CURE MITO
FOUNDATION

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

Welcome to our April 2024 Newsletter!

In this edition of our newsletter, we're thrilled to announce an exciting patient registry update. Thanks to a partnership with Sumptuous Data Sciences, we've achieved full data interoperability with the OMOP Common Data Model, enhancing our capabilities for data sharing and analysis.

Additionally, we're excited to update you on the growth of the C-Path mito task force, which now includes 17 members!

Finally, don't miss our upcoming events: a roundtable discussion with C-Path at the World Orphan Drug Congress in Boston, a poster presentation at the Rare Disease Drug Development Symposium in Philadelphia, and our 3rd Leigh syndrome symposium, for which registration is now open.

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

The Cure Mito team

"Where there's hope, there's life. It fills us with fresh courage and makes us strong again."—Anne Frank

Leigh syndrome global patient registry

Leigh syndrome families, become part of the world's largest Leigh syndrome patient registry.

We provide real, tangible results, ensure data is available to researchers and consistently share results with our community, keeping you informed.

Join the Registry Now

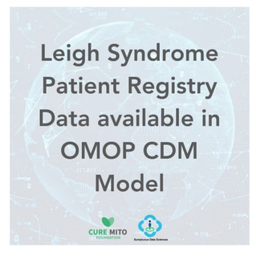
Our published registry papers

[Leigh Syndrome Global Patient Registry: Uniting Patients and Researchers Worldwide]

[Interoperability of Leigh Syndrome Patient Registry Data with Regulatory Submission Standards]

If you would like to join the registry in Spanish, Portuguese, Italian, French, Turkish, Polish, or Chinese please contact us at info@curemito.org.

Latest registry news: Cure Mito Patient Registry Data in OMOP CDM Model



We are pleased to announce that we now have Cure Mito patient registry data available in OMOP CDM model. This project was completed through collaborative efforts with Sumptuous Data Sciences.

Observational Medical Outcomes Partnership (OMOP) Common Data Model is an open community data standard designed to standardize the content and structure of observational data. This data model is developed and maintained by OHDSI (Observational Health Data Sciences & Informatics). The modelling process of patient registry data can allow us to use of advanced analytics tools built on OMOP CDM data and conduct more comprehensive data analysis. In addition to this, OMOP based modelling and data transformation allows us to seamlessly share the data as well as analytic results with the research community, regulatory bodies, and other stakeholders.

This follows our previously shared project about data interoperability with CDISC. As a part of this project both CDISC datasets as well as raw data were converted to OMOP, **establishing a three-way interoperability for Cure Mito registry data between CDISC and OMOP-CDM.**

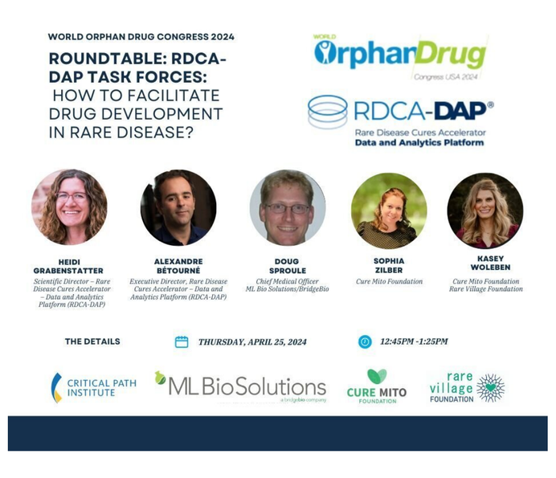
We are excited to share this update with the community and look forward to share additional updates!

If you are a researcher or an industry representative and would like to learn how our patient registry can help you, please request a slide deck HERE.

Mitochondrial and Inherited Metabolic Diseases Taskforce update

We are excited to welcome Sanford Research to the Mitochondrial and Metabolic disease taskforce led by Critical Path Institute, bringing us to 17 members! Sanford Research, a nonprofit research institution, houses CoRDS (Coordination of Rare Diseases at Sanford), a centralized international patient registry for all rare diseases that currently supports Leigh syndrome and PDCD patient registries. Learn more about the taskforce HERE.

Meet us in Boston!

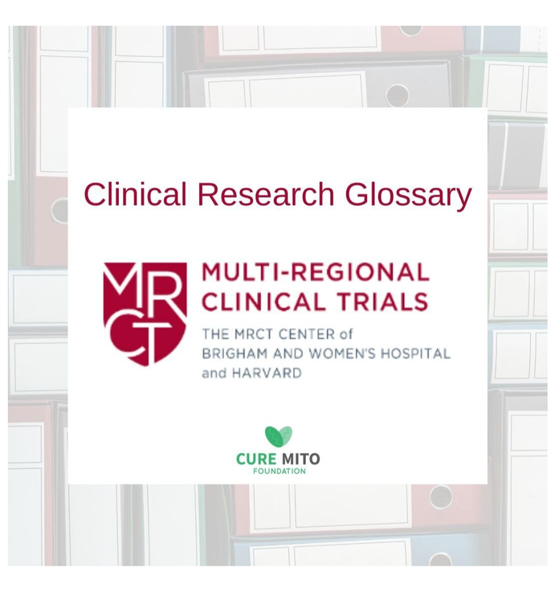


Come and hear us speak in #Boston at World Orphan Drug Congress USA on Tuesday, April 25, 2024 as we will be participating in a roundtable: **RDCA-DAP TASK FORCES: How to facilitate drug development in rare diseases?** We will be sharing our experience in developing and launching of the Mitochondrial and Inherited Metabolic Disease Task Force.

Find our poster in Philadelphia!

Are you attending Rare Drug development symposium hosted by Global Genes and Orphan Disease Center at University of Pennsylvania? If so check out our poster: **"Empowering Leigh Syndrome Families: The Creation of 'About Leigh Syndrome' an Online Resource"**.

Clinical Research Glossary



To help patients and families make informed decisions about participating in clinical research, the MRCT Center of Brigham and Women's Hospital and Harvard, along with patient advocates and research professionals, has created a plain-language Clinical Research Glossary. This resource, available for free download, features 167 definitions complete with images and resources, rigorously reviewed by the public to set a global standard. You can find many terms implemented in Cure Mito glossary. Learn more HERE.

Empower and Inspire: 3rd Annual Leigh Syndrome Symposium registration is open!

Please save your spot today, our conference platform was at full capacity the previous 2 years.

If you are interested in speaking please fill out the form by clicking HERE.

If you are interested in sponsoring, please reach out to us at info@curemito.org

REGISTER NOW

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

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

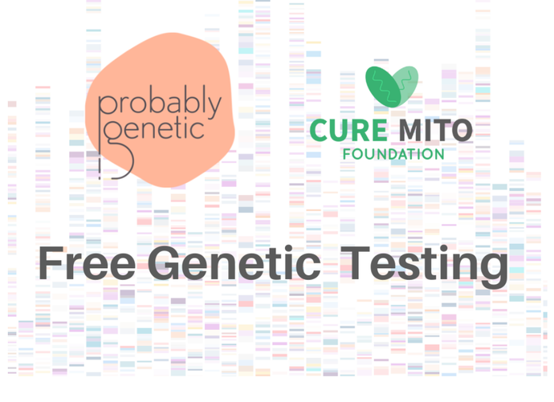
Make a donation
give.curemito.org/curemito

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.



FREE GENETIC TESTING

Cure Mito has partnered with Probably Genetic to increase access to genetic testing within our community. Probably Genetics' 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.

For many ways to give, please click here:
https://www.curemito.org/ways-to-give

Donate Now

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