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CURE MITO FOUNDATION

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

Thank you for reading our August 2023 Newsletter! This newsletter is one of our longer ones - you will find lots of information on how you can be involved in the Mitochondrial Disease Awareness week (and win exciting prizes!), Leigh syndrome symposium, Mito drug development meeting with C-path and other upcoming conferences where you can meet our team, free genetic testing opportunity, and much more.

If you find this newsletter interesting and useful, please share it with your own network!

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

The Cure Mito team

"Dream more, learn more, care more, and be more."

-Dolly Parton

MITOCHONDRIAL DISEASE AWARENESS WEEK
SEPTEMBER 18-23 2023


COLOR FOR MITO!
Enter to WIN!!!
and show you care
1st Prize- iPad mini
2nd Prize- Apple AirPods
3rd Prize- $50 Amazon Gift Card
*all prizes have been donated
Deadline to Enter Contest
September 17th
sponsored by:
Winners will be announced on 9/19 at the Virtual Leigh Syndrome Conference!

COLOR FOR MITO!

This year, we are excited to invite you to participate in the "Color for Mito" contest.

Participate in 3 easy steps:

1) Download a coloring page
2) Color! Kids and siblings can participate, parents can help :)
3) Email us your completed picture along with the name of the participant!

Win prizes:
1st Prize- iPad mini
2nd Prize- Apple AirPods
3rd Prize- $50 Amazon Gift card

Winners to be announced at the Leigh syndrome symposium, please register

The first 20 to participate will receive a FULL SIZE (24x36) Mito Awareness Poster to display at your school!

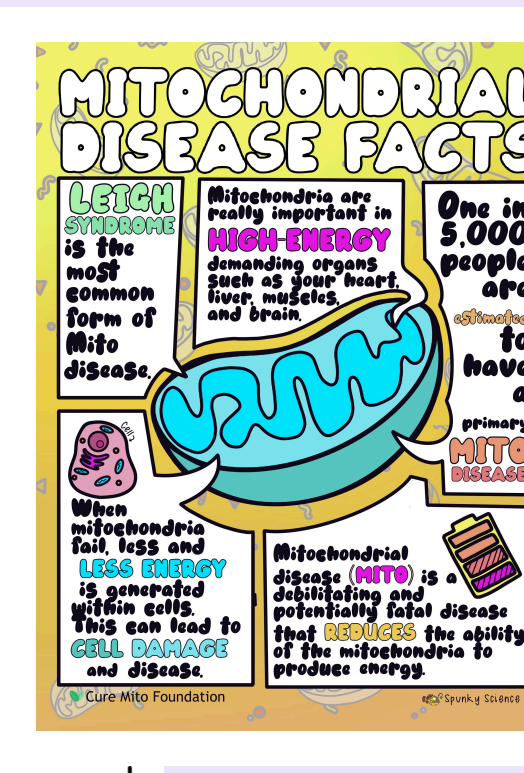
If you have a Mito Warrior in school this is a GREAT way to spread awareness. Consider sharing with your schools, libraries, community centers and work places!

Find all details HERE

THANK YOU TO OUR SPONSORS OF THIS MITO AWARENESS WEEK

Standigm — The workflow AI drug discovery company
SAOL
Reneo Pharmaceuticals

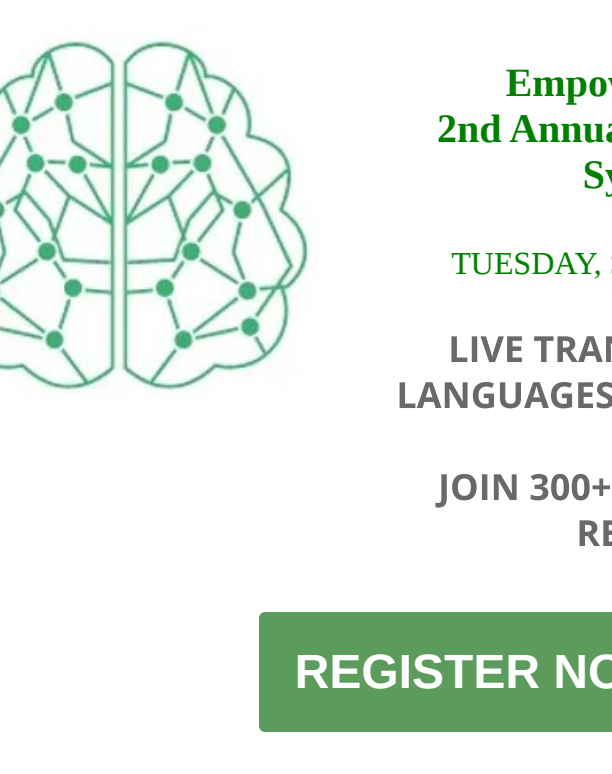
Launch a fundraiser by September 17th, raise vital funds, and get a FREE Mito Awareness Poster and a T-shirt of your choice as a token of our appreciation for your commitment!



