

Chelsea's Hope Lafora Children Research Fund's 2023 ANNUAL REPORT

Reflecting on the past transformative year, we want to express our sincere gratitude for your unwavering belief in Chelsea's Hope. We are proud to share the progress we've achieved in 2023, thanks to your support and the collective will of the Lafora community.

The only U.S.-based patient advocacy organization for Lafora Disease, Chelsea's Hope began as a website in the fall of 2007 to share [Chelsea Gerber's Lafora story](#) with her family and friends. The ravages of this progressive and degenerative disease took everything, and Chelsea lost her fight in December 2016. As you know, there is still no cure; Lafora Disease is fatal.

We became a 501c(3) organization in 2009 to bring together families impacted by Lafora and fight for a cure. [Our mission](#) is to improve the lives of those affected by Lafora Disease and help accelerate the development of treatments.



Chelsea's Hope
Lafora Children
Research Fund

Chelsea's Hope envisions a world where treatment options can accompany a Lafora Disease diagnosis. Thanks to your generosity, that is closer than before. As we share our impact from the past year, we recognize there is so much more to do in 2024 and beyond.

Thank you for being an essential part of our work - we couldn't do it without you.

Together, we fight Lafora.

With hope,

Frank Harris, Ph.D.
President

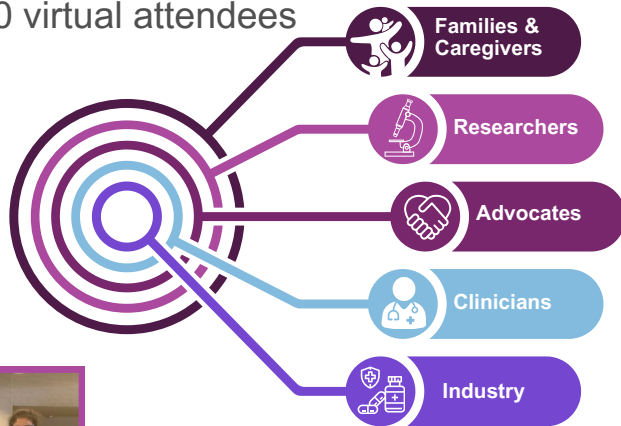




8TH ANNUAL LAFORA DISEASE SCIENCE SYMPOSIUM

Lafora Disease researchers and clinicians at **Instituto delle Scienze Neurologiche di Bologna IRCCS** hosted the largest Symposium yet, in Bologna, Italy. Chelsea’s Hope proudly supported the event, along with **Tempo Zero**, **A.I.L.A.**, and the **Lafora Epilepsy Cure Initiative** labs.

200 attendees. 110 in-person and 90 virtual attendees



Dr. Sharmistha Mitra “

I was aware of the wonderful and necessary work they [Chelsea’s Hope] were doing. My face-to-face meeting in Bologna fortified that feeling.

Participants from 29 countries joined



Dr. Katarzyna Stopinska & Dr. Lidia Kiryla “

We learned about the Symposium from the father of our patient, Weronika, who has been battling Lafora disease for more than 10 years... Until the Symposium, we believed that Weronika was the only person with Lafora in Poland. However, in Bologna, we met Krystian, the father of Dawid, who came in search of new treatment opportunities for his son. He hadn't expected to encounter anyone from Poland.

2023 IMPACT

Lafora Disease Research Roundtables

149 members of the Lafora community joined three discussions.



Research Roundtables

ICD-10 Code G40.C for Lafora Disease

The designation of a unique ICD-10 code is a crucial milestone for the Lafora Disease community. This code will...

- improve insurance claims processing.
- track essential data for researchers to conduct epidemiologic research and retrospective studies.
- determine true prevalence rates.
- recruit patients for clinical trials.
- track outcomes of clinical interventions.
- develop protocols for standard of care.

Volunteer Network



We were excited to launch our formal volunteer network program in 2023. We welcomed two amazing part-time volunteers to help with graphic design and translation. We look forward to growing the program in 2024.

Sibling Support Group

Chelsea's Hope was delighted to relaunch the [sibling support group](#) in 2023 to build community among siblings of those with Lafora Disease.



Mariah Merriam

As the sister of two Lafora Disease patients, I understand how isolating grieving a sibling can be. That's why I founded the sibling support group with Chelsea's Hope!

Board Updates

- Welcomed a new [secretary](#) to the Board of Directors.
- Appointed a new [Vice President](#).
- Developed a new mission statement.

Our mission

is to improve the lives of those affected by Lafora Disease and help accelerate the development of treatments.

