



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

## **Social Media Toolkit for Lafora Body Disease Day 2022**

Please help us raise awareness for patients with Lafora disease in our mission to find a cure for this devastating rare disease. This year will be our second annual Lafora Body Disease Day that starts on October 1<sup>st</sup>.

Lafora Disease is a degenerative neurological condition affecting children. It is terminal; there is no cure. Perfectly healthy children first show symptoms in their early teens and typically die within 10 years. Lafora disease is ultra-rare with around only 80 registered children affected in the world and a suspected 200-300 patients worldwide.

We will be creating awareness and sharing patient and family stories throughout October for you to see the devastating result of the shocking degeneration of young teens who had a whole life ahead of them. No child should face their own death.

Help us reach a cure!! Please share our stories via your social media channels by posting, sharing, reposting and retweeting throughout the month.

You can tag us on:

- [Facebook](#): @chelseashopelaforacure
- [Instagram](#): @chelseashopelaforacure
- [Twitter](#): @Chelseashopela1
- [LinkedIn](#): Chelsea's Hope Lafora Children Research Fund USA
- [Tiktok](#): @chelseashopelaforacure

Images you can share:

- [#FightLafora English](#)
- [#FightLafora Spanish](#)
- [#FightLafora French](#)
- [Helping create awareness to #FightLafora](#)
- [#FightLafora because no child should face their own death](#)

Hashtags:

- #LaforaBodyDiseaseDay
- #FightLafora
- #ChelseasHopeLaforaCure
- #LaforaDisease
- #RareDiseaseAwareness



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## **Suggested text for October 1st:**

*Please share or reply to our posts throughout the month! On Twitter, retweet, quote tweet, or reply.*

### **FACEBOOK** - attach image for post

Today, October 1st we are creating awareness for [#LaforaBodyDiseaseDay](#). Lafora Disease is a degenerative neurological condition affecting children. It is terminal and there is no cure. Perfectly healthy children first show symptoms in their early teens and typically die within 10 years. Go to Chelsea's Hope Lafora Children Research Fund [[@chelseahopelaforacure](#)] to learn how help [#FightLafora](#) head on, as no child should face their own death!

[#chelseashopelaforacure](#) [#laforadisease](#) [#RareDiseaseAwareness](#)

### **INSTAGRAM** - attach image for post

Today, October 1st we are creating awareness for [#LaforaBodyDiseaseDay](#). Lafora Disease is a degenerative neurological condition affecting children. It is terminal and there is no cure. Perfectly healthy children first show symptoms in their early teens and typically die within 10 years. Go to Chelsea's Hope Lafora Children Research Fund [[@chelseahopelaforacure](#)] to help [#FightLafora](#) head on, as no child should face their own death!

[#chelseashopelaforacure](#) [#laforadisease](#) [#RareDiseaseAwareness](#)

### **TWITTER** - attach image for post

It's [#LaforaBodyDiseaseDay](#) today! [#LaforaDisease](#) is a degenerative neurological condition affecting children. Terminal with no cure. Symptoms present in healthy teens before death within 10 years. [#FightLafora](#) with [@Chelseashopela1](#) No child should face their own death!

### **LINKEDIN** - attach image for post

Today, October 1st is [#LaforaBodyDiseaseDay](#). Lafora Disease is an ultra-rare degenerative neurological condition affecting children. It is terminal with no cure. Perfectly healthy children first show symptoms in their early teens and typically die within 10 years. It causes epilepsy, childhood dementia, cognitive decline, ataxia, difficulty walking and eating. Chelsea's Hope Lafora Children Research Fund [Chelsea's Hope Lafora Children Research Fund USA] wants help to [#FightLafora](#) head on, as no child should face their own death!

Go to <https://chelseashope.org/> to learn more.

[#chelseashopelaforacure](#) [#laforadisease](#) [#RareDiseaseAwareness](#)