

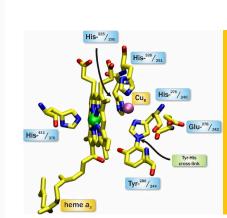
Dear friends, partners, and followers of the Cure Mito Foundation,

Thank you for reading our April 2023 Newsletter! In this newsletter you will find information on our new and existing projects, annual Leigh syndrome symposium, patient registry updates, drug repurposing updates, conferences we plan to attend, 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

"Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible." - Francis of Assisi



Drug repurposing update

We are excited to share that we will be screening six more Leigh Syndrome genes as we continue our collaboration with Perlara! The next LS gene currently in the queue is AFG3L2.

Please learn more by clicking HERE



Empower & Inspire: 2nd Annual Leigh Syndrome Symposium

TUESDAY, SEPTEMBER 19, 2023

Brought to you by: Cure Mito Foundation

integrative Cardiovascular Metabolism and Pathophysiology
Laboratory (iCaMP) at Boston University

Keynote speaker:

Steven Gray, PhD

Associate Professor, University of Texas Southwestern Medical Center

"Gene Therapy for Neurological Disorders"

REGISTER NOW

To learn more, please click <u>HERE</u>

If you are interested in speaking, please complete <u>speaker interest form</u>

Please click <u>HERE</u> 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

ATTENTION!

We are so excited to share that a poster with our latest Leigh syndrome patient registry results was accepted to be shared at the Euromit conference in

If you planned to enroll but didn't, please be sure to enroll by April 30th for your data to be included in the results!

Additionally, if you have not responded to both surveys - general and Leigh syndrome survey - please complete both by April 30th!

If you are not sure what you need to do complete, please reach out to cords@sanfordhealth.org



Meet us at upcoming conferences!



Sophia will speak about our patient registry and use of patient-reported registry data for research and drug development at the Rare Drug Development Symposium in Philadelpha, May 1-3, organized by Global Genes and Orphan Disease Center at University of Pennsylvania.

Kasey will be at Euromit in Bologna, Italy June 11-15 and represent our poster, "Leigh syndrome global patient registry"



LEIGH SYNDROME CLINICAL NETWORK UPDATE

If you see a medical provider of any specialty who sees patients with Leigh syndrome OR if you are yourself such medical provider, please complete the form by clicking HERE

ABOUTLEIGHSYNDROME.COM UPDATE

ABOUTLEIGHSYNDROME.COM is a new website and a landing place for patients, families, providers, and the entire global Leigh syndrome community. We are getting closer to seeing it live and will continue to share updates!

A huge thank you to <u>PTC Therapeutics, Inc.</u> for their generous sponsorship that is making this resource possible for our community.

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:

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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Platinum Transparency 2022







2022 TOP-RATED

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