Patient-Partnered Collaborations Grant

In partnership with the University of Texas-Southwestern, we received a Chan Zuckerberg Initiative grant to advance Lafora Disease research. The project is titled [Closing the Knowledge Gaps in Lafora, a Fatal Neurodegenerative Disease](#). Dr. Kit Donohue oversees the grant for Chelsea's Hope.

CHELSEA'S HOPE PROJECT GOALS

- Engaging patients in research.
- Accelerating the path to therapy.
- Connecting researchers to the patient community.



RESEARCH TEAM

- Dr. Berge Minassian
- Dr. Maria Chahrour
- Dr. Sharmistha Mitra
- Dr. Felix Nitschke
- Dr. Matthew Gentry



Jaume & Jordi Duran

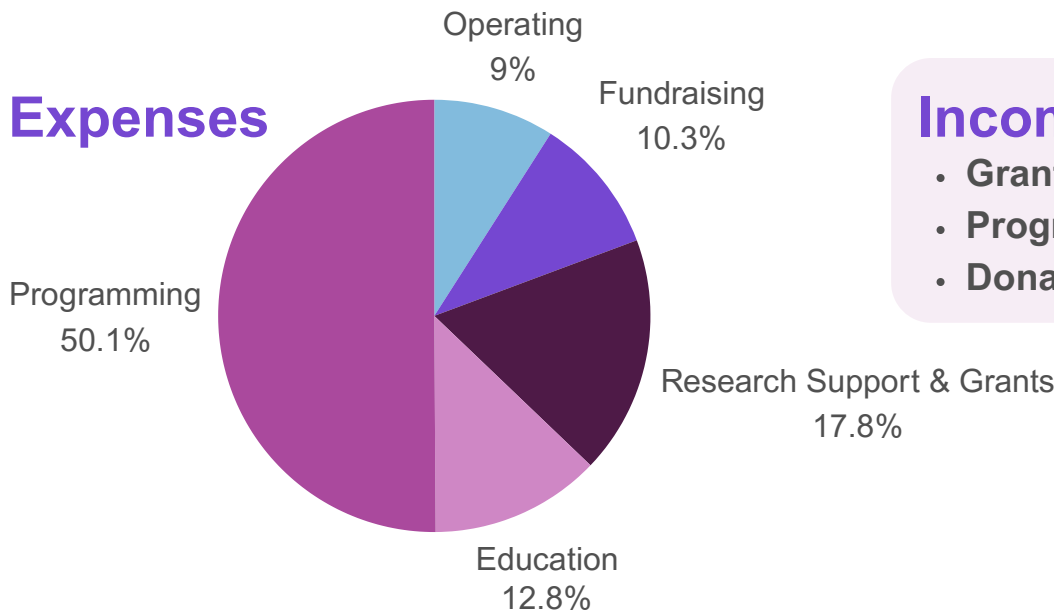
Fighting the Rare would not have been possible without the invaluable assistance of Chelsea's Hope. Their support during the filming of the San Diego scenes and their efforts in connecting us with Lafora Disease families were essential to the success of the project.



2023

FINANCIALS

Expenses



Income

- **Grants:** \$300,000
- **Program revenue:** \$2,025
- **Donations:** \$50,147

2024

GOALS

We strive to support families and the Lafora research network in developing treatments for our children. As a Chan Zuckerberg 'Rare as One' grantee through September 2024, we have an opportunity to continue to develop our organization's capacity to achieve our mission. Through the 'Rare as One' grant, Chelsea's Hope is working to:



Grow and accelerate science objectives that further clinical treatments.



Strengthen the Chelsea's Hope organization through hiring dedicated staff.



Expand and maintain a strong, collaborative, and actionable research network.



Be an essential source and repository of information for families, clinicians, and researchers.

What's next?

- Building consensus for standards of care and biomarkers.
- Drug Screening for potential repurposing to treat Lafora Disease.
- Expanding the Lafora Disease Patient Registry and the launch of a new Caregiver Registry.
- Hosting the 2024 Lafora Disease Science Symposium and quarterly Research Roundtables.
- 2024 Internship Program to make scientific research more accessible to the patient community.



Chelsea's Hope Board of Directors and staff at the 2023 Symposium.



THANK YOU!

Our impact is only possible because of you. Together, we fight Lafora. We are very grateful to all our donors and sponsors who support our work.

Thank you to our sponsors:

Chan Zuckerberg Initiative




Protecting Kids With Epilepsy



Marina, Zaro,
& the Weiss
Family

Thank you to our collaborators: [AEVEL](#), [A.I.L.A.](#), [Lafora France](#), Tempo Zero, and all Lafora Epilepsy Cure Initiative labs, researchers, and clinicians.

STAY CONNECTED

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