



Press Release February 28, 2024

FOR IMMEDIATE RELEASE

SHINING A LIGHT ON LAFORA DISEASE IN GAZA, GLOBALLY

Chelsea's Hope will raise awareness about Lafora on Rare Disease Day 2024.

SACRAMENTO, Calif. – February 28, 2024 – [Chelsea's Hope Lafora Children Research Fund](#), a 501(c)(3) nonprofit organization, joins the global rare disease community to advocate for patients like 17-year-old Zaina in Gaza and raise awareness about Lafora on the rarest day of the year - February 29, 2024.

Lafora Disease is a neurodegenerative condition affecting an estimated 200 children worldwide. It is a genetic condition in which patients cannot maintain a normal glycogen concentration, resulting in a toxic accumulation of glycogen, or Lafora Bodies, in the heart, spine, and brain. Symptoms include ataxia, childhood dementia, cognitive decline, and difficulty speaking, walking, and eating.

Zaina was diagnosed with the ultra-rare epilepsy at the age of 13. A stellar student, Zaina applied herself to physical, occupational, and speech therapy just as she had in school. She relied on medication to manage her seizures and lost the ability to speak and move because of her Lafora symptoms.

Currently, Zaina is surrounded by violence and destruction in Gaza. The hospital where she received treatment is no longer operable, and her family has evacuated their home and moved across Gaza several times to escape the fighting. Chelsea's Hope has remained in contact with her mother, Doaa, since October 8. The worldwide Lafora community has shared their story and supports the family however we can.

"There is nothing in pharmacies...There is no clean place here... Everything is bad... Anyone who can help us and follow Zaina's topic, please," shared Doaa.

While Zaina's Lafora story is similar to other children, she is experiencing extraordinary conditions compared to other patients. This Rare Disease Day, join us in raising awareness. To help her family evacuate Gaza, visit <https://www.gofundme.com/f/save-zeina-and-the-rest-of-my-family-evacuate-gaza>.

###

Chelsea's Hope was created in 2007 when Linda Gerber and a small group of dedicated friends developed a website to share her daughter Chelsea's story. Today, the mission of Chelsea's Hope Lafora Children Research Fund is to improve the lives of those affected by Lafora Disease and help accelerate the development of treatments. Follow Chelsea's Hope across social media [@chelseashopelaforacure](#) and find more information online or donate to reach a cure at chelseashope.org. Contact info@chelseashope.org for press inquiries.