



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2025-2026

LFIR # 1050

1. Project Title

2. Senate Sponsor

3. Date of Request

4. Project/Program Description

Florida has the highest number of Sickle Cell Disease cases in the Country. Advancements in technology of gene therapy have led to 2 functional cures for Sickle Cell Disease. In December 2023, the FDA approved the first gene therapy for SCD, marking a groundbreaking advancement in treatment. This therapy works by introducing a functional gene into a patient's stem cells to address the genetic defect causing SCD. The process requires blood collection, preparation, processing, storage, and transportation. The requested funding will support the acquisition of specialized equipment needed to supply the critical source product for research.

5. State Agency to receive requested funds

State Agency contacted?

6. Amount of the Nonrecurring Request for Fiscal Year 2025-2026

Type of Funding	Amount
Operating	600,000
Fixed Capital Outlay	0
Total State Funds Requested	600,000

7. Total Project Cost for Fiscal Year 2025-2026 (including matching funds available for this project)

Type of Funding	Amount	Percentage
Total State Funds Requested (from question #6)	600,000	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 2025-2026	600,000	100%

8. Has this project previously received state funding?

If yes, provide the most recent instance:

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

9. Is future-year funding likely to be requested?

a. If yes, indicate nonrecurring amount per year.

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



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Complete questions 10 and 11 for Fixed Capital Outlay Projects

10. 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)?

c. What is the estimated start date of construction?

d. What is the estimated completion date of construction?

e. What funding stream will be used for ongoing operations and maintenance of the project?

11. 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.

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

Spending Category	Description	Amount
Administrative Costs:		
Executive Director/Project Head Salary and Benefits		0
Other Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other	Specialized equipment to collect and safely store , storing, freezing and processing equipment. Instruments for collecting Hematopoietic stem cells, Sterile connecting device welder, LNC freezer, refrigerated centrifuge, plasma expressor, cryoshippers, etc.	600,000
Consultants/Contracted Services/Study		0
Operational Costs		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study		0
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0
Total State Funds Requested (must equal total from question #6)		600,000

13. Program Performance

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

The NIH, HRSA, CMS and other public and private organizations support curative research for Sickle Cell Disease. Florida has the highest number of Sickle Cell Disease in the country. Estimates indicate that approximately 13,886 are living in Florida with SCD, while there are over 100,000 nationwide. This high prevalence underscores the importance of targeted health resources for potential eradication.



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

A documented initiative collecting, preparing and providing blood to support and advance gene therapy research for a functional cure for Sickle Cell Disease, hemophilia, and various blood-related cancers.

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

To enhance and expedite transformative gene therapy research to functionally cure Sickle Cell disease, hemophilia, and various blood-related cancers.

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

Those afflicted with Sickle Cell Disease, hemophilia, and various blood related cancers.

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

Ultimately, the expected benefit and outcome is accessible treatment for sickle cell disease, hemophilia and various blood cancers that result in curative gene therapy leading to a functional cure. Outcomes will be measured by tracking the blood products provided for research, the studies supported, and their progress toward developing treatments that reduce hospitalizations and improve daily functioning and Health-Related Quality of Life (HRQoL) for sickle cell patients.

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 in the contract?

Notification with opportunity to cure.

14. Is this project related to mitigation, response, or recovery from a natural disaster?

a. If Yes, what phase best describes the project?

- Mitigation (reducing or eliminating potential loss of life or property)
- Response (addressing the immediate and short-term effects of a natural disaster)
- Recovery (assisting communities return to normal operations, including rebuilding damaged infrastructure)

b. Name of the natural disaster (or Executive Order # for events not under a federal declaration):

15. Has the entity applied for or received federal assistance for this project?

- Yes, Applied
- Yes, Received
- No
- No, but intends to apply

a. If yes, provide the FEMA project worksheet ID#:

b. Provide the total project cost listed on the FEMA project worksheet:



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16. Has the entity applied for or received state assistance for this project (other than this request)?

- Yes, Applied
- Yes, Received
- No
- No, but intends to apply

a. If yes, specify the program and state agency (ex. Local Government Emergency Bridge Loan, Department of Commerce):

17. Requester Contact Information

a. First Name **Last Name**

b. Organization

c. E-mail Address

d. Phone Number **Ext.**

18. 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 **Ext.**

19. Lobbyist Contact Information

a. Name

b. Firm Name

c. E-mail Address



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d. Phone Number

The information provided will be posted to the Florida Senate website for public viewing if sponsored by a Senator.