



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2023-2024

LFIR # 2724

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

4. Project/Program Description

These funds will be used to initiate the FSU Institute for Rare Diseases, which will focus on researching diseases that impact our youngest and most vulnerable. The pharmaceutical industry is not incentivized to invest in cures and treatments for pediatric rare diseases because of how uncommon they are. FSU is uniquely positioned to bridge this gap. The Institute for Pediatric Rare Diseases at FSU will focus on research and development of gene therapies and research and development of improving immune response. For the body to accept the gene therapy, most require intense suppression of the immune system that can last 6 months or longer. In the case of the Tay Sachs Disease trial at UMASS, children have been responding well to the treatment but have unfortunately died from common infections. Improving immune response to these therapies would be beneficial to a large population including the rare disease community and help advance gene therapy trials across the board.

5. **State Agency to receive requested funds**
- State Agency contacted?** Yes

6. Amount of the Nonrecurring Request for Fiscal Year 2023-2024

Type of Funding	Amount
Operations	1,000,000
Fixed Capital Outlay	0
Total State Funds Requested	1,000,000

7. Total Project Cost for Fiscal Year 2023-2024 (including matching funds available for this project)

Type of Funding	Amount	Percentage
Total State Funds Requested (from question #6)	1,000,000	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 2023-2024	1,000,000	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?** No
- a. **If yes, indicate nonrecurring amount per year.**

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

N/A



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

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

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	Funds will be used to equip interdisciplinary teams of scientists, clinicians, and educators to collaborate and advance the understanding and treatment of pediatric rare diseases. By leveraging the latest research and technology, the Institute for Pediatric Rare Diseases aims to make a real impact in the lives of children and families affected by rare pediatric diseases.	500,000
Consultants/Contracted Services/Study	FSU will work to conduct a study to formulate the institute's scope of research relating to pediatric rare diseases.	500,000
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0



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Total State Funds Requested (must equal total from question #6)	1,000,000
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14. Program Performance

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

The requested funds will be used to establish the FSU Institute for Pediatric Rare Diseases, which will focus on researching diseases that impact our youngest and most vulnerable. These diseases are rare in nature and therefore, the pharmaceutical industry does not have the bandwidth to invest in a cure or treatment. At Florida State University, we have the opportunity and desire to fill the gap in the research necessary to find the treatments for these ailments.

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

These funds will be used to establish essential infrastructure and build a strong foundation for the institute. This includes recruiting top-tier scientists, purchasing equipment and supplies, and developing innovative research and treatment programs.

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

These funds will also be used to create educational resources and support services for families and patients affected by rare pediatric conditions. The goal is to provide the best possible resources for families and to advance our understanding and treatment of these rare and complex diseases.

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

The target population is the 15 million children across Florida and the United States who suffer from rare pediatric diseases.

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

This project will improve the physical health of millions of children across the state and country who could benefit from critical research conducted on their rare pediatric diseases. This can be measured by rates of hospitalization for children with rare diseases, as well as the development and approval of new treatments and therapies developed at Florida State University. This project will also improve the quality of education by offering research opportunities to students at Florida State University.

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

For Profit Entity



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- 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