CURE MITO FOUNDATION

Dear Friends, Partners, and Followers of the Cure Mito Foundation,

Thank you for reading our July 2023 Newsletter! In this newsletter we are sharing with you more information about upcoming Leigh syndrome symposium, our new press release about continued collaboration with Critical Path Institute, a beautiful blog post by one of our families, and much more!

As our reach, as well as the scope of our work, is growing rapidly, we have many opportunities for involvement! Feel free to reach out to us at info@curemito.org to learn more!

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

The Cure Mito team

"Do what you can with all you have, wherever you are."

-Theodore Roosevelt

Have you registered?

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

HIGHLIGHTS:

Gene Therapy for Neurological Disorders: Keynote, Steven Gray, PhD, University of Texas Medical Center

The immunological origins of Leigh syndrome: Allison Hanaford, PhD, Seattle Children's Research Institute

Developmental and rehabilitation therapies in mitochondrial disease: PT, OT, Speech and beyond: Ibrahim Elsharkawi, MD, Icahn School of Medicine at Mt. Sinai

Interoperability of patient registry data with regulatory standards: Pallavi Bakare, MS, Sumptuous Data Sciences

Accelerating Mitochondrial Drug Development through a Public Private Partnership: Amanda Klein, Critical Path Institute

VIEW AGENDA

LIVE TRANSLATION TO 30+ LANGUAGES WILL BE AVAILABLE

THANK YOU TO OUR SPONSORS

THANK YOU TO OUR COMMUNITY PARTNERS

If you would like to be a conference sponsor or a media partner please reach out to us at info@curemito.org

SECURE YOUR SPOT

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

LEARN MORE

SANFORD HEALTH RARE DISEASE DATA REGISTRY PARTNERS WITH C-PATH'S RDCA-DAP, CUREMITO FOUNDATION

We are thrilled to share that Leigh syndrome patient registry data that we have collected is now being integrated into Critical Path Institute (C-Path)'s RDCA-DAP platform.

RDCA-DAP provides a centralized and standardized infrastructure to support and accelerate rare disease characterization targeted to accelerate clinical drug development.

"We are excited to collaborate with Sanford Research, integrating the invaluable patient data they collected to help drive research for rare mitochondrial disorders including Leigh syndrome," said Alexandre Bélouzard, PhD, PharmD, FMP, Executive Director, RDCA-DAP. "This partnership demonstrates our shared commitment towards eliminating information silos in the field of rare mitochondrial disorders and an important milestone achieved through our collaboration with the Cure Mito Foundation.

LEARN MORE IN THE PRESS RELEASE

REGISTRY POSTER TRANSLATIONS

Thanks to our friends at AGM Association Guerrier Mitochondrial in France for translating our latest registry poster to French and to our friends at Fundación Sonríe SURI'I in Argentina who are working on the translation to Spanish!

Our registry would not be what it is today without the encouragement, support, and participation from so many in the community. THANK YOU.

The Endurance We Didn't Choose

"Holding him on my lap, I wept for all the things I could not fix. I wept for his feelings of frustration, and for my own. I wept because I loved him so deeply, because he was perfect and beautiful, and because he was not going to be OK."

Kim Gilsdorf is a mom to Lucas whom we lost to Leigh syndrome in December 2022. We encourage you to read her beautiful blog post published by Courageous Parents Network. Please find the blog post HERE.

You can also donate to the fund Lucas's family started in his memory by clicking HERE.

Need to explain Leigh syndrome to your child's doctor, therapist, or a family member? Download one-page resource shown below by clicking HERE. If you'd like it to be mailed to you please reach out to us at info@curemito.org

Thanks to your support, we have gotten a Great Nonprofits Award in 2022! We hope to extend it to 2023! Please support us by sharing a brief story HERE.

HAVE YOU SEEN THE NEW WEBSITE ABOUT LEIGH SYNDROME?

AboutLeighSyndrome.com is a first of its kind informational website about Leigh syndrome with resources and support for both families and healthcare professionals.

Please find more information in the press release: Cure Mito Foundation releases the first-of-its-kind online resource about Leigh syndrome (news-medical.net)

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

Many volunteer opportunities are also available!

Skills and expertise currently needed: fundraising, marketing, writing (scientific writing, grant writing, blog writing). Please contact us at info@curemito.org to learn more.

DONATE NOW

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