



Dear Friends, Partners, and Followers of the Cure Mito Foundation.

Thank you for reading our September 2023 Newsletter! September is a month of Mitochondrial Disease Awareness Week and we are so grateful to share that we really felt the love and support of our community this month!

From the incredible energy we felt at the 2nd Leigh Syndrome Symposium to the beautiful mitochondria pictures we received from kids for the Color for Mito contest, the generosity of our sponsors and donors, receipt of the Great Nonprofits 2023 award, the support from many at the various conferences we participated in this month—the list can go on!

Please find detailed updates below! We have lots of work to do, so as you're reading our updates, if you feel compelled to learn more, collaborate, partner, volunteer - please get in touch with us!

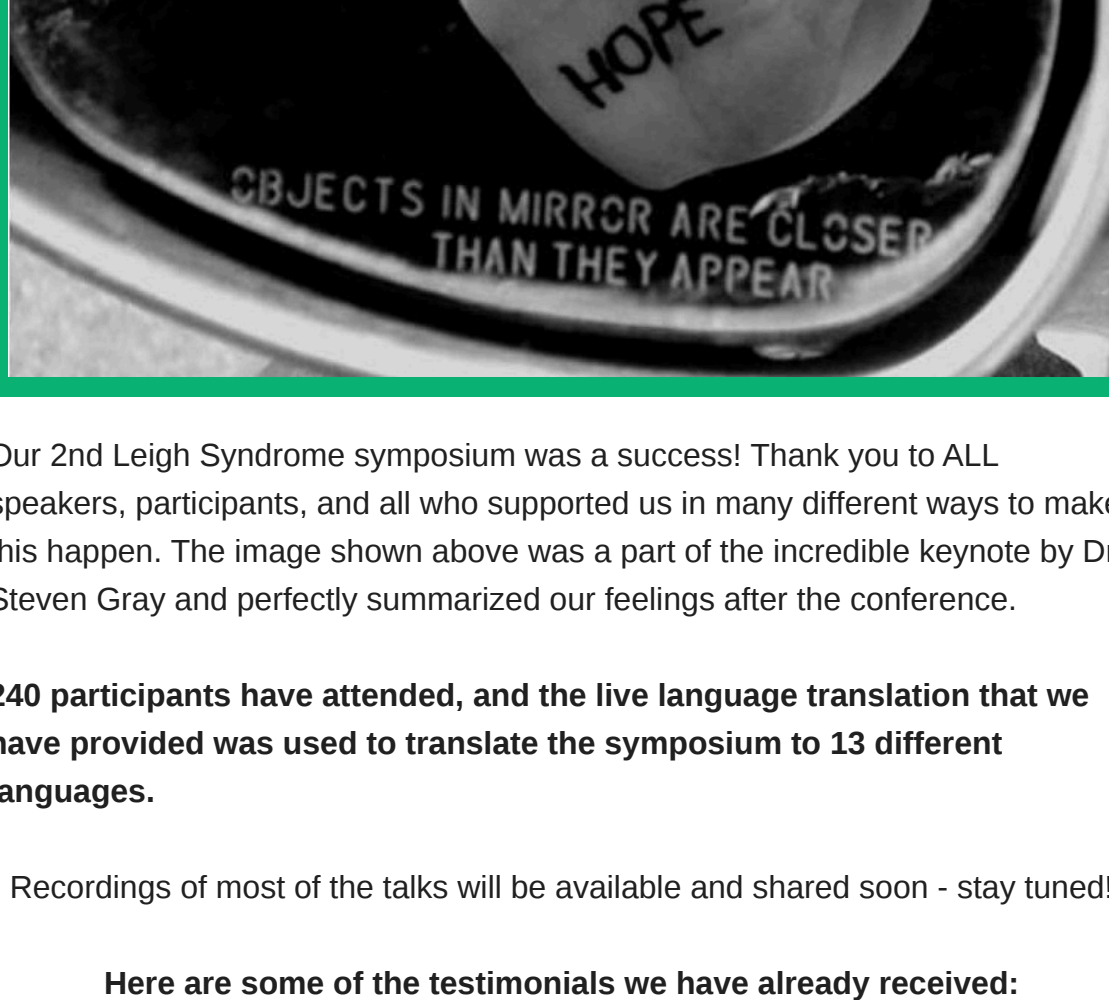
As always, we hope this newsletter will leave you feeling a little bit more hopeful and a little more inspired.

The Cure Mito team

"Courage Starts With Showing Up & Letting Ourselves Be Seen."

-Briee Brown

### Empower and Inspire: 2nd Annual Leigh Syndrome Symposium Update



Our 2nd Leigh Syndrome symposium was a success! Thank you to ALL speakers, participants, and all who supported us in many different ways to make this happen. The image shown above was a part of the incredible keynote by Dr. Steven Gray and perfectly summarized our feelings after the conference.

240 participants have attended, and the live language translation that we have provided was used to translate the symposium to 13 different languages.

Recordings of most of the talks will be available and shared soon - stay tuned!

Here are some of the testimonials we have already received:

"I loved to see everyone coming together towards a common goal of helping our kids."

"This was incredibly well organized and executed. 10/10 worth my time. I'm so glad resources like this exist for our family!"

