

Appropriations Project Request - Fiscal Year 2020-21

For projects meeting the Definition of House Rule 5.14

1. Title of Project: University of Florida - Center for Rare Disease Research Excellence

2. Date of Submission: 11/15/2019

3. House Member Sponsor: James Grant

Members Copied:

4. DETAILS OF AMOUNT REQUESTED:

- a. Has funding been provided in a previous state budget for this activity? Yes
If answer to 4a is "No" skip 4b and 4c and proceed to 4d, Col. E
- b. What is the most recent fiscal year the project was funded? 2019-20
- c. Were the funds provided in the most recent fiscal year subsequently vetoed? No
- d. Complete the following Project Request Worksheet to develop your request:

FY:	Input Prior Year Appropriation for this project for FY 2019-20 (If appropriated in 2019-20 enter the appropriated amount, even if vetoed.)			Develop New Funds Request for FY 2020-21 (Requests for additional RECURRING funds are prohibited.)		
Column:	A	B	C	D	E	F
Funds Description:	Prior Year Recurring Funds	Prior Year Nonrecurring Funds	Total Funds Appropriated (Recurring plus Nonrecurring: column A + column B)	Recurring Base Budget (Will equal non- vetoed amounts provided in Column A)	Additional Nonrecurring Request	TOTAL Nonrecurring plus Recurring Base Funds (Will equal the amount from the Recurring base in Column D plus the Additional Nonrecurring Request in Column E.)
Input Amounts:		100,000	100,000		850,000	850,000

5. Are funds for this issue requested in a state agency's Legislative Budget Request submitted for FY 2020-21? No

5a. If yes, which state agency?

5b. If no, which is the most appropriate state agency to place an appropriation for the issue being requested? Department of Health

5c. Has the appropriate state agency for administering the funding, if the request were appropriated, been contacted? No

5d. Describe penalties for failing to meet deliverables or performance measures which the agency should provide in its contract to administer the funding if appropriated.

Penalties could include returning the funds to the state associated with unmet deliverables.

6. Requester:

- a. Name: Barry Byrne
- b. Organization: UF Health
- c. Email: bbyrne@ufl.edu
- d. Phone #: (352)494-4473

7. Contact for questions about specific technical or financial details about the project:

- a. Name: Barry Byrne
- b. Organization: UF Health
- c. Email: bbyrne@ufl.edu
- d. Phone #: (352)494-4473

8. Is there a registered lobbyist working to secure funding for this project?

- a. Name: Monica Rodriguez
- b. Firm: Ballard Partners
- c. Email: monica@ballardfl.com
- d. Phone #: (850)766-6287

9. Organization or Name of entity receiving funds:

- a. Name: University of Florida
- b. County (County where funds are to be expended): Alachua
- c. Service Area (Counties being served by the service(s) provided with funding): Statewide

10. What type of organization is the entity that will receive the funds? (Select one)

- ☐ For Profit
- ☐ Non Profit 501(c) (3)
- ☐ Non Profit 501(c) (4)
- ☐ Local Government
- ☒ University or College
- ☐ Other (Please describe)

11. What is the specific purpose or goal that will be achieved by the funds being requested?

Research focuses on correction of both the cardiac and neurological manifestations of the disease which cause early mortality and significant disability. FA is an inherited disease and is caused by changes in the frataxin gene. Currently, there are no treatments available. UF's research will work to restore frataxin levels and establish a high impact treatment for FA.

12. Provide specific details on how funds will be spent. (Select all that apply)

Spending Category	Description	Nonrecurring (Should equal 4d, Col. E) Enter "0" if request is zero for the category
Administrative Costs:		
<input type="checkbox"/> a. Executive Director/Project Head Salary and Benefits		
<input type="checkbox"/> b. Other Salary and Benefits		
<input type="checkbox"/> c. Expense/Equipment/Travel/Supplies/Other		
<input type="checkbox"/> d. Consultants/Contracted Services/Study		
Operational Costs:		
<input type="checkbox"/> e. Salaries and Benefits		
<input checked="" type="checkbox"/> f. Expenses/Equipment/Travel/Supplies/Other	\$245,000 equipments expense for a bioreactor and liquid handling equipment; \$180,000 non-recurring expense for animal studies	425,000
<input checked="" type="checkbox"/> g. Consultants/Contracted Services/Study	\$425 for study startup and study patient support	425,000
Fixed Capital Construction/Major Renovation:		
<input type="checkbox"/> h. Construction/Renovation/Land/Planning Engineering		
TOTAL		850,000

13. For the Fixed Capital Costs requested with this issue (In Question 12, category "h. Fixed Capital Outlay" was selected), what type of ownership will the facility be under when complete? (Select one correct option)

☐ For Profit

☐ Non Profit 501(c) (3)

☐ Non Profit 501(c) (4)

☐ Local Government (e.g., police, fire or local government buildings, local roads, etc.)

