



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 1884

1. Project Title

2. Senate Sponsor

3. Date of Request

4. Project/Program Description

Prader-Willi syndrome is the most recognized and researched of all conditions involving intellectual deficiency and is known worldwide for its unique problems of severe obesity and behavioral abnormalities. This funding would establish, at the University of Florida (UF) Center of Excellence deliver services throughout Florida that would improve the lives of those with Prader-Willi syndrome and support their families. The center would organize and enhance the behavioral and medical resources by coordinating and establishing an interdisciplinary team of experts at UF that have historically been focused on research and treatment of the syndrome. The center would function programmatically within the UF Raymond C. Philips Research and Education Unit, a program already established by Florida Statutes, 393.064.

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	500,000
Fixed Capital Outlay	0
Total State Funds Requested	500,000

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)	500,000	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 2024-2025	500,000	100%

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.

There is no alternative source of funding identified at this time

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



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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
 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	A PhD psychologist, with experience in Prader-Willi syndrome, is anticipated to assume the duties of half-time director of the Center for excellence.	68,000
Other Salary and Benefits	Clerical assistance is needed to support the clinical director	30,000
Expense/Equipment/Travel/Supplies/Other	Travel expenses are required in order to traverse the state of Florida and promote the goals throughout the state of the Center for Excellence. In addition, money will be required to develop a user-friendly website which will be an important component to remotely deliver services and consultation expertise throughout Florida.	17,000
Consultants/Contracted Services/Study		0
Operational Costs: Other		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other	Funds needed in this category support expenses required or requested by consultants to complete assigned projects. It covers occasional subscriptions to in training programs by various consultants and on occasion would support travel and other suppliers requested by the consultants.	10,000
Consultants/Contracted Services/Study	The Center of Excellence requires a large group of University of Florida consultants and specialists who will be retained through contracts for services. Specialists include a medical geneticist, pediatric endocrinologist, internal medicine/family medicine physician, nutritionist, behavioral specialists and other psychologists as well as behavioral programmers and staff required to monitor behavioral and nutritional programming initiatives.	375,000
Fixed Capital Construction/Major Renovation:		



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Construction/Renovation/Land/ Planning Engineering		0
Total State Funds Requested (must equal total from question #6)		500,000

14. Program Performance

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

Goal of the Center of Excellence is to deliver improved care to those with Prader-Willi syndrome and their families by enabling access to the medical, behavioral and psychological expertise at the University with emphasis on the regional group homes as resource behavioral-oriented programs to help support other individuals with Prader-Willi syndrome across all of Florida.

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

Clients with Prader-Willi syndrome who receive services will be provided a treatment plan based on their individual medical and behavioral needs. Clients will be physically examined and a plan of therapy will be formulated that includes genetic, endocrine and general medical care as well as behavioral and nutritional strategies. Families of those with a child or adult with the syndrome will be given informational and practical strategies for coping with aberrant behaviors that can disrupt the family home or out-of-home living environment.

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

The proposed center enables client and family access to the medical, behavioral and psychological expertise at UF, with emphasis on the regional group homes as resource behavioral-oriented programs to support individuals with Prader-Willi syndrome across all of Florida. Clients will have direct access to new treatment modalities for effective behavioral treatments for hyperphagia, obesity, self-injurious behavior, aggressive outbursts. Consultants in the center will provide clients with new avenues of dietary, biomedical, genetic, pharmacological treatment of the syndrome. The center will disseminate educational and training services throughout Florida related to diagnosis, early treatment and long lifetime transitional care for those with the syndrome.

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

Target population are those throughout Florida both children and adults who have the Prader-Willi syndrome. It is estimated to 400 individuals in Florida are known at this time to have the syndrome. Families of these individuals would receive services and as well as caregivers, health practitioners, nutritional and behavioral specialists and physical therapists and other allied health professionals who treat any individual with the syndrome. These individuals could interface with the center and receive services through consultation with its various experts.

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

Progress is measured based on improvements from baseline assessments identified during the initial intake, and is determined by the reduction of targeted aberrant behaviors such as those involving abnormal eating habits, anxiety and obsessive-compulsive behaviors and negative/disrupting behaviors. We will monitor for increased engagement in family life or work-shop/employment settings. We will also monitor for compliance to medical treatment regimens. Our goal is that 80% of clients served will demonstrate improved medical and/or behavioral functioning over 6-12 months as measured by clinical notes, clinical observation, client, caregiver and family feedback, and where available, results from psychometric evaluation tools.

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?

Standard contract penalties are sufficient. The funding portion related to unmet deliverables would be returned to the state.

15. Requester Contact Information

a. First Name **Last Name**

b. Organization



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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
- 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