



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 2383

1. Project Title

2. Senate Sponsor

3. Date of Request

4. Project/Program Description

Funding will provide access for ALS patients to receive comprehensive quality care through ALS Multidisciplinary Clinics in Florida. There are five certified centers in the state, located at Mayo Clinic (Jacksonville), UF Health Jacksonville, University of Miami, Holy Cross Health (Ft. Lauderdale) NOVA SE , Orlando Health (Orlando) and University of South Florida(Tampa) that are collaborating with The ALS Association Florida Chapter, Inc. on this project. This multidisciplinary approach is proven to increase life expectancy for ALS patients by 40 percent. The impact to the State is a reduction in costs in community-based/home-based care, Medicaid, and hospitalizations as well as increased federal/private investments in research and an increase in medical tourism.

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	2,500,000
Fixed Capital Outlay	0
Total State Funds Requested	2,500,000

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)	2,500,000	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	2,500,000	100%

8. Has this project previously received state funding?

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	Nonrecurring		
2023-24	0	2,500,000	522	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.

We are not aware of any other funding sources.

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



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 2383

Yes

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

The ALS Association Florida Chapter received two draws through the Payroll Protection Program, which allowed the organization to maintain staffing levels despite an inability to host traditional fundraising events. The first draw was for \$190,595 and the second draw was for \$222,896. Both loans have been forgiven by the SBA.

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	Executive and contract manager handle all contract tasks and deliverables, manage subcontracts with the ALS clinics and direct staff in all tasks related to th	15,000
Other Salary and Benefits	Clinic liaison staff participate in the implementation of the multidisciplinary care model, assuring each patient's needs are met. Marketing staff develop and host a statewide patient symposium.	70,000
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study	Contract management expenses include attorney services, printing/ mailing costs, supplies, staff travel to ALS Clinics, expenses related to developing, executing and hosting the annual ALS Symposium. Additionally, subcontracts with ALS Clinics at Mayo Clinic (Jacksonville), University of South Florida (Tampa), University of Miami, UF Health (Jacksonville), Holy Cross Health (Ft. Lauderdale), Orlando Health (Orlando) and NOVA	2,415,000
Operational Costs: Other		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/Other		0
Consultants/Contracted Services/Study		0
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 2383

Total State Funds Requested (must equal total from question #6)	2,500,000
--	------------------

14. Program Performance

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

Funding the Initiative at \$2.5 million annually will help ensure Mayo Clinic, USF, University of Miami, Holy Cross Health , NOVA SE Orlando Health and University of Florida Jacksonville will be able to continue providing much needed care to the growing number of ALS patients who attend these clinics. Funding the Initiative also ensures that clinics can function in a financially sustainable model, and avoid cutting back on the number of clinic days, or denying services to uninsured or underinsured ALS patients.

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

Multidisciplinary ALS Clinics have emerged as the gold standard for treating and supporting patients with ALS and their families. At a Multidisciplinary ALS Clinic, patients receive efficient, comprehensive care from a team of specialists at a single location, on a single day. The team includes a neurologist, specialized nurse case manager, pulmonologist (available as needed), gastroenterologist (available as needed), respiratory therapist, physical therapist, occupational therapist, speech therapist, dietitian, social worker, psychologist, palliative care expert and an ALS Association Chapter-Clinic Liaison. Multidisciplinary ALS Clinics coordinate care and interface with the primary care physician, local neurologist, and community-based services.

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

Even though ALS is currently incurable, studies have clearly demonstrated that patients who attend a Multidisciplinary ALS Clinic: (1) have 40 percent longer survival rates; (2) benefit from improved quality of life; (3) receive a higher standard of evidence-based care; and, (4) receive more assistance in managing their activities of daily living. In fact, multidisciplinary care is an independent predictor of survival. Patients attending multidisciplinary clinics had fewer hospital admissions and shorter inpatient stays than those who are cared for by a single provider. Additionally, a 2017 study titled "Multidisciplinary clinics coordinate care and interface with the primary care physician, local neurologist, and community-based services" found "survival of people attending a specialist ALS clinic have improved over a 13-year period... This supports the notion that specialist integrated multidisciplinary care provides benefit in ALS that can be measured in survival improvement"

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

There are currently ~1,350 people living with ALS in Florida, indicating a prevalence rate of 6 per 100,000. Because of the fatal nature of the disease, the number of people treated for ALS during a given year is actually much greater because some pass away during the year and are replaced by others who are newly diagnosed. Additionally, military veterans are twice as likely to be diagnosed with ALS than those without a military background so this program supports our veterans as well. In fact, ALS is considered a "service-related disease" by the US Department of Defense.

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

Decreased costs related to community-based and home-based care services because ALS patients can live independently longer; reduced drains on Medicaid; reduction in frequency and length of hospital stays; less burden on transportation services for the medical needy thanks to coordination of care. Additionally, the program helps to increase research investment from the Federal Government and the Pharmaceutical Industry thanks to improved access to ALS patients.

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.

15. Requester Contact Information

a. First Name **Last Name**

b. Organization



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2024-2025

LFIR # 2383

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