



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

Thank you for reading our May 2023 Newsletter! We have many ongoing activities and projects as well as those coming up that we are sharing in this newsletter!

If you find this newsletter useful, please share it with your friends, family, and colleagues!

As always, we hope this newsletter will leave you feeling a little bit more hopeful and a little more inspired.

The Cure Mito team

"The world needs dreamers and the world needs doers. But above all, the world needs dreamers who do."

-Sarah Ban Breathnach



Rare Disease Families Advocate For Change

We are thrilled to share that an article about our work and our patient registry for Leigh Syndrome has been featured on WebMD!

Please read the full article [HERE](#).

ABOUT LEIGH SYNDROME

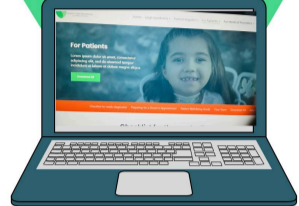
STAY TUNED FOR A LIVE WEBSITE AND A PRESS RELEASE IN THE COMING WEEKS

ABOUTLEIGHSYNDROME.COM is a new website and a landing place for patients, families, providers, and the entire global Leigh syndrome community.

A huge thank you to [PTC Therapeutics, Inc.](#) for their generous sponsorship that is making this resource possible for our community.

COMING SOON
New Website!

www.aboutleighsyndrome.com





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

REGISTER NOW

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.

THANK YOU TO OUR SPONSORS



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 UPDATE

A poster with most up to date results will be presented at Euromit in Italy in June. We will also share the poster online at that time. We look forward to sharing latest results with the community!

REGISTRY FACT YOU MAY NOT HAVE KNOWN ABOUT!

Leigh syndrome can be caused by more than 110 nuclear DNA and mitochondrial DNA genes. We collect patient's responses about which gene is affected in free text and then using a special algorithm we have developed map it to an actual gene and gene type in structured format that we report in our results!

We have attended several conferences!

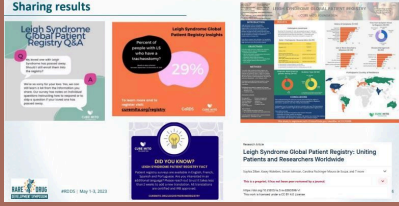


Kasey was in St. Jude and participated in the #PTNI workshop on the advancement of Pediatric Translational Neuroscience to ensure Leigh syndrome and mitochondrial disease are represented in the new research initiative.

Kasey also attended American Society of Gene & Cell Therapy (ASGCT) conference and represented Leigh syndrome and Rare Diseases!

Sophia participated in a panel and shared how patient groups can make the best use of their registry data and share our work on Leigh syndrome patient registry at the Rare Drug Development Symposium organized by Global Genes and Orphan Disease Center at University of Pennsylvania

Recording of the panel can be found [HERE](#)



Sophia is co-leading a working group "Best Data Practices for Rare Disease Patient Foundations and Researchers". The group recently produced several resources to provide guidance for patient organizations developing registries. You can learn more about the working group and view and download those resources [HERE](#).

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](#)

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

Follow Us:

