



REGISTRATION IS NOW OPEN FOR:

**EMPOWER AND INSPIRE:
Understanding and Accelerating Research for Leigh Syndrome**

Co-hosted by Cure Mito Foundation and integrative Cardiovascular Metabolism and Pathophysiology Laboratory (iCaMP) at Boston University

Please join us Virtually on

Tuesday, September 20, 2022

Register and more information at:
<https://www.curemito.org/conference>

As we're working on the detailed agenda and confirming additional speakers, all information will be posted at the link above - please continue to check it for updates!

EMPOWER AND INSPIRE
UNDERSTANDING & ACCELERATING RESEARCH FOR LEIGH SYNDROME

VIRTUAL AGENDA INCLUDES:
Understanding Leigh Syndrome
Updates On Current Research
Drug Development Process
Accelerating Research Through Data
Managing LS Symptoms
Caregiver Wellness

Keynote Address: Vamsi Mootha, MD
Intro to Gene Therapy: Steven Gray, PhD

More Details To Come Soon!

For sponsorship or speaking inquiries please contact info@curemito.org

Brought to you by:
CURE MITO FOUNDATION

SAVE THE DATE
Tuesday, September 20, 2022
[curemito.org/conference](https://www.curemito.org/conference)

THANK YOU TO OUR CONFERENCE SPONSORS



Leigh Syndrome Global Registry Updates

Thank you to all who has enrolled so far!

We now have 180 enrolled patients. Our giveaway is over, and 2 \$ 150 VISA gift card raffle winners have been drawn and will be notified by our registry partner [Sanford Cords](#)

We're working on all the data collected so far and will be sharing all results with the community!

If you or your loved one has Leigh syndrome and have not yet enrolled - please enroll - each patient helps us understand the disease better, raise awareness, create additional research opportunities, find treatments, and build a stronger community!

If you see a Mito specialist, please download and share our printable IRB-approved flyer with your medical team: <https://www.curemito.org/registry>

First registry results can be seen here: <https://www.curemito.org/results>
Surveys in Spanish and Portuguese are available. All translations are certified and IRB approved. If you have interest in additional languages please reach out to us!

Helpful links

Newly diagnosed patients guide: <https://www.curemito.org/newly-diagnosed>
Birthday club: <https://www.curemito.org/birthdays>
Support: <https://www.curemito.org/support>
Books about finding resilience, hope, and courage: <https://www.curemito.org/recommended-books>
Just for kids: <https://www.curemito.org/for-kids>

Clinical trial updates

If you or your child has confirmed mitochondrial disease diagnosis with associated epilepsy you may qualify for MIT-E study by [PTC Therapeutics, Inc.](#). The study is currently open and enrolling patients. Please note that the study inclusion criteria has been expanded to include men and women up to 20 years of age.

More information can be found at:

www.themit-estudy.com or <https://clinicaltrials.gov/ct2/show/NCT04378075?term=NCT04378075&rank=1>

With questions please contact MitoStudy@ptcbio.com.

Children 6 months-17 years old with genetically confirmed pyruvate dehydrogenase complex (PDC) Deficiency may qualify for a Trial of Dichloroacetate in Pyruvate Dehydrogenase Complex Deficiency: (DCA/PDCD).

More information can be found at:

[Trial of Dichloroacetate in Pyruvate Dehydrogenase Complex Deficiency: - Full Text View - ClinicalTrials.gov](#)

To search complete list of clinical trials please visit: <https://clinicaltrials.gov/>

Get in touch and join us!

Please visit our website to learn about our research projects, resources, and more: <https://www.curemito.org/>

We invite you to join us in our efforts! For ways to get involved please visit: <https://www.curemito.org/get-involved>

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