



Dear friends, partners, and followers of the Cure Mito Foundation,

Thank you for reading our March 2023 Newsletter! In this newsletter you will find information on our new and existing projects, annual Leigh syndrome symposium, patient registry updates, NIH research studies, ways to get involved and much more!

We hope this newsletter will leave you feeling a little bit more hopeful and a little more inspired.

The Cure Mito team

"Always remember, you have within you the strength, the patience, and the passion to reach for the stars, to change the world." - Harriet Tubman

NEW! YOUR PARTICIPATION IS NEEDED IN THE LEIGH SYNDROME MEDICAL NETWORK

We are building a database to help Leigh syndrome patients find doctors who have treated other Leigh syndrome patients. You can list doctors of any specialties - neurology, genetics, cardiology, physical/occupational therapy, genetic counseling, and more. We would greatly appreciate our community support with this important initiative that can help families to find physicians they need!

If you are a clinician, you can refer yourself!

Please click [HERE](#) to refer a doctor. To submit multiple doctors please fill out the form more than once.

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NEW! FAMILY PLANNING GUIDE

Family planning options for Leigh syndrome and mitochondrial disease depend on the type of inheritance and information can be difficult to find. We hope our new guide will help.

We would like to thank and acknowledge the following organizations and individuals for making this guide possible:

Authors of the paper "Genetic testing for mitochondrial disease: the United Kingdom best practice guidelines", who have written an extremely useful paper and allowed us to use it as a guide.

Breanna Lima Martinez, genetic counselling student at University of Pennsylvania who created this guide.

Orphan Disease Center at University of Pennsylvania for a collaboration that made this project possible.

Dr. Shamima Rahman, FRCP, FRCPC, PhD for review and editing of this guide.

NEW! Clinical Trials

We have a new and updated clinical trials page. You can find clinical trials that are currently recruiting, those that are active or recruiting by invitation only. Everything is linked directly to clinicaltrials.gov for most updated information!

Additionally, you can learn more about clinical trial process, the FDA, and your rights as a participant.



We are getting ready for the 2nd Annual Leigh Syndrome Symposium!

Empower & Inspire: Understanding and Accelerating Research for Leigh Syndrome

TUESDAY, SEPTEMBER 19, 2023

Brought to you by: Cure Mito Foundation & integrative Cardiovascular Metabolism and Pathophysiology Laboratory (iCaMP) at Boston University

REGISTER NOW

AGENDA INCLUDES

- Research news and updates
- Multi-disciplinary panel discussions
- Leigh syndrome patient registry updates
- Patient and Caregiver perspectives
- Networking opportunities

To learn more, please click [HERE](#)

If you are interested in speaking, please complete [speaker interest form](#)

Please click [HERE](#) to learn more about sponsorships.



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

[CLICK HERE TO LEARN MORE](#)

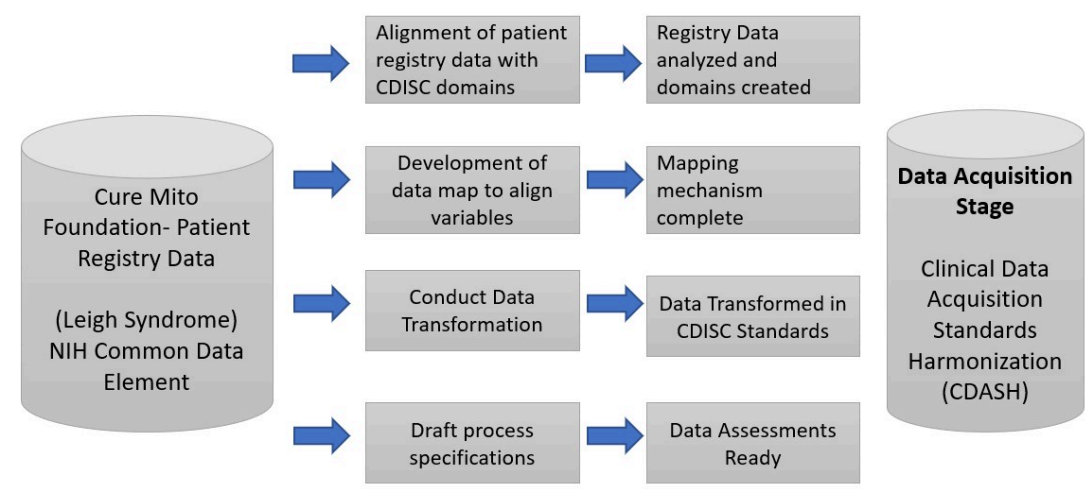
LATEST REGISTRY NEWS

We are partnering on the patient registry with Association Guerrier Mitochondrial in France. French translation of our surveys will be shared with patient families!

We are grateful to Association Guerrier Mitochondrial for this collaboration!

Did you know that as a result of a collaboration with Sumptuous Data Sciences, our registry data is interoperable with regulatory submission standards (CDISC)? Please reach out to us to learn more about how this pilot project can help mitochondrial disease community!

Collaboration Case Study- Cure Mito Foundation and Sumptuous Data Sciences, LLC



Reference: Clinical Data Interchange Standards Consortium (www.cdisc.org)

Cure Mito - Upenn Collaboration

We have collaborated with Orphan Disease Center at University of Pennsylvania on a project meant to improve the way patient foundations work with data collected through patient registries. As a result of the project the following slideshow as well as FAQ were created, please find them at: <https://www.orphandiseasecenter.med.upenn.edu/patientregistriesfaq>



RESEARCH STUDIES

NIH has studies that maybe of interested to Leigh syndrome patients. Please see details below and click on each image to see posters in full size.

https://www.nih.gov/NIHMMI."/>

https://www.nih.gov/COVID19."/>

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>

If you have expertise and skills to contribute, such as fundraising, writing, marketing, and much more, volunteer opportunities are available! Please contact us at info@curemito.org to learn more.

DONATE NOW

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