

LFIR # 2526

- **Project Title** 1. UF Health Program to Cure Dystonia and other Involuntary Muscle Disorders
- 2. **Senate Sponsor** Keith Perry
- 3. Date of Request 01/27/2020

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.

State Agency to receive requested funds Department of Education 5.

○ Yes ● No State Agency contacted?

Amount of the Nonrecurring Request for Fiscal Year 2020-2021 6.

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 %

Has this project previously received state funding? 8. Yes O No If yes, provide the most recent instance:

Fiscal Year	Amo	ount	Specific	
(уууу-уу)	Recurring	Nonrecurring	Appropriation #	Vetoed
2019-20	00	300,000		No

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

If yes, indicate nonrecurring amount per year.



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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				
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: Oth				
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 Re	equested (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?

Advancements in Dystonia treatments and/or a cure

b. What activities and services 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 direct services will be provided to citizens by the appropriation project?

The funding will provide citizens affected by movement disorders (including dystonia) with improved treatments, while proviidng 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.



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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.

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Requestor Contac	t Information			
a. First Name	Richard	Last Nam	ne	Staab
b. Organization	Tyler's Hope for a Dystonia Cure			
c. E-mail Address	rstaab@intermed1.com			
d. Phone Number	(352)494-4417	Ext.		
Recipient Contact	Information			
a. Organization	UF Health Movement Disorders Cli	inic		
b. Municipality and				
-				
 For-profit E Non-Profit : 	•			
Non-Profit				
 Local Entity 				
 University d 				
Other (plea	ise specify)			
d. First Name	Michael	Last Nar	ne	Okun
e. E-mail Address	okun@neurology.ufl.edu			
f. Phone Number	(352)2945400			
Lobbyist Contact				
a. Name	Nick larossi			
b. Firm Name	Capital City Consulting			
c. E-mail Address	Nlarossi@capcityconsult.com			
d. Phone Number	(850)2229075	Ext.		