



**SAVE THE DATE**  
**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 save the date and stay tuned for more details!!!

**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](mailto:info@curemito.org)

Brought to you by:  
CURE MITO FOUNDATION

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

**Leigh Syndrome Global Patient Registry**

Please remember to enroll into the patient registry by **April 30, 2022** in order for your data to contribute to the paper. All who enroll and respond to 2 surveys between now and April 30, 2022, will be entered into a raffle - 2 winners will be drawn randomly by our registry partner [Sanford Cords](#) - winners will win a \$150 VISA gift card

First results can be seen here: <https://www.curemito.org/results>

More information: <https://www.curemito.org/registry>

Surveys in Spanish and Portuguese are available. All translations are certified and IRB approved.

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

With questions please contact [MitoStudy@ptcbio.com](mailto: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/>

**Partner with us!**

Families are invited to partner with us. As a partner family you will:

Have an opportunity to participate and have a voice in Cure Mito initiatives as well as propose new ones

Participate in Facebook group for partner families

And more!

For more information please reach out to use at [info@curemito.org](mailto:info@curemito.org)

**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>

**DONATE**

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