

**LFIR # 2143** 

1. Project Title	Enhancing Under Cause of Death I	rstanding of Mortal nitiative	lity in Sickle Cell Disea	se through a	
2. Senate Sponsor	Darryl Rouson				
3. Date of Request	3/3/2025				
4. Project/Program De	escription				
Sickle cell disease ( the precise cause of SCD-related mortalit insights into the und legislative request p	(SCD) is a chronic are feath remains unkrety. An initiative to enderlying causes of de roposes the establis	nown. This lack of courage autopsies ath, leading to imp hment of a compre	data impedes advance for individuals who pa proved care, prevention	ements in treatments away from SCD ass away from SCD attracting and act and Initiative to increase.	uccumb to the disease, t and understanding of would provide critical dvocacy efforts. This ease autopsy consent
5. State Agency to red			ent of Health		
State Agency conta	•				
6. Amount of the Noni		iar Figaal Vaar 20	12E 2026		
	ecurring Request i	OI FISCAI TEAI 20			l
Type of Funding			Amou		
Operating  Fixed Capital Outland				2,500,000	
Fixed Capital Outlay  Total State Funds I				2,500,000	
Total Otale I ulius I	requesteu			2,300,000	I
7. Total Project Cost f	or Fiscal Year 2025	5-2026 (including	matching funds avai	lable for this proje	ect)
Type of Funding			Amount	Percentage	
Total State Funds R	equested (from ques	stion #6)	2,500,000	100%	
Matching Funds					
Federal			0	0%	
•	amount of this requi	est)	0	0%	
Local			0	0%	
Other			0	0%	
Total Project Costs	for Fiscal Year 20	25-2026			
	eviously received s	tate funding?	0	0%	
8. Has this project prediction of the life yes, provide the life year	eviously received s most recent instand	tate funding? ce:	0 2,500,000 No Specific	0%	
8. Has this project pro If yes, provide the	eviously received s most recent instand	tate funding? ce:	0 <b>2,500,000</b> No	0% <b>100</b> %	
8. Has this project profif yes, provide the Fiscal Year (уууу-уу) 9. Is future-year fundia. If yes, indicate n	eviously received s most recent instance Amo Recurring ing likely to be required to the confection of	tate funding? ce: unt Nonrecurring uested? nt per year.	0 2,500,000 No Specific	0% <b>100</b> %	



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### **Complete questions 10 and 11 for Fixed Capital Outlay Projects**

	"shovel ready" ( stimated start da	(i.e permitted)?		
		etion date of construc	tion?	
. What funding	stream will be u	ised for ongoing oper	ations and mainten	ance of the project?

#### 12. Details on how the requested state funds will be expended

Spending Category	Description	Amount
Administrative Costs:		
Executive Director/Project Head Salary and Benefits	Responsible for the oversight and overall management of the project	150,000
Other Salary and Benefits	Grants and finance administrators are responsible to provide financial and administrative support services to designated program staff, assist with oversight of implementation and monitoring.	50,000
Expense/Equipment/Travel/Supplies/ Other		0
Consultants/Contracted Services/Study		0
Operational Costs		
Salary and Benefits	Relevant staff for education campaigns, data collection infrastructure and community engagement efforts	600,000
Expense/Equipment/Travel/Supplies/ Other	Operational expenses related to education campaigns, data collection infrastructure and community engagement efforts	1,700,000
Consultants/Contracted Services/Study		0
Fixed Capital Construction/Majo	r Renovation:	
Construction/Renovation/Land/ Planning Engineering		0
Total State Funds Requested (m	ust equal total from question #6)	2,500,000

#### 13. Program Performance

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



### **The Florida Senate Local Funding Initiative Request** Fiscal Year 2025-2026

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Sickle cell disease (SCD) is a chronic and life-threatening condition, yet for many individuals who succumb to the disease, the precise cause of death remains unknown. This lack of data impedes advancements in treatment and

u w	nderstanding of SCD-related mortality. An initiative to encourage autopsies for individuals who pass away from SCD rould provide critical insights into the underlying causes of death, leading to improved care, prevention strategies, and dvocacy efforts.
b.	What activities and services will be provided to meet the intended purpose of these funds?
2 3 4	I. Creation of an Autopsy Consent Program . Incentivizing Family Consent . Standardized Autopsy Protocols . Data Collection and Research . Community Engagement and Education
C.	What direct services will be provided to citizens by the appropriation project?
P	Autopsies and data collection and research, as well as community engagement
d.	Who is the target population served by this project? How many individuals are expected to be served?
I	ndividuals living with Sickle Cell Disease. Over 800
	What is the expected benefit or outcome of this project? What is the methodology by which this outcome will e measured?
•	Increase in autopsy rates for SCD-related deaths by 40% within five years.
•	Improved understanding of SCD mortality trends and contributing factors.
•	Development of new prevention and treatment strategies informed by autopsy findings.
F	For a failure to meet deliverables, service provider may be penalized by determined percentage with respect to any adulure by service provider to meet the acceptance criteria for any deliverable as set forth in the applicable work
	this project related to mitigation, response, or recovery from a natural disaster? No
	f Yes, what phase best describes the project?
	Mitigation (reducing or eliminating potential loss of life or property)
	Response (addressing the immediate and short-term effects of a natural disaster)
	Recovery (assisting communities return to normal operations, including rebuilding damaged infastructure)
b. I	Name of the natural disaster (or Executive Order # for events not under a federal declaration):
5. Ha	as the entity applied for or received federal assistance for this project?
	Yes, Applied
	Yes, Received
	No
	No, but intends to apply



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a. If yes, provide th	e FEMA project worksheet ID#:
b. Provide the total	project cost listed on the FEMA project worksheet:
16. Has the entity app	lied for or received state assistance for this project (other than this request)?
☐ Yes, Applied	
☐ Yes, Received	
□ No	
☐ No, but intends to	o apply
a. If yes, specify the Commerce):	e program and state agency (ex. Local Government Emergency Bridge Loan, Department of
17. Requester Contact	Information
a. First Name	Lanetta Last Name Bronte
b. Organization	Foundation for Sickle Cell Disease Research
c. E-mail Address	lbronte@fscdr.org
d. Phone Number	(954)397-3251 <b>Ext.</b>
18. Recipient Contact	Information
a. Organization	Foundation for Sickle Cell Disease Research
b. Municipality and	I County Statewide
c. Organization Ty <sub>l</sub>	pe e
□For Profit Entity	
☑Non Profit 501(c	)(3)
□Non Profit 501(c	)(4)
□Local Entity	
□University or Co	llege
□Other (please sp	pecify)
d. First Name	Lanetta Last Name Bronte
e. E-mail Address	lbronte@fscdr.org

Ext.

**f. Phone Number** (954)397-3251



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). Lobbyist Contact I	nformation	
a. Name	None	
b. Firm Name		
c. E-mail Address		
d. Phone Number		

The information provided will be posted to the Florida Senate website for public viewing if sponsored by a Senator.