



# CURE MITO FOUNDATION

We are a nonprofit patient advocacy organization led by parents who volunteer our time to change the future for families affected by Leigh syndrome - a debilitating neurodegenerative mitochondrial disease, impacting 1 in 40,000 people and caused by over 110 genes in mitochondrial or nuclear DNA.

Our mission is to unite the global Leigh syndrome community to accelerate patient-centered research, treatments, and cures.

By sponsoring, you will be directly contributing to supporting families, promoting awareness and education, and development of treatments and potential cures for those affected by Leigh syndrome and mitochondrial disease. Your support allows us to continue our mission and make a significant difference in the community.

Let's get started!





# Recent Accomplishments

In 2021, we initiated the Leigh Syndrome Global Patient Registry, which has rapidly grown to become the world's largest Leigh syndrome registry, currently including nearly 300 participants from 35+ countries. We regularly disseminate registry findings through posters, social media, and our website. A peer-reviewed paper has been published, and another is currently undergoing the peer review process.

In 2022 and 2023, we organized a virtual conference - "Empower and Inspire: Leigh Syndrome Symposium". This event united more than 250 patients, researchers, and other stakeholders each year. The symposium's impact has been widely recognized and a peer-review paper describing the impact of the event is accepted and nearing publication.

In 2022-2023, we launched [www.aboutleighsyndrome.com](http://www.aboutleighsyndrome.com), an online resource dedicated to Leigh syndrome and accessible to both families and healthcare professionals. The initiative was made possible through collaboration among Cure Mito, patients, and experts from various fields.

For Mito awareness week 2023, we organized a "Color for Mito" contest for mito kids and their siblings and friends. We received nearly 50 beautiful coloring pages. Kids won prizes and we continue to share the pictures through social media.

In 2023, we 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.

Some of the resources we have developed include: family planning guide is available for download and is the only such guide available from a US based patient advocacy organization specifically developed for mitochondrial disease., tips for healthcare providers for sharing difficult news and for appointment with a family, list of podcasts, and books for adults and kids.



# Sponsorship Opportunities

## Vision sponsorship

**Contribution: \$50,000+**

**Benefits:** Knowing you are making a significant, long-lasting impact for our community. Recognition on social media, newsletters, and website. Recognition during annual symposium as a Vision sponsor. Featured newsletter and social media content. Co-branded resources. Personalized appreciation plaque. Invitation to join Cure Mito Corporate Advisory Council for sponsors who are companies working on mitochondrial diseases.

## Hope Sponsorship

**Contribution: \$25,000 - \$49,999**

**Benefits:** Knowing your commitment is shaping the future of our community. Recognition on social media, newsletters, and website. Recognition during annual symposium as a Hope sponsor. Featured post in the newsletter. Framed appreciation certificate. Invitation to join Cure Mito Corporate Advisory Council for sponsors who are companies working on mitochondrial diseases.

## Dream Sponsorship

**Contribution: \$10,000 - \$24,999**

**Benefits:** Knowing you are playing a pivotal role in advocacy and support. Recognition on social media, newsletters, and website. Recognition during annual symposium as a Dream sponsor. A customized appreciation letter. Invitation to join Cure Mito Corporate Advisory Council for sponsors who are companies working on mitochondrial diseases.

## Inspire Sponsorship

**Contribution: <\$10,000**

**Benefits:** Knowing you are directly contributing to the vitality of our initiatives. Recognition on social media, newsletters, and website. Recognition during annual symposium as an Inspire sponsor. A thank you email from our leadership. Invitation to join Cure Mito Corporate Advisory Council for sponsors who are companies working on mitochondrial diseases and with contribution of at least \$5,000.



# More Opportunities

## **Corporate Advisory Council - open to companies with interest in mitochondrial diseases**

**Contribution: \$5,000**

### **Benefits:**

Have a voice within the patient advocacy community, raise visibility of your company and programs, work with others in the industry in a non-competitive environment, and make a difference in bringing mitochondrial disease stakeholders together. Recognition during annual symposium as a Corporate Advisory Council member.

## **Newsletter Sponsorship**

**Contribution: \$300/newsletter, \$700 - 3 newsletters, \$1000 - 5 newsletters**

### **Benefits:**

Highlight your company in a fast growing and well-read monthly newsletter. Audience includes industry, academia, doctors, patients.

## **About Leigh Syndrome Sponsorship**

**Contribution: Sponsorship cost - \$3000 per page if content is provided to us. Otherwise TBD.**

Sponsor additional content on [AboutLeighSyndrome.com](http://AboutLeighSyndrome.com). This resource is the first of its kind providing information and resources about Leigh syndrome.

## **Mito Awareness Week Sponsorship**

**Contribution: TBD**

Help us raise awareness during Mitochondrial Disease Awareness Week - 3rd week of September.

## **Empower and Inspire: Annual Leigh Syndrome Symposium**

**Contribution: TBD**

Annual symposium that brings together patients, industry, and researchers for a day of learning and collaboration.



# What Others Say About Us

*“Not only are they helping children with Leigh's Syndrome and their families, they are also helping other patient advocacy groups and empowering them with knowledge to make wise choices. Their work is foundational and transformational.”*

*- Frances Muenzer Pimentel, co-founder, Hope for PDCD*

*“What they are doing for the Leigh Disease community is amazing, but what they are doing by blazing a trail for other rare disease groups to follow is even more amazing. Together we really are stronger and Cure Mito demonstrates that in spades!”*

*- Russell Wheeler, Patient Advocate & Trustee, Leber's Hereditary Optic Neuropathy Society*

*“Cure Mito Foundation is dedicated to advancing the drug development needs of those living with mitochondrial disease. They are excellent partners, willing to collaborate efficiently and ethically.”*

*- Amanda Klein, PharmD, CDCES, Executive Direction, Critical Path Institute (C-Path)*

*I have been impressed with Cure Mito's proactive efforts to collect data about Leigh's Syndrome. As part of the data advisory board for the Leigh's Syndrome Registry, I have seen how the organization has brought together the people with the right skills and the right motivations. The progress made in such a short time has far exceeded my expectations.*

*- Kevin Freiert, MBA, Salem Oaks, Cure Mito advisor*

*“Working with Cure Mito has been such a wonderful experience. They are very professional, knowledgeable, and committed to improving diagnosis and treatment for all individuals with mitochondrial diseases. They make it their mission to have everyone they touch benefit from the interaction.”*

*- Susan Clement, Senior Director Strategic Marketing at Saol Therapeutics*

Find more at: <https://greatnonprofits.org/org/cure-mito-foundation>



# Thank you

## Get in touch with us!



646-483-7073



info@curemito.org



www.curemito.org



@cure-mito-foundation



@cure\_mito

501(c)(3) EIN: 82-4665767



**CURE MITO**  
FOUNDATION