



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 3052

1. Project Title

2. Senate Sponsor

3. Date of Request

4. Project/Program Description

The purpose of these funds is to make the patient registry more robust in its data collection and reporting for those with Sickle Cell Disease and any sickle variant. This includes the data infrastructure and technological support needs.

5. State Agency to receive requested funds

State Agency contacted? Yes

6. Amount of the Nonrecurring Request for Fiscal Year 2024-2025

Type of Funding	Amount
Operations	3,500,000
Fixed Capital Outlay	0
Total State Funds Requested	3,500,000

7. Total Project Cost for Fiscal Year 2024-2025 (including matching funds available for this project)

Type of Funding	Amount	Percentage
Total State Funds Requested (from question #6)	3,500,000	100%
Matching Funds		
Federal	0	0%
State (excluding the amount of this request)	0	0%
Local	0	0%
Other	0	0%
Total Project Costs for Fiscal Year 2024-2025	3,500,000	100%

8. Has this project previously received state funding? No

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	Nonrecurring		

9. Is future funding likely to be requested? No

a. If yes, indicate nonrecurring amount per year.

b. Describe the source of funding that can be used in lieu of state funding.

10. Has the entity requesting this project received any federal assistance related to the COVID-19 pandemic?

No

If yes, indicate the amount of funds received and what the funds were used for.



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Complete questions 11 and 12 for Fixed Capital Outlay Projects

11. Status of Construction

a. What is the current phase of the project?

- Planning
 Design
 Construction
 N/A

b. Is the project "shovel ready" (i.e permitted)?

No

c. What is the estimated start date of construction?

d. What is the estimated completion date of construction?

12. List the owners of the facility to receive, directly or indirectly, any fixed capital outlay funding. Include the relationship between the owners of the facility and the entity.

13. Details on how the requested state funds will be expended

Spending Category	Description	Amount
Administrative Costs:		
Executive Director/Project Head Salary and Benefits	Responsible for Project Management which is needed to coordinate the components of the registry; to manage timelines, milestones, deliverables, and budgets; and to ensure communication with sites, stakeholders, oversight committees, and funding sources.	400,000
Other Salary and Benefits	Grants and finance administrators are responsible to provide financial and administrative support services to designated program staff, assist with oversight of implementation and monitoring.	150,000
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study	Software development, training materials and workshops, hardware infrastructure, and maintenance and support	600,000
Operational Costs: Other		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study	Stakeholders meetings, Collaborative Agreements, Liaison Personnel, Integration with Existing Databases, Secure Data Storage Solutions, Database Management Systems, Data Security Measures, Privacy Protocols and Compliance, Continuous Monitoring and Upgrades	2,350,000
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0
Total State Funds Requested (must equal total from question #6)		3,500,000

14. Program Performance

a. What specific purpose or goal will be achieved by the funds requested?

The purpose of these funds is to make the patient registry more robust in its data collection and reporting for those with Sickle Cell Disease and any sickle variant. This includes the data infrastructure and technological support needs.

b. What activities and services will be provided to meet the intended purpose of these funds?



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Patient assessment, disease management, connecting patients, to providers to care through direct in-person services, telemedicine, telehealth

c. What direct services will be provided to citizens by the appropriation project?

This funding is for comprehensive research initiative for Sickle Cell Disease, one that doesn't just seek answers but strives for actionable insights that can bring about tangible improvements in patient care and understanding.

d. Who is the target population served by this project? How many individuals are expected to be served?

The target population served by this project is elderly persons, persons with poor physical and mental health, jobless persons, economically disadvantaged persons, at-risk youth, homeless, developmentally disabled, physically disabled, preschool students, grade school students,, high school students, university/college students, currently or formerly incarcerated persons, and individuals with sickle cell disease or sickle hemoglobinopathy. The individuals expected to be served are over 800.

e. What is the expected benefit or outcome of this project? What is the methodology by which this outcome will be measured?

The expected benefit is to improve the physical health by reducing sickle cell disease related emergency room visits, hospitalizations, ICU admissions and deaths. The method to measure the benefit is to claim data Florida Health Information Exchange Data from the Sickle Cell Disease Electronic Health Record HEDIS data from health plans.

f. What are the suggested penalties that the contracting agency may consider in addition to its standard penalties for failing to meet deliverables or performance measures provided for the contract?

Failure to meet deliverables. Service provider shall be penalized by determined percentage with respect to any failure by service provider to meet the acceptance criteria for any deliverable as set forth in the applicable work agreement.

15. Requester Contact Information

a. First Name Last Name

b. Organization

c. E-mail Address

d. Phone Number Ext.

16. Recipient Contact Information

a. Organization

b. Municipality and County

c. Organization Type

- For Profit Entity
- Non Profit 501(c)(3)
- Non Profit 501(c)(4)
- Local Entity
- University or College
- Other (please specify)

d. First Name Last Name



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e. E-mail Address

f. Phone Number

17. Lobbyist Contact Information

a. Name

b. Firm Name

c. E-mail Address

d. Phone Number