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FOR IMMEDIATE RELEASE

SHINING A LIGHT ON LAFORA DISEASE

We will show our stripes for Lafora disease on 2023 Rare Disease Day.

SACRAMENTO, Calif. – February 27, 2023 – [Chelsea's Hope Lafora Children Research Fund](#), a 501(c)(3) nonprofit organization, wants to share stories of Lafora disease patients like Alexis Rodriguez to raise awareness about the ultra-rare epilepsy.

Lafora Disease is a degenerative neurological condition affecting children. 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.

[Alexis Rodriguez](#)'s first symptom was a seizure. Now 19, she was a healthy and bright student before the onset of her symptoms. She played the violin, was an avid reader, and was a swimmer on her high school team. Her dream was to become a registered nurse.

Over the past three years, Alexis experienced frequent seizures, could no longer attend school in person and lost her ability to walk and talk. Now, she relies on a customized wheelchair, feeding tube, and full-time care from her single mother, AC, godmother, and nurse.

"Lafora robs the children of the right to live," says AC.

Alexis's story is similar to other Lafora patients. Children first show symptoms in their early teens and typically die within 10 years. There are an estimated 200 Lafora patients worldwide. Lafora Disease is terminal; there is no cure. But Rare Disease Day provides hope and a platform to share these stories. Today is the day to help raise awareness!

Alexis's doctors have applied for FDA approval for the emergency use of a medication to target the glycogen buildup in her muscles. Unfortunately, her insurance company will not cover the cost of this treatment, even though it could slow down the pace of this disease and give Alexis a fighting chance. Her mother started Angels for Alexis in December 2022. To help her family access the treatment, visit <https://chelseashope.org/donate/> and specify that you're donating to "TEAM ALEXIS" for a tax-deductible donation. Follow [@angelsforalexis](#) on Instagram for updates.

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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, Chelsea's Hope Lafora Children Research Fund aims to improve the lives of those affected by Lafora Disease by raising

awareness, connecting families, and accelerating research. Follow Chelsea's Hope across social media @chelseashopelaforacure and find more information online or donate to help accelerate research at chelseashope.org.

Contact info@chelseashope.org for press inquiries.

Chelsea's Hope Lafora Children Research Fund is an IRS 501(c)3 non-profit organization. Post Office Box 348626, Sacramento, CA 95834 | 949-812-8823 – Frank Harris (President) www.chelseashope.org