



The Florida Senate

Local Funding Initiative Request - Fiscal Year 2018-2019

1. **Title of Project:** Newborn Screening for Rare Diseases

2. **Senate Sponsor:** Lauren Book

3. **Date of Submission:** 01/11/2018

4. **Project/Program Description:**

Implement Newborn Screening to ensure that babies in Florida are screened at birth for life threatening diseases.

5. **State Agency Contacted?** Yes

a. If yes, which state agency? Department of Health

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

6. **Amount of Non-recurring Requested for fiscal year 2018-19:**

Amount Requested for Operations	Amount Requested for Fixed Capital Outlay	Total Amount of Requested State Funds
1,911,628		1,911,628

7. **Type, amount and percent of matching funds available for this project for fiscal year 2018-19:**

Type	Amount	Percent
Federal	0	0.0%
State (excluding the amount of this request)	0	0.0%
Local	0	0.0%
Other	0	0.0%
TOTAL	0	0.0%

8. **Total Project Cost for fiscal year 2018-19 (including the Total Amount of Requested State Funds):** 1,911,628

9. **Previous Year Funding Details:**

a. Has funding been provided in a previous state budget for this activity? Yes

b. In the previous 5 fiscal years, how many years was funding provided? (Optional) 5

c. What is the most recent fiscal year the project was funded? 2017-18

d. Were the funds provided in the most recent fiscal year subsequently vetoed? No

e. Complete the following Worksheet.

FY:	Input Prior FY Appropriation for this project for FY 2017-18
-----	---



The Florida Senate

Local Funding Initiative Request - Fiscal Year 2018-2019

	(If appropriated in FY 2017-18 enter the appropriated amount, even if vetoed.)		
Column:	A	B	C
Funds Description:	Prior Year Recurring Funds *	Prior Year Nonrecurring Funds *	Total Funds Appropriated (Column A + Column B)
Input Amounts:	1,331,492		1,331,492

10. Is future-year funding likely to be requested?

Yes

a. If yes, indicate non-recurring amount per year.

Between \$1,000,000 and \$2,000,000 per year

11. Program Performance:

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

Implement Newborn Screening for Pompe Disease and Mucopolysaccharidosis type 1 to ensure that babies in Florida are screened at birth for these life threatening diseases.

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

Disease screening for newborns

c. How will the funds be expended?

Spending Category	Description	Amount
Administrative Costs		
<input type="checkbox"/> Executive Director/Project Head Salary and Benefits		
<input checked="" type="checkbox"/> Other Salary and Benefits	2 additional chemists for state laboratory and 2 registered nursing consultants to provide education to healthcare providers and conduct surveillance and tracking of newborns	339,628



The Florida Senate

Local Funding Initiative Request - Fiscal Year 2018-2019

<input checked="" type="checkbox"/> Expense/Equipment/Travel/Supplies/Other	300,000 specimens for each condition at \$2.50 per screen	750,000
<input checked="" type="checkbox"/> Consultants/Contracted Services/Study	Second tier molecular lab and genetic centers	822,000
Operational Costs		
<input type="checkbox"/> Salary and Benefits		
<input type="checkbox"/> Expense/Equipment/Travel/Supplies/Other		
<input type="checkbox"/> Consultants/Contracted Services/Study		
Fixed Capital Construction/Major Renovation		
<input type="checkbox"/> Construction/Renovation/Land/Planning Engineering		
TOTAL		1,911,628

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

Parents of newborns with Pompe and MPS will be notified and have the opportunity to seek treatment for their babies preventing disability and death

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

Newborns

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

Improve physical health for newborns. Method: early diagnosis and treatment will give the child the best chance at a healthy and productive life.

g. 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 would be returned to the general revenue fund

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: Julia Jenkins

b. Organization: EveryLife Foundation for Rare Diseases



The Florida Senate

Local Funding Initiative Request - Fiscal Year 2018-2019

- c. **Email:** jjenkins@everylifefoundation.org
- d. **Phone Number:** [\(415\)254-5758](tel:(415)254-5758)

14. Recipient Contact Information:

- a. **Organization:** [EveryLife Foundation for Rare Diseases](#)
- b. **County:** [Statewide](#)
- 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:** [Julia Jenkins](#)
- e. **E-mail Address:** jjenkins@everylifefoundation.org
- f. **Phone Number:** [\(415\)254-5758](tel:(415)254-5758)

15. If there is a registered lobbyist, fill out the lobbyist information below.

- a. **Name:** [Kelly Mallette](#)
- b. **Firm:** [Ronald L. Book, P.A.](#)
- c. **Email:** kelly@rlbookpa.com
- d. **Phone Number:** [\(305\)935-1866](tel:(305)935-1866)