



# The Florida Senate

## Local Funding Initiative Request

### Fiscal Year 2025-2026

LFIR # 1963

1. Project Title

2. Senate Sponsor

3. Date of Request

#### 4. Project/Program Description

The Florida Institute for Pediatric Rare Diseases, established within the Florida State University College of Medicine, will serve as a statewide hub for research, clinical care, education, and advocacy for pediatric rare diseases. The institute will advance the diagnosis, treatment, and support for children and families affected by these conditions. A key initiative, the Sunshine Genetics Pilot Program, will provide opt-in genetic testing for newborns beyond the state's standard newborn screening program. This three-year pilot program will partner with universities, healthcare providers, and genetic specialists to offer early detection, enabling faster diagnosis and treatment. Families will receive comprehensive clinical services, genetic counseling, and support resources to navigate these conditions.

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	20,000,000
Fixed Capital Outlay	0
<b>Total State Funds Requested</b>	<b>20,000,000</b>

#### 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)	20,000,000	100%
<b>Matching Funds</b>		
Federal	0	0%
State (excluding the amount of this request)	0	0%
Local	0	0%
Other	0	0%
<b>Total Project Costs for Fiscal Year 2025-2026</b>	<b>20,000,000</b>	<b>100%</b>

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)?

No

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
<b>Administrative Costs:</b>		
Executive Director/Project Head Salary and Benefits		0
Other Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study		0
<b>Operational Costs</b>		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other	Funds will support institute operations, including laboratory research, genetic testing, and clinical services. Expenses include equipment purchases for advanced diagnostics, staffing (geneticists, researchers, and healthcare providers), data infrastructure for secure patient records, and educational programs for medical professionals.	20,000,000
Consultants/Contracted Services/Study		0
<b>Fixed Capital Construction/Major Renovation:</b>		
Construction/Renovation/Land/Planning Engineering		0
<b>Total State Funds Requested (must equal total from question #6)</b>		<b>20,000,000</b>

### 13. Program Performance

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



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Funds will support the Sunshine Genetics Pilot Program, a part of Florida Institute for Pediatric Rare Diseases at FSU's College of Medicine, providing opt-in genetic testing for newborns, improving early detection and treatment. Additionally, funds will create the Sunshine Genetics Consortium to facilitate collaboration and data-sharing among researchers and healthcare providers.

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

The funds will support genetic testing for newborns through the Sunshine Genetics Pilot Program, expanding early detection of pediatric rare diseases. Services will include multidisciplinary clinical care, genetic counseling, and patient advocacy for affected families. The program will also foster research collaboration through the Sunshine Genetics Consortium, collecting and analyzing deidentified data to advance medical knowledge. Additionally, healthcare professionals will receive training to enhance diagnosis and treatment capabilities for rare diseases.

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

The funding will provide opt-in genetic testing for newborns, offering early detection of rare diseases. Families will receive comprehensive clinical care, genetic counseling, and patient support services. The institute will train healthcare professionals, improving diagnosis and treatment statewide. Through the Sunshine Genetics Consortium, data-sharing will enhance research, benefiting children.

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

The target population for this project includes newborns and children diagnosed with pediatric rare diseases, as well as their families. Additionally, healthcare professionals in the fields of genetics, pediatrics, and rare disease management will be served through training programs. The program aims to serve thousands of newborns in Florida through the opt-in genetic testing during the pilot program. It is expected that hundreds of healthcare professionals will benefit from the training and education initiatives. The Sunshine Genetics Consortium will facilitate broader collaboration, impacting a significant number of research institutions and medical centers across the state.

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

The expected benefits of this project include improved health outcomes for children with rare diseases through early diagnosis, reduced healthcare costs via early intervention, and enhanced expertise in rare disease management. Families will receive critical support, and the project will advance research in pediatric rare diseases. Outcomes will be measured by tracking the number of newborns screened and diagnosed, monitoring health improvements through early treatment, evaluating the success of healthcare professional training, and assessing the effectiveness of the Sunshine Genetics Consortium through collaborative research and data sharing.

**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?**

Revert state appropriations and withhold future funding for this initiative.

**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



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- ☐ 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:

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



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☐ 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

d. Phone Number

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