CURE MITO FOUNDATION

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

In this newsletter, we are sharing with you our updates from this month, reflecting on all we did in 2023 and planning for what we have coming up in 2024.

This year we will continue expanding our patient registry for Leigh syndrome and sharing findings with the community, continue funding gene therapy, gene editing, and drug repurposing projects, collaborate with C-Path and other organizations through a new Mitochondrial and Metabolic disease taskforce and Mitochondria World, advocate through a Health Defense Research consortium; we will host a 3rd annual Leigh syndrome symposium, continue our corporate advisory council, and more - all with the ultimate goal of treatments and cures for children and adults affected by Leigh syndrome.

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

The Cure Mito team

"Some see things as they are and say, why; others dream things that never were and say, why not."

— George Bernard Shaw

What we did in 2023!

C-Path to Lead New Task Force Aimed at Accelerating Drug Development for Mitochondrial and Inherited Metabolic Diseases

This new task force will allow our community to collaborate, share data, and accelerate development of treatments with the support of C-Path and their Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP ®). RDCA-DAP is an FDA-funded platform that creates the collaborative, non-competitive space to share existing patient-level data and encourages the standardization of new data collection.

We would like to thank C-Path for their commitment to our community and our incredible partners who embarked on this journey together with us: **Astellas, Champ Foundation, Cure LBSL Foundation, Hope for PDCD Foundation, Midwestern University, Mitochondria World**.

This task force has been formed through informing an entire community about its planning and ensuring that each stakeholder in our community had a chance to join. We hope this inclusive and transparent approach will set a new precedent for future collaborative projects in our community.

Find press release here.

Corporate Advisory Council 2024

We are excited to announce our Corporate advisory council (CAC) members for 2024 - Astellas, Saol Therapeutics, Khondrion. The CAC's goal is to unite mitochondrial disease stakeholders across different organizations with a common goal to accelerate the development and delivery of treatments, and ultimately a cure, for Leigh syndrome and mitochondrial disease. CAC members have a seat around the table within the patient advocacy community while raising awareness and visibility of its companies and their programs. Companies who would like to join are encouraged to reach out to info@curemito.org

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

Leigh syndrome families checklist

Many of you are asking us how you can be involved. Our foundation is growing and expanding in its reach and projects and we welcome your involvement and help! We have created a checklist with some ideas! If you have another idea please reach out to us! Please download the checklist here. Spanish version is also available.

We have also started a Facebook group for parents and caregivers to their loved one with Leigh syndrome. Please join here.

Check out our updated homepage

We updated our homepage to make it easier to learn who we are, what we do for the community, and find the information you need!
Please see it and let us know what you think!

Are you following us on social media?

Don't miss our daily updates on social media - our LinkedIn page has recently surpassed 2000 followers. You can follow us on Facebook, LinkedIn, X/Twitter, and Instagram! We share our research updates, news, and more! Find all our links 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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2023 TOP-RATED Nonprofit