



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2022-2023

LFIR # 2783

1. Project Title

2. Senate Sponsor

3. Date of Request

4. Project/Program Description

The Sickle Cell Patient Registry collects information on the health status of people with sickle cell disease and who receive care in the Foundation for Sickle Cell Disease Research Centers and agrees to participate in the Registry. This information is used to create Sickle Cell care guidelines, assist care teams in providing care to individuals with Sickle Cell Disease, and guide quality improvement initiatives at care centers. The registry will also allow researchers to study Sickle Cell treatments and outcomes and to design Sickle Cell clinical trials.

5. State Agency to receive requested funds

State Agency contacted? Yes

6. Amount of the Nonrecurring Request for Fiscal Year 2022-2023

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

7. Total Project Cost for Fiscal Year 2022-2023 (including matching funds available for this project)

Type of Funding	Amount	Percentage
Total State Funds Requested (from question #6)	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 2022-2023	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? Yes

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



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

11. 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.	20,000
Other Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study		0
Operational Costs: Other		
Salary and Benefits	Experts in the treatment of sickle cell disease (SCD) and Warrior representatives (individuals living with SCD) will apply all of the latest published clinical, social, and outcome data to components of the registry and determine which elements are necessary. The registry will comply with all Federal and State laws applicable to patient information. Experts in quality assurance to assist the continuous quality improvement of the registry. The quality assurance report will report results achieved	180,000
Expense/Equipment/Travel/Supplies/Other	The scope of a registry includes building on the existing registry infrastructure and linking to data sources relevant to the purposes of the registry. Data Science Machine Learning tools and algorithms to efficiently and securely acquire and validate healthcare data from various sources. Integrating advanced analytics to uncover drivers to outcome and variation. Delivering insights via interactive reports and tools that inspire data-driven action.	150,000
Consultants/Contracted Services/Study	Registry science: Machine Learning, Epidemiology, and biostatistics to develop a mutual understanding of the registry's objectives and data needed. Consultants work with the subject matter experts to ensure that appropriate analytic methods are being used to address the clinical issues relevant to achieving the goals of the registry.	150,000
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0
Total State Funds Requested (must equal total from question #6)		500,000

12. Program Performance

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

The purpose of the funds will be to create a patient registry that will collect information on the health status of people with Sickle Cell Disease. It will also provide invaluable information to researchers to help with Sickle Cell treatments.

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



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Types of Disease Surveillance - will be able to monitor disease trends and plan public health programs. We will use two primary types of disease surveillance: passive and active. Passive- we will use passive disease surveillance through autoassign where healthcare providers or laboratories initiate the reporting to state or local officials. Reportable diseases are submitted on a case-by-case basis, based on a published list of conditions. Active - we will use active disease surveillance to actively include current health information from clinic records and patients' reported outcomes. We will also search for information by contacting healthcare providers, laboratories, schools, nursing homes, workplaces, etc. as permitted.

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

Bi-Annual follow ups that include EKGs, LABS, Hemoglobin "F" treatments, Eye Exams, Mental Health checks, transfusion history, etc.;
Acute Sickle Cell Treatment plan;
Advocates for you if you are hospitalized;
Participation in clinical trials.

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

All individuals with sickle cell disease; 10,000 - 14,000.

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

We will utilize python data science and machine learning that will serve as a powerful tool to observe the course of the disease; to understand variations in treatment and outcomes; to examine factors that influence prognosis and quality of life; to describe care patterns, including appropriateness of care and disparities in the delivery of care; to assess effectiveness; to monitor safety and harm, and to measure the quality of care. Through functionalities such as feedback of data, registries are also being used to study quality improvement.

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.

13. 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.

NA



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14. Requestor Contact Information

a. First Name Last Name

b. Organization

c. E-mail Address

d. Phone Number Ext.

15. 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

e. E-mail Address

f. Phone Number

16. Lobbyist Contact Information

a. Name

b. Firm Name

c. E-mail Address

d. Phone Number