"Accessible to academics and parents."

"This was fantastic! I had no idea how much was going on for the Leigh's community. Very eye opening. I had gotten discouraged several years ago and just focused on caring for our daughter. This has re-energized me to do more and try to stay current on research and drug opportunities. Thank you for all the work that went into this symposium and to all the presenters!"

### HUGE THANK YOU TO OUR CONFERENCE SPONSORS



Thank you to our co-hosting partners at Integrative Cardiovascular Metabolism and Pathophysiology Laboratory (iCaMP) at Boston University for their support and collaboration.

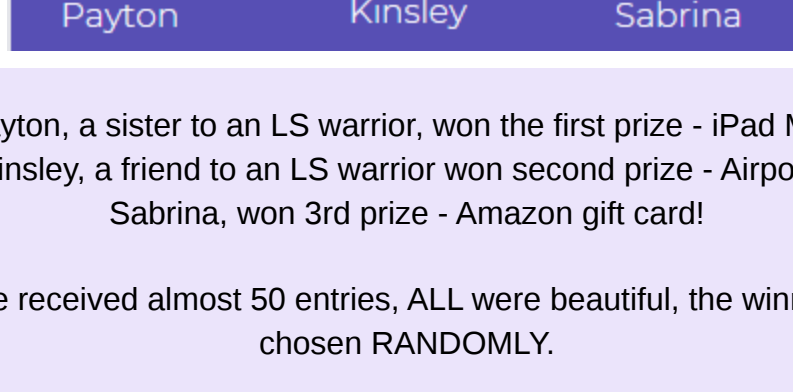
### \$73,000 raised for LS research this September!!!

Thanks to an incredible support from our community, we have raised \$73,000 for Leigh Syndrome research this September.

This was made possible through the support of over 230 individual donors, including a generous \$25,000 match from an anonymous donor.

THANK YOU.

### COLOR FOR MITO - WE HAVE 3 WINNERS!

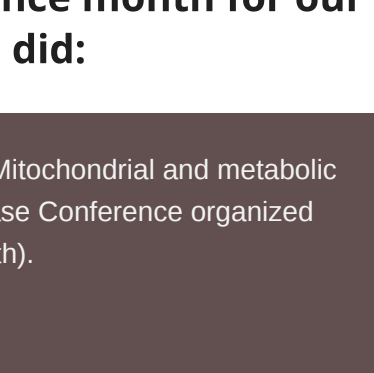


Payton, a sister to an LS warrior, won the first prize - iPad Mini! Kinsley, a friend to an LS warrior won second prize - AirPods! Sabrina, won 3rd prize - Amazon gift card!

We have received almost 50 entries, ALL were beautiful, the winners were chosen RANDOMLY.

Thank you to all for participating, we will be sharing all pictures in the coming weeks, please follow our social media to see all the beautiful pictures and support the kids!

THANK YOU TO OUR SPONSORS OF THIS MITO AWARENESS WEEK



### September has been a busy conference month for our team! Here's what we did:

Our scientific advisor, Dr. Danielle Boyce spoke at the Mitochondrial and metabolic drug development session at Rare and Orphan Disease Conference organized by Critical Path Institute (C-Path).

Other speakers were:

Dima Martin-Drew - Astellas

Amara Klein - C-Path

Alexandre Bétourné - C-Path

Petroula Spinkou - BioMarin Pharmaceuticals



Sophia spoke at the Mitochondria-Related Drug Development Summit in Boston about Leigh syndrome patient registry, patient engagement and what it means, how to make sure patient inclusion is successful and truly involves patients in a meaningful way, what Cure Mito does to amplify patient voice and collaborate and how others stakeholders can help.



Kasey participated in a panel at the Global Genes conference discussing actionable strategies for Community and Capacity building - the panel was moderated by Wendy Eiler (VP, Global Head Patient Experience, Patient Advocacy & Patient and Caregiver Insights) from Alexion Pharmaceuticals.



THANK YOU for your reviews that helped us be recognized as a Top-Rated Nonprofit for 2023 on GreatNonprofits! Includes excerpts from reviews.

Find us in the news! Includes article from Dallas Morning News about Cure Mito Foundation.

Zander's story has been featured in the Indiana Gazette. Includes photo of Zander.

Congratulations to Dr. Simon Johnson! Includes photo of Dr. Johnson and text about his research.

September in the Time of Grief. Includes photo of a child and text about grief and donation opportunities.

Leigh Syndrome Families - Please Join the Patient Registry and Be Counted. Includes text about the registry and a LEARN MORE button.

Leigh syndrome patient registry 2 year overview. Includes a grid of statistics about the registry.

About Leigh Syndrome. Includes Cure Mito Foundation logo and text about the website.

LEIGH SYNDROME CLINICAL NETWORK UPDATE. Includes text about the network and a form to join.

FREE GENETIC TESTING. Includes text about genetic testing and a Free Genetic Testing button.

Your donation matters! Includes text about donations and a link to donate.

Many volunteer opportunities are also available! Includes text about volunteer opportunities and a link to learn more.

DONATE NOW. Includes social media icons and a Platinum Transparency 2022 award badge.

GreatNonprofits 2023 Top-Rated Nonprofit award badge.