

LFIR # 1788

1. Project Title	Jordan Avi Ogman Foundation for Research & Development of TECPR2
-	Disease Cure

2. Senate Sponsor Tina Polsky

3. Date of Request 02/22/2021

4. Project/Program Description

Research and development of the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, Pediatric genetic disease. The gene therapy cure for TECPR2 being developed to save the lives of the children battling this debilitating disease will enable the research to advance as its transitional to understanding how to further develop gene therapy for similar devastating neurodegenerative disease for children throughout our state of Florida.

5. State Agency to receive requested funds

Department of Health

State Agency contacted? No

6. Amount of the Nonrecurring Request for Fiscal Year 2021-2022

Type of Funding	Amount
Operations	50,000
Fixed Capital Outlay	0
Total State Funds Requested	50,000

7. Total Project Cost for Fiscal Year 2021-2022 (including matching funds available for this project)

Type of Funding	Amount	Percentage	
Total State Funds Requested (from question #6)	50,000	100%	
Matching Funds			
Federal	0	0%	
State (excluding the amount of this request)	0	0%	
Local	0	0%	
Other	0	0%	
Total Project Costs for Fiscal Year 2021-2022	50,000	100%	

8. Has this project previously received state funding? No

Fiscal Year	Amo	ount	Specific	Vetoed
(уууу-уу)	Recurring	Nonrecurring	Appropriation #	

9. Is future funding likely to be requested?

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a. If yes, indicate nonrecurring amount per year.

b. Describe the source of funding that can be used in lieu of state funding.

Outside of state funding, the research and development of TECPR2 neurodegenerative disease is a grassrotos effort by individual donors. The pace of which donations are raised are preventing the scientists from receiving the necessary funding to develop the cure.

10. Has the entity requesting this project received any federal assistance related to the COVID-19 pandemic?

No



No

If yes, indicate the amount of funds received and what the funds were used for.

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

Spending Category	Description	Amount
Administrative Costs:		
Executive Director/Project Head Salary and Benefits	No Salaries and No Benefits to any officers of the Jordan Avi Ogman Foundation.	0
Other Salary and Benefits	No Salaries and No Benefits to any officers of the Jordan Avi Ogman Foundation.	0
Expense/Equipment/Travel/Supplies/ Other		0
Consultants/Contracted Services/Study		0
Operational Costs: Other		
Salary and Benefits		0
Expense/Equipment/Travel/Supplies/ Other	Our team of Scientists have been conducing research to develop the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, genetic disease. Now that the research is complete, and as we further develop the gene therapy constructs to examine efficacy and safety, we are progressing towards the manufacturing, production, and associated costs of developing the vector to be perfected so that it provides the desired outcome.	25,000
Consultants/Contracted Services/Study	Working with a team of scientists at the University of Florida, and next steps include engaging outside experts and companies involved in the progression of the development of the Gene Therapy to be administered for the children diagnosed with this genetic disorder.	25,000
Fixed Capital Construction/Majo	r Renovation:	
Construction/Renovation/Land/ Planning Engineering		0
Total State Funds Requested (m	ust equal total from question #6)	50,000

12. Program Performance

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

The purpose and/or goal is research and development of the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, Pediatric genetic disease. The gene therapy cure for TECPR2 being developed to save the lives of the children battling this debilitating disease will enable the research to advance as its transitional to understanding how to futher develop gene therapy for similar devastatying neurodegenerative disease for children throughout our state of Florida.

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

Research and development of the life-saving gene therapy cure for TECPR2, a rare, fatal, and progressive, neurodegenerative, Pediatric genetic disease. The gene therapy cure for TECPR2 being developed to save the lives of the children battling this debilitating disease will enable the research to advance as its transitional to understanding how to further develop gene therapy for similar devastating neurodegenerative disease for children throughout our state of Florida.

c. What direct services will be provided to citizens by the appropriation project?

Direct services provided to citizens will be the life-saving gene therapy cure.



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

Pediatric population of children battling rare, fatal, and progressive, neurodegenerative, genetic disease.

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

Benefit is life-saving gen therapy cure to cure TECPR2 neurodegenerative disease in children.

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 the contract?

Failure to meet performance is unacceptable, as our kids require this life-saving gene therapy cure, so we will continue to research and develop the cure until it is perfected for our children in the state of Florida.

13. The owners of the facility to receive, directly or indirectly, any fixed capital outlay funding. Include the relationship between the owners of the facility and the entity.

David Ogman is the father of 5 year old Jordan who was diagnosed with TECPR2, a rare, fatal, and progressive, neurodegenerative, Jewish Genetic Disease. Capital will be allocated to either the University of Florida or outside entities involved in the research and development of the life-saving gene therapy cure which includes operations, manufacturing, production, research, development, and associate costs of desired outcome of Gene Therapy cure for the children.



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14. Requestor Contact Information

	a. First Name	David		Last Name	Ogman		
	b. Organization	Jordan Avi Ogman Foundation					
	c. E-mail Address	David.M.Ogman@gmail.com					
	d. Phone Number	(561)945	-5040	Ext.			
15. Recipient Contact Information							
	a. Organization	Jordan Av	vi Ogman Found	ation			
	b. Municipality and	I County	Palm Beach				
	c. Organization Ty	be					
	□For Profit Entity						
	⊠Non Profit 501(c	:)(3)					
	□Non Profit 501(c)(4)					
	□Local Entity						
	□University or Co	llege					
	□Other (please sp	se specify)					
	d. First Name	David		Last Name	Ogman		
	e. E-mail Address	David.M.	David.M.Ogman@gmail.com				
	f. Phone Number	(561)945	-5040				
16.	. Lobbyist Contact I	nformatio	n				
	a. Name	NA					
	b. Firm Name						
	c. E-mail Address						
	d. Phone Number						