

Social Media Toolkit for *Fighting the Rare* Awareness

Please celebrate the upcoming launch of the documentary [Fighting the Rare](#) by sharing about it on social media. It explores the importance of biomedical research to find treatments for rare diseases. In this toolkit, you will find a description of the documentary, social media handles, graphics, hashtags, and example captions.

About the project:

[Fighting the Rare](#) is a glimpse into research on Lafora disease through the testimonies of researchers, patients, and their relatives.

Lafora Disease is a rare neurodegenerative condition affecting children. It is terminal; there is no cure. Healthy children first show symptoms in their early teens, epilepsy followed by cognitive decline, 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.

Research on Lafora Disease is an example of how a disease can be studied, from its discovery to obtaining the first treatments. In [Fighting the Rare](#), using family stories and the study of Lafora as a backbone, general concepts related to biology and medicine, diseases, the scientific process, and the importance of research are explained. It is a must-watch for the rare disease and health community.

The documentary was created by Dr. Jordi Duran, Dr. Jaume Duran, and César Valdivia, who collaborated with a worldwide network of people fighting Lafora disease, including these Lafora disease researchers: Dr. Berge A. Minassian (University of Texas Southwestern Medical Center); Dr. José María Serratosa (Institute for Health Research F. Jiménez Díaz); Dr. Matthew S. Gentry (University of Florida); and Dr. Joan J. Guinovart (Biomedical Research Institute); in addition to other researchers such as Dr. Salvador Borrós and Dr. Cristina Fornaguera (Chemical Institute of Sarrià).

You can [watch the trailer on YouTube](#). The full documentary is scheduled for release on **June 26**, so please check the [Fighting the Rare website](#) on that day.

Accounts to follow and tag:

Fighting the Rare

- [Instagram](#): @fightingtherare
- [Twitter](#): @FightingTheRare

Chelsea's Hope Lafora Children Research Fund

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

Graphics you can share:



**Fighting the Rare:
a documentary on the
importance of biomedical
research to find treatments
for rare diseases**

**A glimpse into research on
Lafora disease, a rare
neurodegenerative
condition, through the
testimonies of researchers,
patients and their relatives.**



**A documentary on the importance of biomedical
research to find treatments for rare diseases.**

It is a glimpse into research on Lafora disease, a rare
neurodegenerative condition, through the testimonies of
researchers, patients and their relatives.

Hashtags:

- #FightingTheRare
- #RareDisease
- #RareDiseaseResearch
- #RareDiseaseAwareness
- #FightLafora
- #ChelseasHope
- #ChelseasHopeLaforaCure
- #LaforaDisease

Example captions:

Please share or reply to the posts you see!

1. #FightingTheRare is a documentary releasing June 26 about #RareDisease research! You can watch the trailer and learn more at fightingtherare.com
2. #FightingTheRare will provide a glimpse into research on #LaforaDisease through testimonies of researchers and families, including #ChelseasHope board members. Watch June 26 at fightingtherare.com
3. #FightingTheRare is out in the world! The documentary highlights biomedical research's importance in finding treatments for rare diseases.

It is a glimpse into research on Lafora disease, a rare neurodegenerative condition, through the testimonies of researchers, patients, and their relatives. Go to fightingtherare.com to watch today!

#RareDisease #RareDiseaseResearch #RareDiseaseAwareness #FightLafora #ChelseasHope
#ChelseasHopeLaforaCure #LaforaDisease