



# The Florida Senate

## Local Funding Initiative Request

### Fiscal Year 2025-2026

LFIR # 1060

1. **Project Title**

2. **Senate Sponsor**

3. **Date of Request**

**4. Project/Program Description**

About 5000 Florida residents suffer from Retinitis Pigmentosa (RP), a genetic disease caused by mutations in more than 125 genes. Nearly half of these patients and families do not have a genetic diagnosis. We intend to establish a database of Florida residents with RP who have not yet obtained a genetic diagnosis. We will obtain whole genome sequencing on those patients with the intent that we will thereby identify the causative gene and inform patients that can now be diagnosed based on the latest information. We will connect those patients with clinical trials as available. We will also make the database available to researchers when new gene variants are discovered.

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	330,000
Fixed Capital Outlay	0
<b>Total State Funds Requested</b>	<b>330,000</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)	330,000	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>330,000</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.**

grants, private donors



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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)?

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	Executive Director	60,000
Other Salary and Benefits	Medical Director, Genetic Counselor, Data Manager	70,000
Expense/Equipment/Travel/Supplies/Other	Testing and Administrative costs	200,000
Consultants/Contracted Services/Study		0
<b>Operational Costs</b>		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
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>330,000</b>

### 13. Program Performance

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

- Establish a database of Florida residents with IRD who have not yet obtained a genetic diagnosis.
- Obtain whole genome sequencing on those patients.
  - Identify and inform patients that can now be diagnosed based on the latest information.
  - Connect those patients with clinical trials as available.
  - Make the database available to researchers when new gene variants are discovered.
  - Connect these patients with researchers for further research purposes aimed at finding a cure.



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

Genetic testing for inherited retinal dystrophies and genetic counseling.

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

Citizens of Florida with as yet undiagnosed genetic visual difficulties will have a diagnosis and be eligible for clinical trials.

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

The 5000 Florida residents suffering from inherited retinal dystrophies.

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

Patients who have not been successfully diagnosed will receive a proper genetic diagnosis and directed to appropriate treatment options. This outcome will be measured on a patient b patient basis.

**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?**

Return funds.

**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
- 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



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- 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**

**e. E-mail Address**

**f. Phone Number**  **Ext.**

**19. Lobbyist Contact Information**

**a. Name**

**b. Firm Name**

**c. E-mail Address**

**d. Phone Number**



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