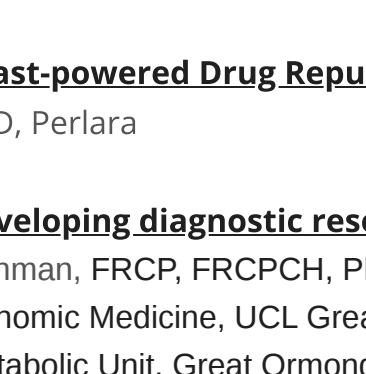
Download a poster or a mito fact sheet and share at your school, work, and community!


MITO DISEASE awareness week
90% of the energy that you need to live and grow are made by mitochondria
"Even though mito disease makes us tired, we still love to laugh & PLAY!"
No cure exists, but we are working towards one.
All cells in the human body, except red blood cells, have mitochondria!
Mito are really important in HIGH-ENERGY demanding organs such as your heart, liver, muscles, and brain
To learn more and to join our efforts visit CureMito.org
LEARN MORE SEPTEMBER 18TH-24TH


MITOCHONDRIAL DISEASE FACTS
LEIGH SYNDROME is the most common form of Mito disease.
Mitochondria are really important in HIGH-ENERGY demanding organs such as your heart, liver, muscles, and brain.
One in 5,000 people are estimated to have a primary MITO DISEASE.
When mitochondria fail, less and LESS ENERGY is generated within cells. This can lead to CELL DAMAGE and disease.
Mitochondrial disease (MITO) is a debilitating and potentially fatal disease that REDUCES the ability of the mitochondria to produce energy.



Help raise awareness and funds for mito research by shopping our bonfire store!



Empower & Inspire: 2nd Annual Leigh Syndrome Symposium

TUESDAY, SEPTEMBER 19, 2023

LIVE TRANSLATION TO 30+ LANGUAGES WILL BE AVAILABLE

JOIN 300+ PEOPLE ALREADY REGISTERED

REGISTER NOW

HIGHLIGHTS:

Yeast-powered Drug Repurposing for Leigh Syndrome: Ethan Perlstein, PhD, Perlara

Developing diagnostic resources for Leigh syndrome: Shamima Rahman, FRCP, FRCPCH, PhD, Mitochondrial Research Group, Genetics and Genomic Medicine, UCL Great Ormond Street Institute of Child Health, and Metabolic Unit, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK

Pluripotent stem cells and brain organoids for Leigh syndrome: Alessandro Prigione, MD, PhD, University of Düsseldorf, Germany

