



# The Florida Senate

## Local Funding Initiative Request

### Fiscal Year 2023-2024

LFIR # 1668

1. **Project Title**

2. **Senate Sponsor**

3. **Date of Request**

4. **Project/Program Description**

The Jordan Avi Ogman Foundation is researching and developing cures for TECPR2, a rare, fatal, and progressive, neurodegenerative disease that affects children. The gene therapy cure being developed will save the lives of children battling pediatric brain disease. The research is enabling the advancement of translational understanding to cure related lysosomal storage disease affecting Florida's elderly population affected by Parkinson's, Alzheimer's, ALS, and similar neurodegenerative disease.

5. **State Agency to receive requested funds**

**State Agency contacted?**

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

Type of Funding	Amount
Operations	50,000
Fixed Capital Outlay	0
<b>Total State Funds Requested</b>	<b>50,000</b>

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)	50,000	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 2023-2024</b>	<b>50,000</b>	<b>100%</b>

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

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

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.**

Outside of state funding, the research and development of TECPR2 neurodegenerative disease is a grassroots effort by families affected by genetic brain disease. The pace of which donations are raised are preventing the scientists from receiving the necessary funding to develop the cure.

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



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No

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

## 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
<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: Other</b>		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study	Our team of Scientists have been conducting research to develop the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, genetic disease in Kids. Now that the research is complete, and as we further develop the gene therapy constructs to examine efficacy and safety, we are progressing towards the manufacturing, production, and associated costs of developing the vector to be perfected so that it provides the desired outcome.	50,000
<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>50,000</b>

### 14. Program Performance

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



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The purpose and/or goal is research and development of the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, Pediatric genetic disease. The gene therapy cure for TECPR2 being developed to save the lives of the children battling this debilitating disease will enable the research to advance as its translational to understanding how to further develop gene therapy for similar devastating neurodegenerative disease for children throughout our state of Florida.

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

Research and development of the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, Pediatric genetic disease. The gene therapy cure for TECPR2 being developed to save the lives of the children battling this debilitating disease will enable the research to advance as its translational to understanding how to further develop gene therapy for similar devastating neurodegenerative disease for children throughout our state of Florida.

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

Direct services provided to citizens will be the life-saving gene therapy cure.

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

Pediatric population of children battling rare, fatal, and progressive, neurodegenerative, genetic disease.

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

Benefit is life-saving gene therapy cure to cure TECPR2 neurodegenerative disease in children.

**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?**

Failure to meet performance is unacceptable, as our kids require this life-saving gene therapy cure, so we will continue to research and develop the cure until it is perfected for our children in the State of Florida.

**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
- 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**

#### 17. Lobbyist Contact Information

**a. Name**

**b. Firm Name**

**c. E-mail Address**

**d. Phone Number**