



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2019-2020

LFIR#: 1880

1. **Title of Project:** UF Health Program to Treat and Cure Dystonia and Other Involuntary Muscle Disorders
2. **Senate Sponsor:** Rob Bradley
3. **Date of Submission:** 02/12/2019

4. **Project/Program Description:**

The funds will be used to support Dystonia research at the University of Florida through Brain Imaging, Development of new Dystonia researchers, new movement disorder specialists, CRISPR CAS-9, Deep Brain Stimulation, Functional Testing, PH.D's, outreach activities, genetic testing, clinical trials, and overall advancement of treatments and a cure.

5. **State Agency to receive requested funds :** Department of Education

State Agency Contacted? No

6. **Amount of the Nonrecurring Request for Fiscal Year 2019-2020**

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

7. **Total Project Cost for Fiscal Year 2019-2020 (including matching funds available for this project)**

Type of Funding	Amount	Percent
Total State Funds Requested (from question #6)	1,000,000	100.00%
Federal	0	0.00%
State (excluding the amount of this request)	0	0.00%
Local	0	0.00%
Other	0	0.00%
Total Project Costs for Fiscal Year 2019-2020	1,000,000	100.0%

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

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	NonRecurring		
2018-19		500,000	147	No

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

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

Spending Category	Description	Amount
Administrative Costs:		
Executive Director/Project Head Salary and Benefits		



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Other Salary and Benefits		
Expense/Equipment/Travel/Supplies/Other	Clinical trials participation; supplies related to research.	100,000
Consultants/Contracted Services/Study	The funds will be used to support Dystonia research at the University of Florida through Brain Imaging, Development of new Dystonia researchers, new movement disorder specialists, CRISPR CAS-9, Deep Brain Stimulation, Functional Testing, PH.D's, outreach activities, genetic testing, and overall advancement of treatments and a cure.	900,000
Operational Costs:		
Salary and Benefits		
Expense/Equipment/Travel/Supplies/Other		
Consultants/Contracted Services/Study		
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		
Total State Funds Requested (must equal total from question #6)		1,000,000

11. Program Performance:

- a. **What is the specific purpose or goal that will be achieved by the funds requested?**
Advancements in Dystonia treatments and/or a cure.
- b. **What are the activities and services that will be provided to meet the intended purpose of these funds?**
Brain imaging, development of Dystonia Research PhDs (Fellowship program), outreach, genetic testing, and overall advancement of treatments and cure.
- c. **What are the direct services to be provided to citizens by the appropriations project?**
The funding will provide citizens affected by movement disorders (including dystonia) with improved treatments, while providing funding for training of movement disorder fellows.
- d. **Who is the target population served by this project? How many individuals are expected to be served?**
All Floridians affected by movement disorders.
- e. **What is the expected benefit or outcome of this project? What is the methodology by which this outcome will be measured?**
Advancements in Dystonia treatments and/or a cure.
- 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?**
Funds will be revoked.

12. The owner(s) of the facility to receive, directly or indirectly, any fixed capital outlay funding. Include the relationship between the owner(s) of the facility and the entity.



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n/a

13. Requestor Contact Information:

- a. **Name:** Richard Staab
- b. **Organization:** Tyler's Hope for a Dystonia Cure
- c. **E-mail Address:** rstaab@intermed1.com
- d. **Phone Number:** (352)494-4417

14. Recipient Contact Information:

- a. **Organization:** UF Health Movement Disorders Clinic
- b. **County:** Alachua
- c. **Organization Type:**
 - For Profit
 - Non Profit 501(c) (3)
 - Non Profit 501(c) (4)
 - Local Entity
 - University or College
 - Other (Please specify)
- d. **Contact Name:** Michael Okun
- e. **E-mail Address:** okun@neurology.ufl.edu
- f. **Phone Number:** (352)294-5400

15. Lobbyist Contact Information

- a. **Name:** Nick Iarossi
- b. **Firm Name:** Capital City Consulting
- c. **E-mail Address:** Nlarossi@capcityconsult.com
- d. **Phone Number:** (850)222-9075