☐ State agency owned facility (For example: college or university facility, buildings for public schools, roads in the state transportation system, etc.)

☐ Other (Please describe)

14. Is the project request an information technology project?

No

15. Is there any documented show of support for the requested project in the community including public hearings, letters of support, major organizational backing, or other expressions of support?

Yes

15a. Please Describe:

Friedrich's Ataxia Research Alliance

16. Has the need for the funds been documented by a study, completed by an independent 3rd party, for the area to be served?

Yes

16a. Please Describe:

Research conducted by the UF Powell Gene Therapy Center

17. Will the requested funds be used directly for services to citizens?

Yes

17a. What are the activities and services that will be provided to meet the purpose of the funds?

Research conducted by the UF Powell Gene Therapy Center

17b. Describe the direct services to be provided to the citizens by the funding requested.

Increased research and expansion of proof-of-concept studies for Friedreich's Ataxia patients

17c. Describe the target population to be served (i.e., "the majority of the funds requested will serve these target populations or groups.").

Select all that apply to the target population:

- ☐ Elderly persons
- ☐ Persons with poor mental health
- ☒ Persons with poor physical health
- ☐ Jobless persons
- ☐ Economically disadvantaged persons
- ☐ At-risk youth
- ☐ Homeless
- ☐ Developmentally disabled
- ☒ Physically disabled
- ☐ Drug users (in health services)
- ☐ Preschool students
- ☐ Grade school students
- ☐ High school students
- ☐ University/college students
- ☐ Currently or formerly incarcerated persons
- ☐ Drug offenders (in criminal Justice)
- ☐ Victims of crime
- ☐ General (The majority of the funds will benefit no specific group)
- ☒ Other (Please describe): Individuals seeking treatment for Friedrich's Ataxia

17d. How many in the target population are expected to be served?

- ☐ < 25
- ☐ 25-50
- ☐ 51-100
- ☐ 101-200
- ☐ 201-400
- ☐ 401-800
- ☒ >800

18. What benefits or outcomes will be realized by the expenditure of funds requested? (Select each Benefit/Outcome that applies)

Benefit or Outcome	Provide a specific measure of the benefit or outcome	Describe the method for measuring level of benefit

<input checked="" type="checkbox"/> Improve physical health	Increased production and utilization of gene therapy product. Demonstration of gene therapy long-term impact on patients	Study Conclusions
<input type="checkbox"/> Improve mental health		
<input type="checkbox"/> Enrich cultural experience		
<input type="checkbox"/> Improve agricultural production/promotion/education		
<input type="checkbox"/> Improve quality of education		
<input type="checkbox"/> Enhance/preserve/improve environmental or fish and wildlife quality		
<input type="checkbox"/> Protect the general public from harm (environmental, criminal, etc.)		
<input type="checkbox"/> Improve transportation conditions		
<input type="checkbox"/> Increase or improve economic activity		
<input type="checkbox"/> Increase tourism		
<input type="checkbox"/> Create specific immediate job opportunities		
<input type="checkbox"/> Enhance specific individual's economic self sufficiency		
<input type="checkbox"/> Reduce recidivism		
<input type="checkbox"/> Reduce substance abuse		
<input type="checkbox"/> Divert from Criminal/Juvenile justice system		
<input type="checkbox"/> Improve wastewater management		
<input type="checkbox"/> Improve stormwater management		

<input type="checkbox"/> Improve groundwater quality		
<input type="checkbox"/> Improve drinking water quality		
<input type="checkbox"/> Improve surface water quality		
<input type="checkbox"/> Other (Please describe):		

19. Provide the total cost of the project for FY 2020-21 from all sources of funding (Enter "0" if amount is zero):

Type of Funding	Amount	Percent of Total	Are the other sources of funds guaranteed in writing?
1. Amount Requested from the State in this Appropriations Project Request:	850,000	100.0%	N/A
2. Federal:	0	0.0%	No
3. State: (Excluding the requested Total Amount in #4d, Column F)	0	0.0%	No
4. Local:	0	0.0%	No
5. Other:	0	0.0%	No
TOTAL	850,000	100%	

20. Is this a multi-year project requiring funding from the state for more than one year?

No