Chelsea's Hope
Lafora Children Research Fund

# You + us =
# incredible 2024 impact

Board and staff at the Symposium

In our **fifteenth year** as a 501c3 organization, Chelsea's Hope made significant strides toward our vision of a world with a cure for Lafora disease. Thanks to your support, we are proud to share the progress we achieved in 2024. I also want to express our sincere gratitude for your unwavering belief in Chelsea's Hope.

Our mission is to improve the lives of those affected by Lafora disease and help accelerate the development of treatments. **United with our sister organizations, TempoZero, A.I.L.A., France Lafora, and Cel-Luz, our global community raised nearly one million dollars to launch the first-ever safety study for a Lafora disease therapy.**

While we celebrated this milestone, we acknowledge that many families are still without a path to treatment for their loved ones. **Every child matters.** We will continue to support all of our Lafora families and push for expanded access to treatments and new therapy development.

Chelsea's Hope would not have had the impactful year we did in 2024 without the contributions of our many volunteers, board members, advisors, and community members!

We are at a pivotal place on the pathway to treatment, and I am so grateful for your support. Your voice and your participation in our mission will make all the difference.

**Together, we fight Lafora.**

With hope,

Jenifer Merriam

Jenifer Merriam, *President of the Board of Directors*

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# KEY ACHIEVEMENTS

- Published the **Lafora Caregiver Registry** survey in English and Italian
- Earned a Platinum Seal of Transparency from Candid
- Launched **Lafora Patient Mutation Database**
- Created **10 educational materials**
- Launched **Lafora Canine Database**
- Welcomed our first **Advisory Board**

*Keep reading for Safety Study, Symposium, and more project impact reporting.*


First Advisory Board meeting, September 2025

# PROJECT & EVENT HIGHLIGHTS

We developed and expanded key events, including monthly support groups to connect families worldwide and clinical and scientific working groups to identify biomarkers for clinical trials.

**Chelsea's Hope shares our progress through frequent email and social media updates to the community.**

**12** Family Support Groups

**5** interns supported scientific communications, database development, and caregiver support

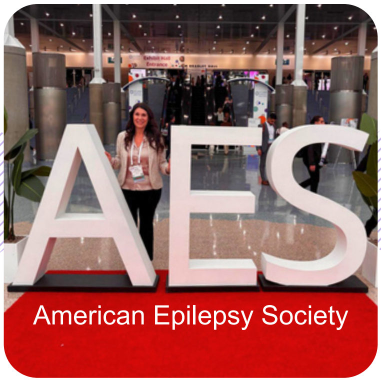
**3** Lafora Disease Research Roundtables

**2** Community Q&A events about the Safety Study

## We represented the Lafora patient community....

At the Rare Disease Day event at the Texas Medical Center. *(Secretary Meredith Williams)*

At CZI's Science in Society 2024 Meeting. *(Dr. Kit Donohue and Nadia Ismail)*



At the AES and Partners Against Mortality in Epilepsy annual meetings. *(Jenifer Merriam)*


2024 in-person Symposium attendees

## Annual Lafora Disease Science Symposium

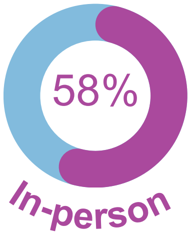
Chelsea's Hope hosted the 9th Symposium in San Diego, California. It was an inspiring and informative event thanks to our Symposium collaborators: Cel-Luz, A.I.L.A., Lafora France, Tempo Zero, and all Lafora Epilepsy Cure Initiative labs, researchers, and clinicians.

**120 attendees** from **19 countries** joined.

We recognized **15 years of progress** and our founder, Linda Gerber, at a special celebratory dinner following the first day of the Symposium.

## Supported the ION283 Safety Study

We **collected $175,000** for the first-ever FDA-approved safety study. In total, combined with the contributions of our sister organizations and community leaders, we raised $838k to support the monumental study.



In-person


Dr. Serratosa


Dr. Kit Donohue, 2024 Symposium


Dr. Gentry


Linda Gerber and Niki Markou


Dennis Unzicker


Dr. Minassian

We hosted a hybrid event via Zoom, including its translation feature, to support a worldwide audience.