VIEW AGENDA

THANK YOU TO OUR SPONSORS

PTC Therapeutics, SAOL, Sumptuous Data Sciences, SSIEM

THANK YOU TO OUR COMMUNITY PARTNERS

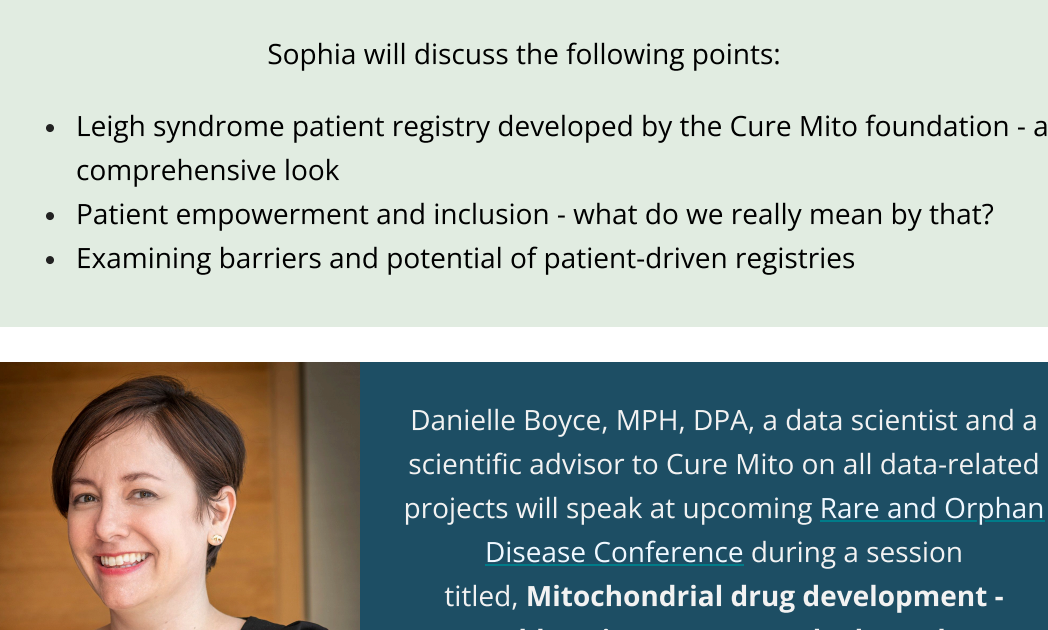
If you would like to be a conference sponsor or a media partner please reach out to us at info@curemito.org

SECURE YOUR SPOT

Meet us at upcoming conferences!

Kasey will speak on the panel, **"Beginner's Guide to Community Activation"** during the Rare Advocacy Summit by Global Genes

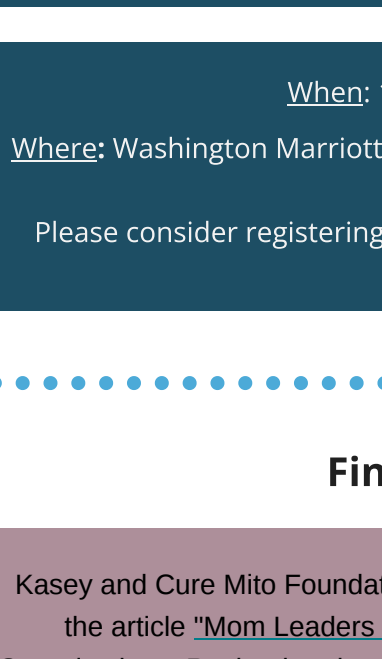
The topic of the panel discussion is to understand how to engage a community, welcome the newly diagnosed, bond through local and online meetups, communicate effectively, and activate people to participate in research and data collection.


3rd Annual
Mitochondria-Related Drug Development
Hear Me Discuss:
Connecting the Dots: Understanding Patient Empowerment, Inclusion, and the Landscape of Patient-Developed Registries
Day 2 | 14, September
Sophia Zilber
Board Director & Patient Registry Director
Cure Mito

Sophia will speak at the Mitochondria-Related Drug Development Summit in Boston and will discuss the topic: **"Connecting the dots: Understanding Patient Empowerment, Inclusion, and the Landscape of Patient-Developed Registries"**

Sophia will discuss the following points:

- Leigh syndrome patient registry developed by the Cure Mito foundation - a comprehensive look
- Patient empowerment and inclusion - what do we really mean by that?
- Examining barriers and potential of patient-driven registries



Danielle Boyce, MPH, DPA, a data scientist and a scientific advisor to Cure Mito on all data-related projects will speak at upcoming Rare and Orphan Disease Conference during a session titled, **Mitochondrial drug development - addressing unmet needs through collaboration."**

Speakers: Alexandre Betourne (C-Path), Danielle Boyce (JHU, Cure MITO Foundation), Amanda Klein (C-Path), Dima Martini (Astellas)

When: 12-12:45 ET on September 11

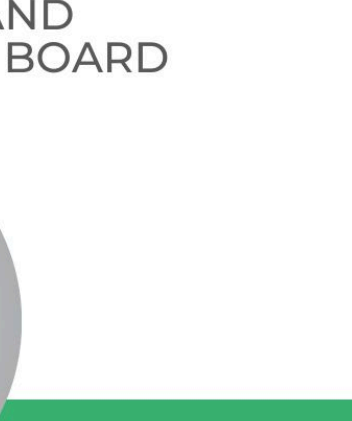
Where**:** Washington Marriott at Metro Center (this will be an in-person meeting only)

Please consider registering for this conference HERE. Registration closes on August 25.

