



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2020-2021

LFIR # 1660

1. **Project Title** Bitner Plante ALS Clinic Initiative of Florida2. **Senate Sponsor** Aaron Bean3. **Date of Request** 12/07/20194. **Project/Program Description**

Funding will provide access for ALS patients to receive comprehensive quality care through ALS Multidisciplinary Clinics in Florida. There are four certified centers in the state, located at Mayo Clinic (Jacksonville), University of Florida Jacksonville, University of Miami 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** Department of HealthState Agency contacted? ☒ Yes ☐ No6. **Amount of the Nonrecurring Request for Fiscal Year 2020-2021**

Type of Funding	Amount
Operations	1,000,000
Fixed Capital Outlay	000
Total State Funds Requested	1,000,000

7. **Total Project Cost for Fiscal Year 2020-2021 (including matching funds available for this project)**

Type of Funding	Amount	Percentage
Total State Funds Requested (from question #6)	1000000	100.0 %
Matching Funds		
Federal	00	0 %
State (excluding the amount of this request)	00	0 %
Local	00	0 %
Other	00	0 %
Total Project Costs for Fiscal Year 2020-2021	1,000,000	100 %

8. **Has this project previously received state funding?** ☒ Yes ☐ No

If yes, provide the most recent instance:

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	Nonrecurring		
2019-20	00	100,000	506	No

9. **Is future-year funding likely to be requested?** ☒ Yes ☐ No

If yes, indicate nonrecurring amount per year. 1,000,000



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10. Details on how the requested state funds will be expended

Spending Category	Description	Amount
Administrative Costs:		
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.	20,000
Expense/Equipment/Travel/Supplies/Other		
Consultants/Contracted Services/Study		
Operational Costs: Other		
Salary and Benefits		
Expense/Equipment/Travel/Supplies/Other	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.	50,000
Consultants/Contracted Services/Study	Subcontracts with ALS Clinics at Mayo Clinic (Jacksonville), University of South Florida (Tampa), University of Miami, University of Florida - Jacksonville.	915,000
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/ Land/Planning Engineering		
Total State Funds Requested (must equal total from question #6)		1,000,000



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11. 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 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 and 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. Multidisciplinary care costs ~\$1,000 per patient per visit. Florida's clinics are increasingly unable to cover these costs given that these costs are not covered for most patients by the Centers for Medicare & Medicaid (CMS) or private insurance.

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 ~1,500 people living with ALS in Florida, indicating a prevalence rate of 6-8 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 in the contract?

The suggested penalties as determined by the state/Florida Department of Health.



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12. **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.

13. **Requestor Contact Information**

- a. First Name Last Name
- b. Organization
- c. E-mail Address
- d. Phone Number Ext.

14. **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

15. **Lobbyist Contact Information**

- a. Name
- b. Firm Name
- c. E-mail Address
- d. Phone Number Ext.