follow up, refused care, or other inability to receive care coordination and confirmatory testing. *Patient Status Forms* will be provided by GNBS staff.

The GNBS program is mandated to report quarterly on the results of newborn screening to all hospitals, physicians, and other groups interested in child welfare. To fulfil this mandate, the GNBS program will publish de-identified cumulative data quarterly.

Reporting

Recipients will be required to submit quarterly progress reports on meeting program goals and expenditure of funds. A final report will be required at the end of the period of performance. Templates will be provided to recipients. Quarterly reporting periods will be defined as follows. Reports will be due no later than 15 days after the end of each reporting period outlining progress to date:

- Q1 – July 1-September 30.
- Q2 – October 1-December 31.
- Q3 – January 1-March 31; and
- Q4 – April 1-June 30.

Meetings

Recipients will be required to meet twice a year with GNBS staff, the newborn screening lab, and/or CSHCS point of contact.

VIII. CONTACTS

Points of Contact

Children's Special Healthcare Services (CSHCS) Division

Madeline Wilks

Integrated Community Services Manager

(317) 234-7991

mwilks@health.in.gov

Genomics & Newborn Screening (GNBS) Program

Jennifer Weaver

Newborn Screening Program Manager

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MCH Invoices

Verna Crenshaw

MCH Program Coordinator

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