



The Florida Senate

Local Funding Initiative Request

Fiscal Year 2019-2020

LFIR#: 1245

1. Title of Project: Advanced Genomics for Critically Ill Newborns

2. Senate Sponsor: Manny Diaz

3. Date of Submission: 02/02/2019

4. Project/Program Description:

The program will implement rapid whole genome sequencing (rWGS) for critically ill children in the neonatal (NICU) and pediatric intensive care unit (PICU) at Nicklaus Children's Hospital (NCH). Approximately 3% of newborns are born with genetic problems, and in the NICU and PICU, unrecognized genetic disorders are much more common. rWGS has already been successfully piloted at NCH and other pediatric hospitals around the US. This test provides a rapid genetic diagnosis, typically under 5 days, to children suspected to have an underlying genetic component to their illness. Early diagnosis allows early treatment, giving children the best chance at a healthy life and ultimately saving health care costs of affected children. To date, ~70% of children that have received rWGS at NCH have been definitively diagnosed. Since health insurance payors do not currently cover rWGS, funds are needed to demonstrate the utility and cost effectiveness of rWGS.

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	880,000
Fixed Capital Outlay	
Total State Funds Requested	880,000

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)	880,000	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	880,000	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



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- a. If yes, indicate non-recurring amount per year. \$880,000

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	Support for data management platform to provide storage and integration of genomic data with other clinical information.	60,000
Consultants/Contracted Services/Study	50 patient samples at \$14,500 per test (\$725,000).	725,000
Operational Costs:		
Salary and Benefits	Salaries: Salary support for Genetic Counselor and Nurse/Patient Navigator to provide patient education, consults, and follow-up.	95,000
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)		880,000

11. Program Performance:

- a. **What is the specific purpose or goal that will be achieved by the funds requested?**

Expand implementation of rWGS at NCH to ensure that more children in Florida with genetic diseases are accurately diagnosed and treated.

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

Genetic diagnosis and tailored medical care of critically ill newborns using rWGS.

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

rWGS will be provided to acutely ill children with the purpose of finding a genetic diagnosis. Accurate diagnosis will allow NCH physicians and other clinical staff to provide the most appropriate and tailored medical care to some of our sickest and medically complex children. For parents and caregivers, this will give their child the best chance at a healthy and productive life.

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

The target population is acutely ill children in the NICU and PICU at NCH. Approximately 50 patients are projected to be served through this project.

- 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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Decreased morbidity and improved long-term health outcomes in children admitted to the NICU and PICU at NCH. Method: With a definitive genetic diagnosis, physicians and clinical staff can provide the most effective care and treatments for critically sick children, a population for which every day counts when determining the optimal medical intervention.

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?

None. Any unused funds would be returned.

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:** Narendra Kini
- b. **Organization:** Nicklaus Children's Health System
- c. **E-mail Address:** lani.ferro@nicklaushealth.org
- d. **Phone Number:** (305)878-9590

14. Recipient Contact Information:

- a. **Organization:** Nicklaus Children's Health System
- b. **County:** Miami-Dade
- 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:** Narendra Kini
- e. **E-mail Address:** narendra.kini@nicklaushealth.org
- f. **Phone Number:** (305)662-8203

15. Lobbyist Contact Information

- a. **Name:** Lani Ferro
- b. **Firm Name:** n/a
- c. **E-mail Address:** lani.ferro@nicklaushealth.org
- d. **Phone Number:** (305)878-9590