**FOR IMMEDIATE RELEASE**

## UNITED AGAINST LAFORA, FAMILIES WORLDWIDE RAISE AWARENESS

*October 1 will be the 6th annual awareness campaign for Lafora disease.*

**Sacramento, California – Thursday, September 24, 2026 –** Chelsea's Hope Lafora Children Research Fund announced that October 1st, 2026, is the 6th annual Lafora Body Disease Day. The organization will raise awareness to support children fighting for their lives, find answers for families feeling overwhelmed, and accelerate the development of treatments for Lafora.

Lafora disease is an ultra-rare, terminal neurodegenerative disorder that primarily affects children and adolescents. It is a genetic condition in which patients cannot maintain a normal glycogen concentration, resulting in a toxic accumulation of glycogen, called Lafora Bodies, in the heart, spine, and brain. Symptoms can include epilepsy, childhood dementia, and progressive difficulty with talking, walking, and eating. Children who appear healthy often begin experiencing symptoms in early adolescence, and most die within 10 years after seizures begin. Lafora disease affects approximately 1 in 5 million people worldwide.

There is currently no cure for this disease; it is terminal. Chelsea's Hope aims to accelerate the development of treatments and ensure families can access information at every step of their journey. Lafora research and potential treatments are rapidly advancing, but as with many rare diseases, the community faces a funding barrier to getting potential therapies to the clinic.

Chelsea's Hope is a key supporter of the first clinical trial for a potential ASO therapy for Lafora patients (ION283), organizing fundraising to cover the clinical costs of the investigator-led Safety Study and Phase I trial at UT Southwestern. 10 patients from around the world are now in the second year of the study with no safety complications. The community is working tirelessly to raise the final $170,000 needed to cover the clinical costs and allow all 10 patients to complete the two-year trial. The children in the trial cannot afford any delays from a shortage of funds, and the entire Lafora community anxiously awaits the results of the study. Hope is finally on the horizon with Elpida Therapeutics recently acquiring the license of ION283 with intentions to advance this potential treatment once the Safety Study is complete.

Jenifer Merriam, President, Chelsea's Hope Board of Directors shares, "My son is participating in the first-ever Lafora Safety Study, giving our family something we have desperately needed: hope. If ION283 can slow or stop the progression of Lafora disease, Ty could have the chance to pursue his dreams and avoid the devastating future this disease has taken from so many young people.

This is our first real opportunity to change the course of Lafora disease; not just for Ty, but for his older sister and every family affected by this devastating disease. We cannot afford to lose this opportunity."

Your support can make a difference to help families access information, training, and resources in their fight against Lafora. Donate to help accelerate the development of treatments and bring hope to patients and their loved ones worldwide: https://chelseashope.org/donate/

Finally, to mark 2026 Lafora Body Disease Day, Chelsea's Hope encourages individuals and organizations to help spread awareness of Lafora through social media. Templates are available for downloading and sharing here. Supporters are encouraged to use #FightLafora and tag @chelseashopelaforacure when they post.

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Chelsea's Hope Lafora Children Research Fund started in 2007 after Linda Gerber and a small group of dedicated friends developed a website to share her daughter Chelsea's Lafora story. Since its founding as a 501(c)3 in 2009, Chelsea's Hope has partnered with dozens of organizations and hundreds of families worldwide to provide support, raise awareness, and advocate for the Lafora community.

Today, the mission of Chelsea's Hope is to improve the lives of those affected by Lafora disease and help accelerate the development of treatments. We envision a future where families can access treatment as soon as they are diagnosed. Contact info@chelseashope.org for press inquiries.