



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!

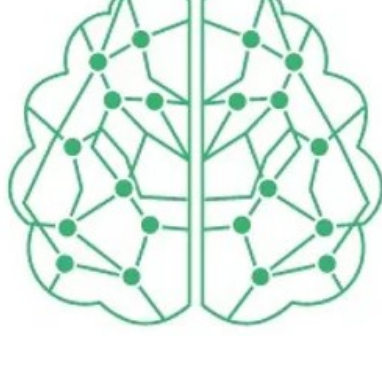
As our reach, as well as the scope of our work, is growing rapidly, we have many opportunities for involvement! Feel free to reach out to us at info@curemito.org to learn more!

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

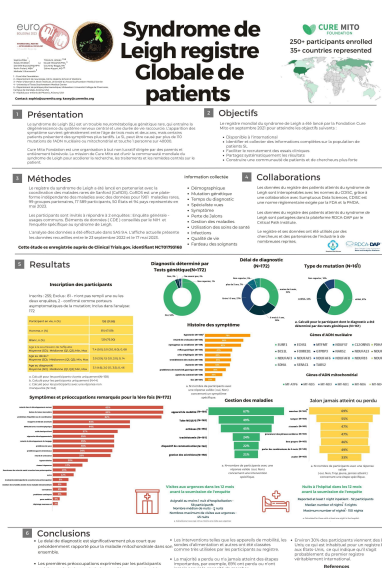
We are thrilled to share that Leigh syndrome patient registry data that we have collected is now being integrated into Critical Path Institute (C-Path)'s RDCA-DAP platform.

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 Bétourné, 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

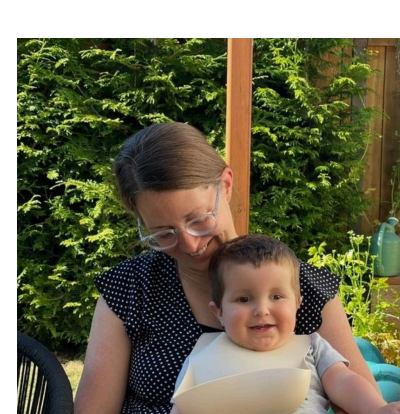
REGISTRY POSTER TRANSLATIONS



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 Sonrie SURF1 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.

WHAT IS LEIGH SYNDROME? Leigh syndrome (sometimes called Leigh's disease) is a rare and severe neurometabolic disorder and a type of primary mitochondrial disease. It is a neurodegenerative disease that causes loss of abilities to walk, talk, swallow. 1 in 40,000 individuals are affected by Leigh Syndrome, although this number may be underestimated. 2 mo - 3 yrs age when symptoms typically start, although earlier or later onset is also possible. 110+ Genetic mutations in nuclear DNA and mitochondrial DNA can cause this syndrome, with more genes continuing to be discovered. Treatments for Leigh syndrome are focused on slowing disease progression. Often, children have difficulties chewing and swallowing and it can be difficult to take in sufficient calories by mouth. A feeding tube - also known as Gastrostomy Tube (G-Tube) - can be really helpful in improving calorie intake and reducing the time needed for feeds. A care team for a person with Leigh syndrome should include multiple specialists, such as geneticists, neurologists, cardiologists, gastroenterologists, ophthalmologists, palliative care, psychologists, speech, physical, occupational therapists, and others depending on the specific symptoms. Caring for a child or loved one with a life-limiting condition like Leigh syndrome can be challenging. Lower stress and the risk of developing depression or anxiety by: Connecting with support groups familiar with Leigh syndrome, Practicing self-care, Asking for help, Talking to a mental health professional if necessary. To learn more about Leigh syndrome, please visit AboutLeighSyndrome.com

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.

About Leigh Syndrome Cure Mito Foundation 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) To learn more about Leigh syndrome, please visit AboutLeighSyndrome.com

LEIGH SYNDROME MEDICAL NETWORK 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 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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