



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2019-2020

LFIR#: 1955

1. Title of Project: Expansion of Newborn Genetics Testing Centers

2. Senate Sponsor: Aaron Bean

3. Date of Submission: 02/23/2019

4. Project/Program Description:

This project expands genetic services and adds one center in Jacksonville as a collaborative effort between the Wolfson’s Children’s Hospital and the Florida Newborn Screening Program to accommodate the growth in newborns, genetics tests, and advances in medicine that provide options for treating newborns with genetic disorders.

5. State Agency to receive requested funds : Department of Health

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		100.0%

8. Has this project previously received state funding? No

Fiscal Year (yyyy-yy)	Amount		Specific Appropriation #	Vetoed
	Recurring	NonRecurring		

9. Is future-year funding likely to be requested? Yes

a. If yes, indicate non-recurring amount per year. \$1,000,000.

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

Spending Category	Description	Amount
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Administrative Costs:		
Executive Director/Project Head Salary and Benefits	Director - Pediatric Geneticist 1.0 FTE.	290,000
Other Salary and Benefits	Staff 2nd Pediatric Geneticist - 1.0 FTE; Genetic Counselor - 1.0 FTE; Case Manager/Telemedicine Coordinator - .50 FTE; and Social Worker - 0.50 FTE.	455,750
Expense/Equipment/Travel/Supplies/Other	Various computers, equipment, and phones.	254,250
Consultants/Contracted Services/Study		0
Operational Costs:		
Salary and Benefits		
Expense/Equipment/Travel/Supplies/Other		
Consultants/Contracted Services/Study		
Fixed Capital Construction/Major Renovation:		
Construction/Renovation/Land/Planning Engineering		0
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?

Develop a much needed Genetics program to allow for regionalization and appropriate timely provision of services.

b. What are the activities and services that will be provided to meet the intended purpose of these funds?

Many medical services related to the diagnosis including, but not limited to, the surgery, nutrition, genetics physician, genetics counselor, and laboratory support.

c. What are the direct services to be provided to citizens by the appropriations project?

Follow-up services to include, but not limited to, children whose genetic testing was discovered to require further evaluation and/or treatment in the mandatory newborn genetic testing.

d. Who is the target population served by this project? How many individuals are expected to be served?

Primarily newborn infants and their families, as well as older children diagnosed as newborns or later. Based on extrapolated DOH data on newborn screening, it is estimated that the program will serve about 850 new children each year as well as the many that require ongoing lifetime care. Each year the centers serve about 3,400 children found to have a condition that warrants additional testing, counseling, and care. This is in addition to the thousands of children that require ongoing care from previous years. By adding a new center to the growing population, additional tests and advancing medical care will allow the centers to reduce time delays and reduce debilitating conditions.

e. What is the expected benefit or outcome of this project? What is the methodology by which this outcome will be measured?



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The expected benefit are timely and appropriate Statewide pediatric services addressing both the extended delays and distances traveled to obtain services. The methodology by which this outcome will be measured is the successful recruitment of additional providers.

- 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 Agencies standard contract penalties are sufficient.

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.**

N/A

13. **Requestor Contact Information:**

- a. **Name:** Dana Ferrell-Birchfield
- b. **Organization:** Florida Association of Children's Hospitals
- c. **E-mail Address:** dferrell@flchildrenshospitals.org
- d. **Phone Number:** (904)910-8050

14. **Recipient Contact Information:**

- a. **Organization:** Wolfson's Children's Hospital in coordination with UF Health Jacksonville
- b. **County:** Duval
- c. **Organization Type:**
 - For Profit
 - Non Profit 501(c) (3)
 - Non Profit 501(c) (4)
 - Local Entity
 - University or College
 - Other (Please specify) Children's Hospitals
- d. **Contact Name:** Michael Aubin
- e. **E-mail Address:** michael.aubin@bmcjax.com
- f. **Phone Number:** (904)202-8731

15. **Lobbyist Contact Information**

- a. **Name:** Michael Cusick
- b. **Firm Name:** Michael Cusick & Associates, Inc.
- c. **E-mail Address:** Mike@MichaelCusick.com
- d. **Phone Number:** (850)222-5620