Find us in the news!

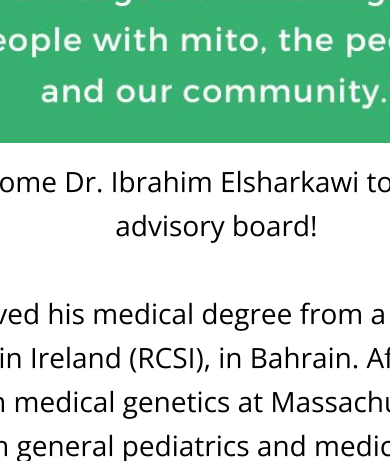
Kasey and Cure Mito Foundation were featured in the article "Mom Leaders of Rare Disease Organizations: Reshaping drug development for rare diseases" by Endpoint News

"We're changing the way these companies are thinking," said Kasey Woleben, co-founder of the Cure Mito Foundation, a patient group dedicated to Leigh syndrome, the most common type of pediatric mitochondrial disease.



CURE MITO FOUNDATION

WELCOME TO THE MEDICAL AND SCIENTIFIC ADVISORY BOARD



Ibrahim Elsharkawi, MD

"I have had the privilege of working closely with the Cure Mito foundation this year, and I am honored and delighted to have been asked to join their scientific advisory board and to continue to work together meaningfully for our shared goal of serving people with mito, the people who love them, and our community."

We are excited to welcome Dr. Ibrahim Elsharkawi to our medical and scientific advisory board!

Dr. Elsharkawi received his medical degree from a constituent of the Royal College of Surgeons in Ireland (RCSI), in Bahrain. After that, he completed a research fellowship in medical genetics at Massachusetts General Hospital, a combined residency in general pediatrics and medical genetics in Washington University in St. Louis, a fellowship in mitochondrial medicine at the Children's Hospital of Philadelphia, and a training with a fellowship in medical biochemical genetics at Harvard Medical School. Dr. Elsharkawi is now an assistant professor of genetics and pediatrics at the Icahn School of Medicine at Mount Sinai, and caring for patients with inborn errors of metabolism and mitochondrial disease.

We have worked with Dr. Elsharkawi a lot in the past year and are extremely grateful for his support and dedication to our patient community!

Cure Mito Foundation congratulates Dr. Navdeep S. Chandel, PhD, and Dr. Vamsi Mootha, MD on being the recipients of 2023 Lurie Prize in Biomedical Sciences for their groundbreaking research in mitochondrial science.

Please read more HERE.

Those of you who attended our first Leigh syndrome symposium in 2022 may have heard an inspiring keynote speech by Dr. Mootha. You can find a recording HERE.

Cure Mito has partnered with Probably Genetic to increase access to genetic testing within our community. Probably Genetic's no-cost genetic testing program for mitochondrial disorders is patient-initiated and includes genetic counseling to explain any questions or findings. If you or a loved one are experiencing symptoms associated with muscle weakness or movement disorders, you can apply to the program HERE.

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

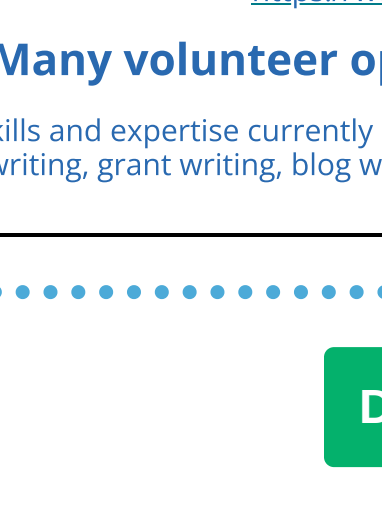
Thanks to your support, we have gotten a Great Nonprofits Award in 2022! We hope to extend it to 2023! Please support us by sharing a brief story HERE.

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)



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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2022 TOP-RATED NONPROFIT