



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 1670

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 2024-2025

Type of Funding	Amount
Operations	5,000,000
Fixed Capital Outlay	0
Total State Funds Requested	5,000,000

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)	5,000,000	77%
Matching Funds		
Federal	0	0%
State (excluding the amount of this request)	1,500,000	23%
Local	0	0%
Other	0	0%
Total Project Costs for Fiscal Year 2024-2025	6,500,000	100%

8. **Has this project previously received state funding?**

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	Nonrecurring		
2023-24		1,000,000	143	No

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



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Yes

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

Revenue: \$69.5M Direct Student Aid and \$85.2M Institutional Support. Expenses: 1) \$69.5M Direct Student Aid; 2) \$85.2M Campus Operations: \$57.2M-Lost revenues in campus auxiliaries; \$8.7M-Campus health/safety; \$8.2M-Reimbursements for housing/study abroad/meal plans; \$1.0M-IT infrastructure and equipment for remote/distance learning; \$0.4M Off-campus quarantine housing; \$9.7M-Other operating costs

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)?

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		0
Other Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study		0
Operational Costs: 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
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0
Total State Funds Requested (must equal total from question #6)		5,000,000



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14. Program Performance

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

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 the contract?

Revert state appropriation and withhold future funding for this initiative.

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



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- 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

17. Lobbyist Contact Information

a. Name

b. Firm Name

c. E-mail Address

d. Phone Number