

Annual Report

Working to cure
Lafora disease.

Inside this report:

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Chelsea's Hope
Lafora Children
Research Fund

Chelsea's Hope Lafora Children Research Fund is a 501(c)(3) nonprofit organization dedicated to improving the lives of those affected by Lafora disease and helping accelerate the development of treatments.



Dear friends and supporters,

As a mom, I am so thankful for your commitment to reaching a cure for Lafora. Together, we are making hope a reality for families like mine.

As President of Chelsea's Hope, I'm proud to share our accomplishments in 2025 with you. We led efforts to support the ION283 Safety study at the University of Texas Southwestern Medical Center while laying the groundwork to improve care for Lafora children worldwide.

While we celebrate our impact in this report, we must continue to look to the future. Our children are enduring one of the most devastating diseases imaginable, and we are running out of time.

We must ensure no one faces Lafora alone, but has access to information, community, support, and hope. Rest assured that Chelsea's Hope will continue to advocate for Lafora treatments in 2026.

With gratitude for your partnership
and hope for a brighter future,

Jenifer Merriam

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President of the Board of Directors



A Year of *Impact*

Thanks to your belief in our mission, Chelsea's Hope grew our programming and support efforts, including:

60+ families surveyed across four languages through listening sessions and the caregiver registry, to identify and address gaps in care for Lafora patients



\$310k

for the ION283 Safety Study at UTSW

Community Connections

16 Committee meetings planned finances, outreach, and family support projects

News/blog posts **14** newsletters



1 warrior profile, Mathilde, shared **2** publications

Outreach

Joined global awareness events **4** news features about Chelsea's Hope

Joined scientific conferences **2** awareness events attended

Family Support

9 new families welcomed

32 families reached through monthly support groups

2 family resource guides

5 research simplifications



Research Support

15 working group meetings to bring together researchers and clinicians to analyze data from the Lafora community and identify potential biomarkers



25 clinicians and scientists collaborating to identify recommended epilepsy medications for Lafora disease



CZI Conferences

Staff attended CZI's Neurodegenerative Network Conference and Science in Society Meeting, connecting with other members of the Rare as One Network.



Research Roundtable

Sara Gerber discussed the Centers of Excellence project, and Mariah Carlson shared data from the Caregiver Registry survey.

Supporting the Advancement of Treatments

In January 2025, we had barely half of the Safety Study funds raised, and only one patient was enrolled. By December 2025, all 10 patients were enrolled, and the study was almost 90% funded.



3

community events hosted to answer questions and plan



Emi

UK

"[This study] could change everything—not just for Emi, but for children like her across the world."

- Fatos, Emi's father



15

fundraisers raised more than \$180k



Ty

USA

"It could mean freedom from seizures, from cognitive decline, from needing 24/7 care."

- Jenifer, Ty's mother



\$100k

grant from the RTW Foundation for full enrollment in the Safety Study



rtw Charitable Foundation



2025 Lafora Disease Science Symposium

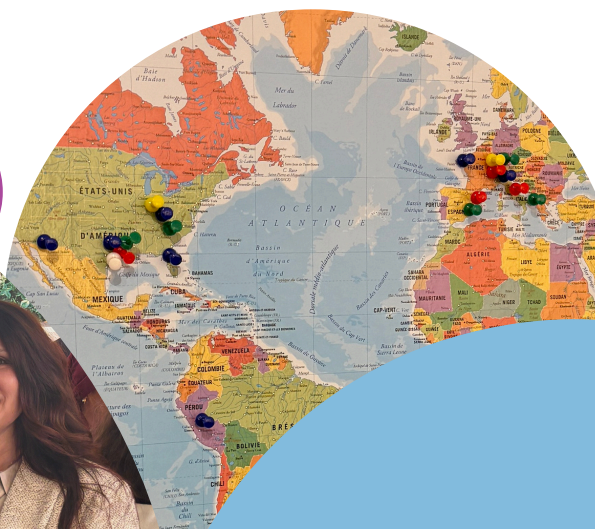
Valencia 29 Sep. - 1 Oct.

Hosted with the Sanz lab in Valencia, we brought together more than 200 in-person and virtual participants at the 2025 Lafora Science Symposium to accelerate therapy development.

Families, researchers, and clinicians from more than a dozen cities were represented at the Annual Science Symposium:

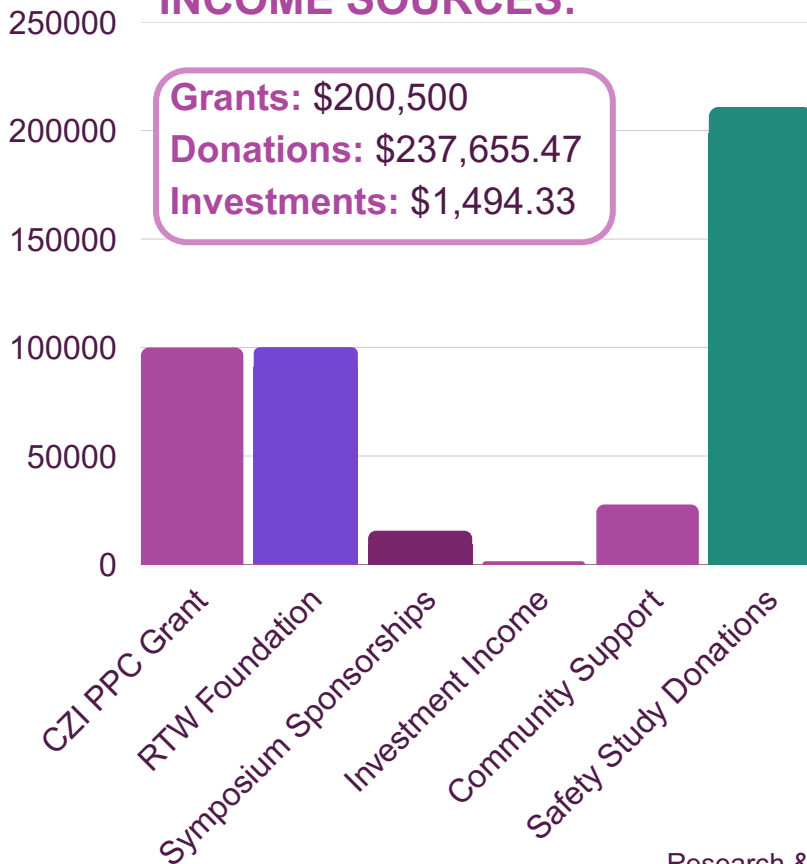


Thank you!



Financial *Stewardship*

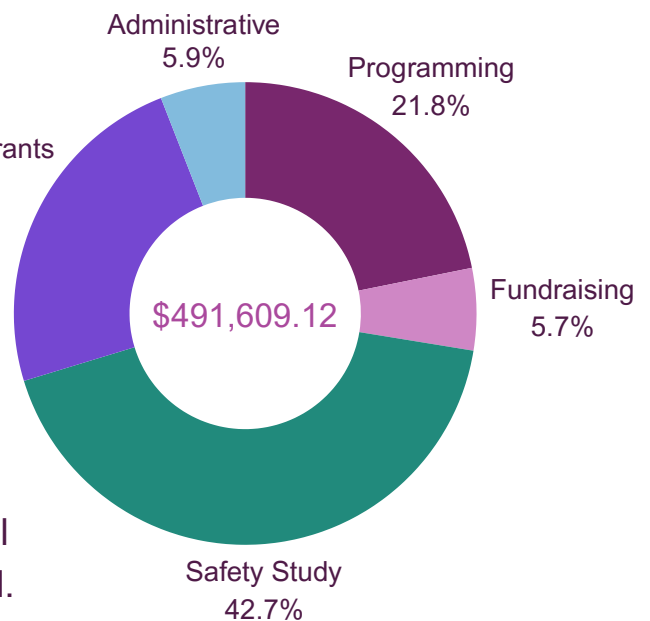
INCOME SOURCES:



Our commitment as families, community leaders, and staff is to act with integrity and transparency.

We take your partnership seriously and are deeply grateful for your generous support in 2025.

EXPENSES:



We got a four-star rating from Charity Navigator.



We achieved a Platinum Seal of Transparency from Candid.

Fundraising for the Safety Study.



Building a *Brighter* Future

2026 Goals

We continue to work towards these goals:

- Get the ION283 Safety Study fully funded.
- Establish Clinical Centers of Excellence & Guidelines for Clinicians.

And specify new priorities for our organization:

- Identify a **biomarker** for Lafora disease progression.
- Establish research priorities for a **Lafora Therapy Roadmap**.
- **Expand resources** to support and connect families worldwide.

Grief and Hope

We recognized December 30, 2025, as the first Lafora Hero Remembrance Day. Loss was deeply personal to the team at Chelsea's Hope this year. In times of despair, we hold fast to hope.

In memory of the beloved family we said goodbye to in 2025, we close this report with a call to honor their memories by continuing to fight Lafora.



Thank You for Making a *Difference*

Board of Directors

Jenifer Merriam
Meredith Williams
Sheila Barter
Nadia Ismail
Niki Markou
Katrina Voe Cotton, MD PhD
Roderick Howard



We welcomed two new board members in 2025. Dr. Cotton raised more than \$100k for the Safety Study.

Staff

Dr. Kit Donohue
Christine Kelly
Kait Fedor

Kait joined us as
Grants Coordinator.



Advisory Board

Dr. Antonio Delgado-Escueta
Dr. Berge Minassian
Dr. Francesca Bisulli
Mr. Jeff Milton
Dr. Jordi Duran
Dr. Jose Serratosa
Dr. Matthew Gentry
Dr. Pascual Sanz
Dr. Roberto Michelucci
Dr. Souad Messahel
Dr. Viet Nguyen



The Advisory Board met twice to offer guidance, including pictured here after the 2025 Symposium.

Special thanks to the four Champions who supported our work as monthly donors. Contact us if you'd like to join Chelsea's Champions in 2026!

Interns

Anna Gould
Jeremiah Paul
Jhanavi Kotian
Sally Leung
Samy Sharif
Sara Gerber
Sophie Stein
Vaishali Jain

We hired eight interns over the summer for scientific communications, fundraising, and research support

We are also grateful to everyone who volunteered, attended a committee, and served as Student Ambassadors; we look forward to working with you in 2026.



**Chan
Zuckerberg
Initiative** 

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