CURE MITO
FOUNDATION

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

Thank you for reading our October 2023 Newsletter!

In this newsletter you will find link to view Leigh syndrome symposium recordings, new resources, fundraising updates, and updates on our projects.

We are preparing for 2024 - please be in touch with us to learn how you can be involved!

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

The Cure Mito team

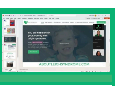
"Passion is the bridge that takes you from pain to change."

— Frida Kahlo

CURE MITO
FOUNDATION
Get to Know Us!
We are a nonprofit patient advocacy organization led by parents who volunteer their time to change the future for families affected by Leigh syndrome.
Our mission is to unite the global Leigh syndrome community to accelerate patient-centered research, treatments, and cures.

NEW! We have a new page where you can download and print flyers and bring to your own event, fundraiser, share with your medical team, and more! Please find the new page HERE.

Empower and Inspire: 2nd Annual Leigh Syndrome Symposium recordings are available HERE


You are not alone in your journey with Leigh Syndrome.
ABOUTLEIGHSYNDROME.COM

We already planning for symposium next year! From the feedback received so far, some suggested updates for the future conferences included: in-person conference, longer (2-3 days) conference, providing continuing education credits, and providing longer breaks.

We are discussing all these options. If you have feedback or want to participate in planning, please do not hesitate to reach out!

THANK YOU!!
MARSHALL FAMILY AND THEIR COMMUNITY FOR RAISING OVER $140,000 FOR RESEARCH!!!
love, the Cure Mito Foundation
CURE MITO
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Thank you Marshall family and friends!!!

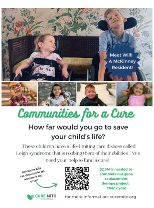
Zander was diagnosed with SURF1 Leigh syndrome just a few months ago. Since then his parents, Patrick and Jenna Marshall have been on a mission to fund Gene Replacement Therapy Research at UTSW.
In just a few WEEKS they have raised over $140,000 towards the $3M goal!!

It takes a village, let's do this together. The FASTER we get to our goal the SOONER kids can be treated.

Setting up your own fund in your child's name is easy! Please reach out to info@curemito.org for more information.

Communities for a Cure

Giving Tuesday and End of Year are approaching! Support Leigh Syndrome research by joining our "Communities for a Cure" campaign. We can personalize flyers to your city and child, making them suitable for display in various locations such as downtown areas and near cash registers. Please email us your information at info@curemito.org to get a customized flyer!


Meet Will! A McKinney Resident!
Communities for a Cure
How far would you go to save your child's life?
These children have a life-limiting rare disease called Leigh syndrome that is robbing them of their abilities. We need your help to fund a cure!
Donations ARE tax-deductible! No amount is too small!
$2.5M is needed to complete our gene replacement therapy project. Thank you!
CURE MITO FOUNDATION
for more information: curemito.org

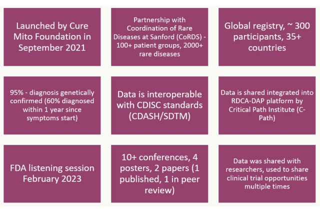
Leigh Syndrome Families - Please Join the Patient Registry and Be Counted

Largest LS patient registry in the world
Accessible and available data
Results are always reported back to the community

LEARN MORE

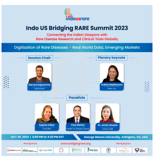
Our paper, " Leigh syndrome global patient registry: uniting patients and researchers worldwide" was published in September. Please find the paper HERE.

Registry 2 year overview:



Launched by Cure Mito Foundation in September 2021	Partnership with Coordination of Rare Diseases at Sanford (CoRDS) - 100+ patient groups, 2000+ rare diseases	Global registry, ~ 300 participants, 35+ countries
95% - diagnosis genetically confirmed (60% diagnosed within 1 year since symptoms start)	Data is interoperable with CDISC standards (CDASH/SDTM)	Data is shared integrated into RDCA-DAP platform by Critical Path Institute (C-Path)
FDA listening session February 2023	10+ conferences, 4 posters, 2 papers (1 published, 1 in peer review)	Data was shared with researchers, used to share clinical trial opportunities multiple times

Meet us at upcoming conferences


indousrare
Indo US Bridging RARE Summit 2023
Connecting the Indian Diaspora with Rare Disease Research and Clinical Trials Globally
Digitization of Rare Diseases - Real World Data, Emerging Markets
Session Chair
Plenary keynote
Harsha Rajasimha
Subha Madhavan
Panelists
Sophia Zilber
Paul Mehta
Dr. Amrin Shukla
OCT 29, 2023 | 3:00 PM to 4:30 PM EST
George Mason University, Arlington, VA, USA
www.bridgingrare.org

Sophia will participate in a panel "Digitization of Rare Diseases" at the Indo-US Bridging Rare Summit. Please find details HERE.

Find us in the news

Their son may never be cured. But these McKinney parents aren't giving up.

Have you missed an article about our families and Cure Mito Foundation published by Dallas Morning News? Please find it HERE.

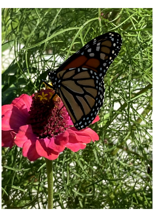
The Dallas Morning News
'You have to hang on to ... hope'

Podcasts and blogs from our families

Kim Gilsdorf & Daniel DeFabio
Chronic Compassion

Please listen to Kim Gilsdorf, a mom from our community join another rare disease parent Daniel DeFabio discuss grief on the Once Upon a Gene podcast with Effie Parks. They both lost their sons, both named Lucas and they've shared much of the same rare disease journey with countless moments of emotions, challenges and unexpected moments of strength. Hear them discuss their grief, exploring how they've managed to hold onto anger and tenderness simultaneously. Listen HERE.

Six years after her daughter's death, a mother receives an email from the clinician who admitted her daughter to the ER acknowledging the impact of her daughter's life on the clinician. Please read a blog post written by Sophia and published by Courageous Parents Network HERE.



Leigh Syndrome

We have worked together with Child Neurology Foundation on Leigh syndrome information page. Please find it HERE.

Thank you to Ibrahim Elsharkawi, MD, Peter McGuire, MS, MD, Shamima Rahman, FRCP, FRCPCH, PhD, UCL for their help with review and edits to this guide.

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.

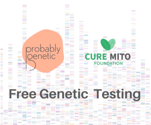
LEIGH SYNDROME MEDICAL NETWORK
We are building a database to help Leigh syndrome patients find doctors who have treated other Leigh syndrome patients.
CURE MITO

LEIGH SYNDROME CLINICAL NETWORK UPDATE

If you see a medical provider of any specialty who sees patients with Leigh syndrome OR if you are yourself such medical provider, please complete the form by clicking HERE

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.


probably genetic
CURE MITO FOUNDATION
Free Genetic Testing

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.

GREATNONPROFITS 2023 TOP-RATED NONPROFIT

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