

Budget Detail Request - Fiscal Year 2016-17

Your request will not be officially submitted unless all questions and applicable sub parts are answered.

1. Title of Project: North Florida Regional Pediatric Genetics Services
2. Date of Submission: 12/09/2015
3. House Member Sponsor(s): Mia Jones

4. DETAILS OF AMOUNT REQUESTED:

- a. Has funding been provided in a previous state budget for this activity? No
If answer to 4a is ?NO? skip 4b and 4c and proceed to 4d
- b. What is the most recent fiscal year the project was funded?
- 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 (Note that Column E will be the total of Recurring funds requested and Column F will be the total Nonrecurring funds requested, the sum of which is the Total of the Funds you are requesting in Column G):

FY:	Input Prior Year Appropriation for this project for FY 2015-16 (If appropriated in FY 2015-16 enter the appropriated amount, even if vetoed.)			Develop New Funds Request for FY 2016-17 (If no new Recurring or Nonrecurring funding is requested, enter zeros.)			
	Column: A	B	C	D	E	F	G
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)	INCREASED or NEW Recurring Requested	TOTAL Nonrecurring Requested (Nonrecurring is one time funding & must be re-requested every year)	Total Funds Requested Over Base Funding (Recurring plus Nonrecurring: Column E + Column F)
Input Amounts:					400,000	0	400,000

- e. New Nonrecurring Funding Requested for FY 16-17 will be used for:
- f. New Recurring Funding Requested for FY 16-17 will be used for:

5. Requester:

- a. Name: Michael Aubin
- b. Organization: Wolfson Children's Hospital

- c. Email: michael.aubin@bmcjax.com
- d. Phone #: (904)202-8732

6. Organization or Name of Entity Receiving Funds:

- a. Name: Wolfson Children's Hospital
- b. County (County where funds are to be expended) Duval
- c. Service Area (Counties being served by the service(s) provided with funding) Baker, Clay, Duval, Nassau, Saint Johns

7. Write a project description that will serve as a stand-alone summary of the project for legislative review. The description should summarize the entire project's intended purpose, the purpose of the funds requested (if request is a sub-part of the entire project), and most importantly the detail on how the funds requested will be spent - for example how much will be spent on positions and associated salaries, specifics on capital costs, and detail of operational expenses. The summary must list what local, regional or statewide interests or areas are served. It should also document the need for the funds, the community support and expected results when applicable. Be sure to include the type and amount of services as well as the number of the specific target population that will be served (such as number of home health visits to X, # of elderly, # of school aged children to receive mentoring, # of violent crime victims to receive once a week counseling etc.)

Funding will support the joint initiative of Wolfson Children's Hospital, University of Florida ? Jacksonville, College of Medicine and Nemours Children's Specialty Care. Funds will be spent on recruitment and hiring of additional personnel, including Pediatric Geneticists, Pediatric Genetics Counselors and social workers and dietitians. The ongoing lack of funding of a Pediatric Genetics center has led to major deficits in Pediatric Genetic services in the Jacksonville/ North Florida Region. Newborn Screening Prevents Child Death and Lifelong Disabilities Florida Law requires newborn screening. The Department of Health Children's Medical Services implements this screening program. This funding will allow the newborn screening centers to improve testing turnaround time and relieve backlog. One out of 1,000 children are born with metabolic disorders and delays in interventions can result in death, disability and dependence for state support for life. Today's centers are funded at 2003 levels, despite a substantial increase in the number of tests per child (2 tests conducted in 1980 compared to 31 tests conducted today). Newborn Conditions:

- o Organic Acidemia (high acid, high ammonium levels or high or low glucose levels): Must Treat within Hours o Delay results in death or brain damage.
- o Phenylketonuria (PKU): Must Treat within Day o Delay results in death, brain damage, blindness, cataracts, death o Genetic Syndromes: Constant Contact with Patient and Parents (typically very complicated testing and analysis) o Requires the most highly specialized testing and genetic intervention for rare metabolic conditions. Delays in reaching a specialist in Florida results in severe delays in child development.

Background The Florida Newborn Screening Program began in 1965 with phenylketonuria (PKU) screening. With the expansion to galactosemia testing in 1980, three Genetics Centers were funded by the Legislature at the then-existing medical schools-the University of Miami, the University of South Florida and the University of Florida- to support the diagnosis and clinical care of identified patients. Between 1980 and 2000, more than 2.6 million Florida newborns were screened for PKU, galactosemia, sickling syndromes, hypothyroidism, and congenital adrenal hyperplasia. Of that group, 2,799 were identified with one of these disorders. Thus, through this program, approximately 1:1000 newborns were identified with a significant disorder that would not otherwise be readily identified at birth. In 2006, screening was expanded to the full panel recommended by the Department of Health and Human Services, including hearing screening , MS/MS screening, Severe Combined Immunodeficiency SCID (2012), and critical congenital heart disease (CCHD) in 2013. It is generally considered

that each \$1 invested in Newborn Screening saves approximately \$7 in total cost. These savings are primarily due to reduction in medical costs and cost of residential treatment associated with severe intellectual disability- which can be prevented with Newborn Screening. The emotional cost for a family caring for a child with severe intellectual disability, which could have been prevented, is impossible to calculate. In short, newborn screening is an invaluable and cost-effective public health service. In 1980, when the three genetics centers were funded, Florida had a population of 9.7 million, and the centers supported children with 2 inborn errors-PKU and galactosemia. In 2014, Florida has a population of over 19 million, and the Genetics Centers support children with 22 diagnoses. Florida has far outgrown the system created in 1980, in terms of patient needs, financial support, and clinical and financial viability. Clinical Pediatric Genetics programs in Florida, as in much of the U.S., are in a precarious state. The causes of this problem are multiple, and include: 1. The high labor intensity of the clinical services, with essentially no medical procedures to enhance revenue. 2. The high Medicaid or poorly- funded patient mix. 3. The fact that Genetic Counselors are not licensed in Florida, precluding successful billing for their services. 4. The small numbers of slots filled in Clinical Genetics residency training programs has effectively reduced the potential supply of physicians in the specialty. 5. A significant fraction of Florida's Clinical Geneticists is within a nominal 5-10 years of retirement. 6. The current reimbursement model prohibitively impedes the hiring of junior faculty. Expansion would encumber a large financial negative in an already financially stressed environment. 7. The three CMS-funded Genetics Centers (UF, USF, Miami) are funded through two separate contracts: 1. \$87,600 per center annually, begun in 2005-2006, to support the MS/MS newborn screening, 2. varying Center amounts to support long-term Genetics care. These contracts have not been increased since 2003-04; the US inflation since 2003 is 26.4%. Therefore, the Centers are effectively receiving roughly 26% less support than in 2003. 8. The population in the State of Florida has continued to grow rapidly, and there has been no increase in funding to support increasing numbers of children requiring Clinical Genetics services under these contracts. In short, without a significant change, it is very likely that within 5-10 years the availability of Clinical Geneticists, particularly Metabolic Geneticists, who can evaluate and manage metabolic patients identified by the Newborn Screening Program, will be woefully inadequate. Delays in evaluation, long drives for care, and referrals out of state will be routine. This entire element of the newborn screening effort will be in jeopardy.

8. Provide the total cost of the project for FY 2016-17 from all sources of funding:

Federal: 0

State: 0 (Excluding the requested Total Amount in #4d, Column G)

Local: 0

Other: 200,000

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

Yes