CURE MITO FOUNDATION

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

This is our last newsletter of 2023!

In this newsletter we are sharing with you a launch of Leigh syndrome provider directory, drug repurposing and gene therapy updates, launch of a new Mitochondria World project, and tips for rare families for the holidays.

As our newsletter reach grows, we are reminding all Leigh syndrome families to make sure you are enrolled into Leigh syndrome global patient registry. Your participation is important, and insights and findings from the data are shared consistently and widely.

We are grateful to all who supported us throughout 2023 and looking forward to all we can accomplish together in 2024.

We are wishing you warmth, light, and peace this holiday season.

The Cure Mito team

"Only from the heart can you touch the sky."

— Rumi

Leigh Syndrome Provider Directory is LIVE!

Leigh syndrome provider directory with over 100 healthcare providers is now LIVE! You will find providers of multiple specialties along with information on whether remote options are available.

Please find it HERE.

This directory is expected to grow over time, patient families are encouraged to submit their doctors, therapists, and other healthcare providers by clicking HERE.
Doctors can also submit themselves.

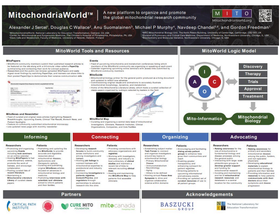
Drug repurposing update

We are partnering with Periara on yeast-powered drug repurposing screens for SURF1 Leigh Syndrome. We found three compounds that increase mitochondrial respiration in SURF1 patient cells. Please read detailed update HERE.

Welcome, Mitochondria World!

We are proud to be partners of the new mitoworld.org project. The Mitochondria World web portal, www.MitoWorld.org, has been developed to inform, communicate, organize and advocate within the various mitochondria research, clinical and patient communities.

Congrats to the MitoWorld team for a successful poster presentation at the UCLA Mitochondrial medicine symposium. Please view poster in full size by clicking HERE.



SURF1 Leigh Syndrome

UT Southwestern Medical Center and Cure Mito are working to fund a toxicology study and to manufacture a drug to hopefully cure SURF1 Leigh Syndrome

Thank you to the Marshall family for incredible fundraising efforts to help their son Zander and other kids, please learn more about our efforts to develop gene therapy for SURF1 Leigh syndrome HERE.

Leigh Syndrome Patient Registry

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

Tips for Navigating the Holiday Season with a Rare Disease

For many of our families holidays are not an easy time. Some of us are grieving for our child or loved one who is not with us. Some are struggling knowing that their child or family can't experience the holidays the "typical" way. Our friends at Global Genes put together a helpful resource, please find it HERE.

Additionally, we encourage you to browse resources on our website, such as books, podcasts, and more that may help. Please find them HERE.

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

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