



# The Florida Senate

## Local Funding Initiative Request

### Fiscal Year 2021-2022

LFIR # 1279

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) and University of South Tampa (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 2021-2022**

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

7. **Total Project Cost for Fiscal Year 2021-2022 (including matching funds available for this project)**

Type of Funding	Amount	Percentage
Total State Funds Requested (from question #6)	1,000,000	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 2021-2022</b>	<b>1,000,000</b>	<b>100%</b>

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

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	Nonrecurring		
2020-21	0	800,000	509	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.**
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10. **Has the entity requesting this project received any federal assistance related to the COVID-19 pandemic?**



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Yes

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

The ALS Association Florida Chapter received \$190,595 through the Payroll Protection Program, which allowed the organization to maintain staffing levels over the summer months.

#### 11. 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	President/CEO and contract manager handle all contract tasks and deliverables, manage subcontracts with the ALS clinics and direct staff in all tasks related to the contract.	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. Finance/Administrative staff manage bookkeeping and other administrative tasks.	69,000
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	Contract management expenses include attorney services, printing/mailling costs, supplies, staff travel to ALS Clinics, expenses related to developing, executing and hosting the annual ALS Symposium.	48,000
Consultants/Contracted Services/Study	Subcontracts with ALS Clinics at Mayo Clinic (Jacksonville), University of South Florida (Tampa), University of Miami, UF Health (Jacksonville) and Holy Cross Health (Ft. Lauderdale).	868,000
<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>1,000,000</b>

#### 12. Program Performance

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

Funding the Initiative at a minimum of \$1 million annually will help ensure Mayo Clinic, USF, University of Miami, Holy Cross Health and University of Florida Jacksonville will be able to continue providing much needed care to the growing number of ALS patients that 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 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. Florida's clinics are increasingly unable to cover costs associated with these visits which are not covered for most patients by the Centers for Medicare & Medicaid (CMS) or private insurance. (~\$1,100/visit)



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**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 an 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.

**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.

**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. Additionally, because Florida is sustaining more ALS clinics than any other state in the Southeastern US, it increases medical tourism in the state.

**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?**

Suggested penalties will be determined by the state/Florida Department of Health.

**13. 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.**

The ALS Association Florida Chapter, Inc.



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#### 14. Requestor Contact Information

a. First Name  Last Name

b. Organization

c. E-mail Address

d. Phone Number  Ext.

#### 15. 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

#### 16. Lobbyist Contact Information

a. Name

b. Firm Name

c. E-mail Address

d. Phone Number