

# About Chelsea's Hope



Chelsea's Hope Lafora Children Research Fund was started by Chelsea Gerber's family to share her story and fundraise to fight Lafora Disease. An IRS 501(c)3 non-profit organization since 2009, our mission is to improve the lives of those affected by Lafora Disease and help accelerate the development of treatments.

## What is Lafora Disease?

Lafora Disease is a fatal, progressive myoclonic epilepsy. It's a genetic glycogen storage disease and healthy children develop symptoms around puberty, including:

- increasingly severe seizures
- ataxia
- dementia
- difficulty walking/talking/eating



80 patients enrolled in registry



Across 32 countries



No available treatments

## There are no approved treatments?

Two treatments are ready to be trialed in children suffering from Lafora disease, but are not moving forward. Unfortunately, drug development partners have dropped rare disease programs deemed unprofitable due to the biotech recession, including our Lafora disease clinical trials.

These promising treatments could mean life or death for many children. Lafora disease progresses quickly and time is critical. **We are so close now.** We can not stand by while our children fade away from the families and communities who love them.

**Corporate business decisions should not stop us from doing the right thing. Chelsea's Hope is working tirelessly to move these clinical trials forward with alternative partners.**

## How to Donate



Chelsea's Hope Lafora  
Children Research Fund  
P.O. Box 348626  
Sacramento, CA 95834



[chelseashope.org/donate](https://chelseashope.org/donate)

SCAN ME

