Chelsea's Hope
Lafora Children Research Fund

Our mission is to raise funds for research, treatment, and ultimately, a cure for those affected by Lafora Disease

FOR IMMEDIATE RELEASE

October 1st Marks Inaugural Awareness Mission for Lafora Disease

Lafora Body Disease Day is raising awareness for funding, research, and medical therapies

SACRAMENTO, Calif. – September 30, 2021 – Chelsea's Hope Lafora Children Research Fund today announced that October 1, 2021, is the inaugural Lafora Body Disease Day. The mission is to create awareness, connect families, fund research, and maintain hope, with awareness efforts continuing throughout the month.

Lafora Disease is a degenerative neurological condition affecting children. Lafora Disease is a genetic condition in which patients are unable to maintain a normal concentration of glycogen, resulting in a toxic accumulation of glycogen, or Lafora Bodies, in the heart, spine and brain. Lafora Disease is terminal, there is no cure. Children first show symptoms in their early teens and typically die within 10 years. Unfortunately, accurate diagnosis is often not made until anti-epileptic medications no longer control the seizures.

"There are no initial signs or symptoms," said Frank Harris, the President of Chelsea's Hope Lafora Children Research Fund. "Children are normal, active and intelligent throughout their elementary school years. Seizures are typically the first symptoms, but then the disease shows its true horror. The seizures become increasingly uncontrollable. Then these once normal, healthy children suffer with further physical and neurological degeneration. They lose their ability to walk and talk. They must be fed via a G-tube and need around-the-clock care. And these families know that without a cure, their children will die in a vegetative state, typically within 10 years of onset."

Families are very involved in raising awareness of Lafora disease, such as Azeza Kasham and Moniqueca Barfield, who have been advocating for medical and financial support in the fight against their children's affliction. Azeza lost her first-born son, Haitham, at age 16 and is now fighting for her 12-year-old son, Gehad. Moniqueca is a mother of 18-year-old Khari, who developed symptoms and experienced her first seizure when she was 12.

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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 with family and friends. Under their leadership, the organization became the key source of information for affected families and the primary source of research support. It is the mission of Chelsea's Hope to raise awareness about Lafora Disease, connect with other Lafora families and help fund research to find a cure.

To help fund research to find a cure for Lafora Disease, visit chelseashope.org/donate. Chelsea's Hope can also be followed on Facebook @chelseashopelaforacure.