



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2025-2026

LFIR # 1671

1. Project Title
2. Senate Sponsor
3. Date of Request

4. Project/Program Description

The Florida State University (FSU) Institute for Pediatric Rare Diseases is a visionary initiative aimed at revolutionizing the landscape of pediatric rare disease diagnosis and treatment. Addressing the slow progress in this field, the institute adopts a unique approach to collectively tackle various pediatric rare diseases. With a strategic focus on biomedical research, education, patient care, community engagement, and technology commercialization, the institute envisions becoming a premier center in Florida. The subsequent fiscal year aims to pivot towards clinical research, seek extramural funding, and establish a Clinical Laboratory Improvement Amendments (CLIA) Lab. Long-term goals include statewide expansion of newborn screening, partnerships with biomedical pharmaceuticals, and the creation of a patient care and research arm.

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	5,000,000
Fixed Capital Outlay	0
Total State Funds Requested	5,000,000

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)	5,000,000	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	5,000,000	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		
2024-25	0	5,000,000	147	No

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.
-



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2025-2026

LFIR # 1671

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?

Available recurring funds will be used to fund the normal operations of the facility, such as utilities, building services, etc. Maintenance will be funded from reserves as required by law, carry forward funding when appropriate, and deferred maintenance appropriations when provided.

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.

Florida State University is a public state university.

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	Newborn Genetic Screening (\$2M one-time) – Funds will help Establish a CLIA laboratory to perform genetic testing by a CLIA certified technician and certified by a College of Medicine physician. Create a Graduate Degree Program in Genetic Counseling (\$2M one time). Biomedical Research Program (\$1M) – preclinical research into disease mechanisms and novel treatments for pediatric rare diseases.	5,000,000
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)		5,000,000

13. Program Performance

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



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2025-2026

LFIR # 1671

To advance knowledge, providing early diagnosis, delivering comprehensive clinical care, and offering education and support for children with rare genetic conditions and their families. The institute strives to make a lasting positive impact on the lives of these children and their families while contributing to research and public health in the field of pediatric rare diseases.

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

Collaborate with experts in genetics, pediatrics, and public health to design a comprehensive newborn screening. Establish state-of-the-art CLIA certified genetic testing laboratories equipped for high-throughput genetic screening equipment which will be provided by FSU valued at \$1.5m.

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

Collaborate with experts in genetics, pediatrics, and public health to design a comprehensive newborn screening. Establish state-of-the-art CLIA certified genetic testing laboratories equipped for high-throughput genetic screening equipment which will be provided by FSU valued at \$1.5m.

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

The primary target population for the FSU Institute for Pediatric Rare Diseases is children who are affected by rare diseases. The institute aims to develop innovative approaches for the diagnosis and treatment of these rare diseases, with a focus on early detection through newborn screening. Additionally, the institute's vision includes community engagement and outreach, suggesting a broader interest in raising awareness and providing resources for families and communities affected by pediatric rare diseases in Florida.

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

The project will contribute valuable data for research, advancing our understanding of rare diseases and potentially leading to new treatment options. Also, it will establish state-of-the-art Clinical Laboratory Improvement Amendments (CLIA) certified genetic testing laboratory equipped for high-throughput genetic screening. Labs that are CLIA certified meet the federal regulations and standards for facilities that test human specimens for health assessment or to diagnose, prevent, or treat disease.

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 appropriation and withhold future funding for this initiative.

14. Is this project related to mitigation, response, or recovery from a natural disaster? No

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



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2025-2026

LFIR # 1671

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

Other (please specify)

d. First Name **Last Name**



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2025-2026

LFIR # 1671

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.