**Dr. Verma, Gonzalo, and Kathya at UTSW, Biomarkers workshop**

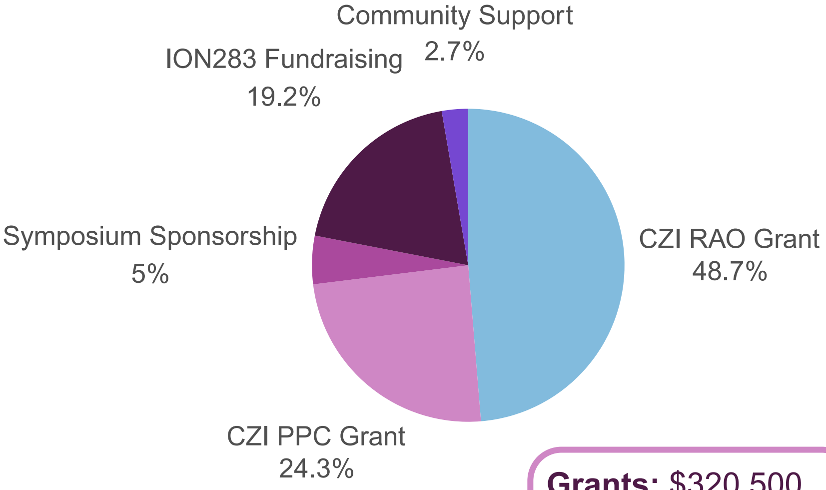
> *"My family was really scared of me traveling so far with Gonzalo, but my peace of mind lay in the fact that all the details were taken care of: airfare, hotel, transportation, medical insurance.*
>
> *With everything organized, traveling became much easier, especially thanks to Kit's support throughout the entire process, the reception in Dallas by Dr. Messahel, and the opportunity to talk with Drs. Minnasian, Verma, and Carla Ochoa..."*
>
> - Kathya Bruquetas, Gonzalo's mom

## Biomarker Workshop

- Supported two families' travel and lodging to Dallas
- Launched Clinical and Scientific Working Groups

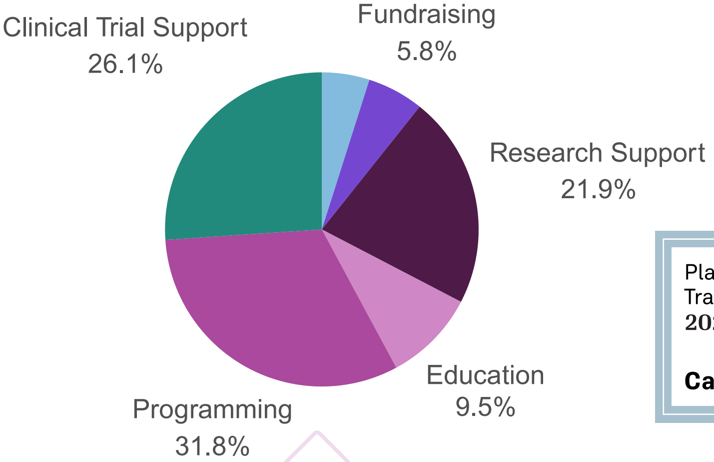
# FINANCIALS

## Income:



**Grants:** $320,500
**Donations:** $90,180

## Expenses:



Platinum
Transparency
2024
Candid.

# 2025 GOALS

- Publish collected data in order to:
  - Drive biomarker development
  - Determine Lafora prevalence rates
- Establish Clinical Centers of Excellence & Guidelines for Clinicians
- Get the ION283 safety study fully-funded

**Thanks to your generosity, five patients can participate in the life-changing safety study.**

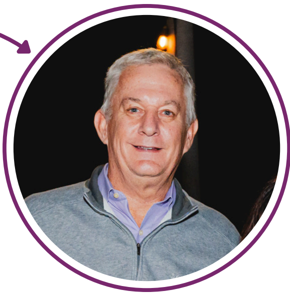
**We must fund the remaining spots!**

**Let's make 2025 even more impactful!**

# LEADERSHIP TEAM

## Board of Directors

Dr. Frank Harris
Jenifer Merriam
Meredith Williams
Sheila Barter
Nadia Ismail
Niki Markou



As President of the Board through 2024, Frank used his talent to make newly diagnosed families feel supported. He devoted a decade to serving the Lafora community with Chelsea's Hope.

## 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

## Staff

Lena Ismail
Dr. Kit Donohue
Christine Kelly

We want to express our deep gratitude to Lena Ismail, who served as Chelsea's Hope's Executive Director for the last three years as part of the Rare as One program by CZI.

## Interns

Celine Lozach
Emilie Heller
Mariah Merriam
Maysoon Hussain
Tomás Quintero

## Volunteers

Spencer Nguyen
Claire Fally
Camilla Bozzi
Callum Carr

*Thank you!*

## THANK YOU TO OUR 2024 SPONSORS:

Chan Zuckerberg Initiative

TEMPO ZERO

vibe bio

France LAFORA Vaincre la maladie

A. I. LA. ASSOCIAZIONE ITALIANA LAFORA ODV

Asociación CEL LUZ

Danny Did FOUNDATION Protecting Kids With Epilepsy

**Your support was critical in making 2024 a significant year for the Lafora community!**