Social Media Toolkit for Lafora Body Disease Day 2023

Share how you #FightLafora on October 1, 2023, our third annual Lafora Body Disease Day. You can join Chelsea's Hope in raising awareness for patients with Lafora Disease!

Lafora Disease is a rare neurodegenerative disorder affecting children. Symptoms include epilepsy, childhood dementia, and difficulty walking, talking, and eating. It is terminal; there is no cure. Healthy, seemingly well-developing children first show symptoms around adolescence and typically die within 10 years. Lafora Disease is ultra-rare, with 80 registered patients and a suspected 200-300 total worldwide.

Raising awareness about Lafora is one step to achieving our mission of improving the lives of those affected by the devastating rare disease and helping to accelerate the development of treatments. We invite you to create awareness on October 1 by sharing your story, the stories of the Children of Chelsea's Hope, educational posts, or encouraging others to watch the recent Fighting the Rare documentary.*

We are also excited about October 1, 2023, because the new ICD-10 Diagnostic Codes for Lafora Disease will go into effect on that day. You can also help us by sharing the news about the unique code G40.C for Lafora Disease! It is an important milestone on the pathway to treatment.

We so desperately need a cure because no child should face their own death. Raising awareness helps identify more patients, find partners, and expand our community dedicated to a brighter future where treatment options can accompany a diagnosis.

Chelsea's Hope founder and Chelsea's mother, Linda Gerber, said it well: *"It is my greatest hope that no family should hear the words, "I'm sorry, your child has Lafora disease, there is no cure."*"[1]

This year, Chelsea would have turned 33 on October 1. Her life was cut short by Lafora, and we continue to fight the disease in her memory.

How do you #FightLafora? We want to know!

Keep reading for some graphics and example text to share in the pages below. You can also help us reach a wider audience by reposting, sharing, and retweeting our posts.

*We also have a Social Media Toolkit for sharing about *Fighting the Rare*.

[1] 1. *Living with Lafora Disease: A Day in Chelsea's Life*, *YouTube* (Chelsea's Hope Lafora Children Research Fund, 2022), https://youtu.be/9Jp6QF7omrA?feature=shared.

You can tag us on:

- Facebook: @chelseashopelaforacure
- Instagram: @chelseashopelaforacure
- TikTok: @chelseashopelaforacure
- Threads: @chelseashopelaforacure
- Twitter: @Chelseashopela1
- LinkedIn: Chelsea's Hope Lafora Children Research Fund USA

Hashtags:

- #LaforaBodyDiseaseDay
- #FightLafora
- #ChelseasHopeLaforaCure
- #LaforaDisease
- #RareDiseaseAwareness
- #EpilepsyAwareness
- #RareEpilepsy

Images you can share on October 1:

- #FightLafora English, #FightLafora '23 English
- #FightLafora Spanish, #FightLafora '23 Spanish
- #FightLafora French, #FightLafora '23 French
- #FightLafora Arabic, #FightLafora '23 Arabic
- #FightLafora Italian, #FightLafora '23 Italian
- Helping create awareness to #FightLafora
- #FightLafora because no child should face their own death

Example captions for October 1st:
Make sure to add an image, hashtags, and tag us!

Today, October 1, 2023, we celebrate a significant step forward in our fight against Lafora Disease. The introduction of the new ICD-10 code G40.C is a beacon of hope and a testament to our collective commitment to #FightLafora.

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.

Until now, there was no unique ICD-10 code for the rare disease, as if our kids were invisible in the healthcare system. Lafora was grouped with generic epilepsy codes, making it difficult to track.

This #LaforaBodyDiseaseDay, we ask you to spread the word, educate, and let's make a difference!

—

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. Learn more about how to #FightLafora: chelseashope.org

—

It's #LaforaBodyDiseaseDay today! #LaforaDisease is a degenerative, terminal neurological condition affecting children. Symptoms present in healthy teens before death within 10 years. #FightLafora with [tag Chelsea's Hope] because no child should face their own death!

—

Learn about #LaforaDisease this #LaforaBodyDiseaseDay. It is an ultra-rare degenerative neurological condition affecting children.

Lafora Disease 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, and difficulty walking and eating.

[Tag Chelsea's Hope] wants to #FightLafora head-on, as no child should face their own death! Go to https://chelseashope.org/ to learn more.

—

Share how you #FightLafora today! Every share, every like, and every conversation counts. Let's make Lafora Disease visible and support the warriors battling it daily. 💜

—

New ICD-10 codes for Lafora Disease, effective today, mark an important milestone as we #FightLafora! Share the news about code G40.C this #LaforaBodyDiseaseDay: [link]

—

Today is a monumental day in our battle against Lafora Disease! The introduction of new ICD-10 code G40.C will improve tracking, recognition, and understanding of the rare disease. Spread the word this #LaforaBodyDiseaseDay!

—

📣 Let's make some noise this #LaforaBodyDiseaseDay and spread the word about a crucial development as we #FightLafora: new ICD-10 codes! Learn more here: [link]

Healthcare providers, please use code G40.C when documenting #LaforaDisease.