CURE MITO FOUNDATION

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

February is a Rare Disease Month! This month we are sharing with you our plans for Rare disease day, an exciting partnership with Rare Science to bring customized, handmade Rare Bears to all our kids, our updates on the patient registry, including a new flyer with registry highlights, C-Path mito taskforce, and more!

As always, we hope you find this newsletter will leave you more hopeful, uplifted and inspired,

The Cure Mito team

"Whatever is worth doing at all is worth doing well."

— Philip Dormer Stanhope

Dear families,

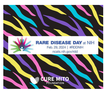
For Rare Disease awareness, we have partnered with RARE Science a volunteer non-profit with the aim to accelerate cures for kids with rare disease by fostering community and research. The RARE Bear Program supports families around the world, brings joy to kids and support to families. The RARE Bears are one of a kind handmade bears matched to a child's favorite colors and things made by sewists around the world.

If you would like to have a one of kind RARE Bear for your one of a kind kiddo please fill out the request here: https://www.rarescience.org/rare-science-partner/curemito/

Last day to request a bear is February 21st! Bears will arrive home in late February - early March!

Where to find us on Rare Disease Day

Kasey will join EveryLife Foundation for Rare Diseases on Capitol Hill to advocate in D.C. for rare diseases like Leigh Syndrome and attend Rare Disease Day at the NIH!



Sophia will attend PHUSE US Connect 2024 in Bethesda, MD, and speak on a panel: "Are We There Yet? Rare Disease Clinical Trials"

Mitochondrial and Inherited Metabolic Diseases Taskforce update

Our taskforce was just launched last month and is already growing! We are so excited to welcome new members:

- Ayer Consulting, LLC
- NIH
- Rare-X
- Washington University, St Louis
- Mepan Foundation

Learn more about the taskforce HERE.

Our poster - **"Critical Path Institute Expands Data Analytics to Mitochondrial and Inherited Metabolic Diseases"** will be presented at the Mitochondrial Medicine - Therapeutic Development Conference in UK.

Leigh Syndrome Patient Registry

Leigh syndrome families - please join the largest Leigh syndrome patient registry in the world.

Our intension with starting the patient registry was to do more than provide hope for the future, it was to provide real tangible results right now.

We've consistently upheld this commitment. Data is accessible to researchers, and results are always reported back to the community, ensuring you are always in the loop.

Join the Registry Now

Our published registry papers

Leigh Syndrome Global Patient Registry: Uniting Patients and Researchers Worldwide

Interoperability of Leigh Syndrome Patient Registry Data with Regulatory Submission Standards

Download our new flyer with registry highlights by clicking on an image below!

In December, our co-founders, Courtney and Jacob Boggs spoke to the iHeart Radio about Cure Mito and their daughter Emma!
Please find their interview HERE

Leigh Syndrome Families Checklist

Join the Global Leigh Syndrome Patient Registry
curemito.org/leighsyndromeregistry

Add your doctors to the medical provider directory
http://tinyurl.com/lsdoctors

Join our Facebook group
http://tinyurl.com/lsfamilies

Become a partner family
curemito.org/partner-families

Volunteer
Email info@curemito.org with your skills and time availability

Join annual Leigh syndrome symposium
curemito.org/conference

Share your story
curemito.org/family-blog

Share our printable flyers with your medical team, family and friends
curemito.org/printables

Follow us on social media
Facebook, LinkedIn, X (Twitter, Instagram, Tiktok

Shop in our Bonfire store
bonfire.com/store/cure-mito-foundation/

Make a donation
give.curemito.org/curemito

Open a fund in honor or memory of your loved one
curemito.org/fundraising

Start your own fundraising event

Suggest your own idea or project

Remember to visit our website to download and print flyers and bring to your own event, fundraiser, share with your medical team, and more! Learn more HERE.

About Leigh Syndrome
Cure Mito Foundation

WANT TO LEARN MORE ABOUT LEIGH SYNDROME?

AboutLeighSyndrome.com is a first of its kind informational website about Leigh syndrome with resources and support for both families and healthcare professionals.

FREE GENETIC TESTING

Cure Mito has partnered with Probably Genetic to increase access to genetic testing within our community. Probably Genetic's no-cost genetic testing program for mitochondrial disorders is patient-initiated and includes genetic counseling to explain any questions or findings. Please learn more HERE.

Cure Mito Foundation is a 501(c)(3) nonprofit organization led by parents who volunteer their time to search for a cure. 100% of your donations are tax-deductible and will go directly to research dedicated to mitochondrial diseases.

Your donation matters!

For many ways to give please visit:
https://www.curemito.org/ways-to-give

Many volunteer opportunities are also available!

Skills and expertise currently needed: fundraising, marketing, writing (scientific writing, grant writing, blog writing). Please contact us at Info@curemito.org to learn more.

DONATE NOW

Follow Us:

Platinum Transparency 2023 Candid.

2023 TOP-RATED NONPROFIT