



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

Thank you for reading our June 2023 Newsletter! June has been a busy month for us. We launched a new website [AboutLeighSyndrome.com](http://AboutLeighSyndrome.com), presented our latest Leigh syndrome patient registry results at Euromit, worked on our upcoming conference, and continued to support all who reached out to us.

We also have celebrated 2 years since Cure SURF1 Foundation expanded its mission to all of Leigh syndrome and became Cure Mito Foundation. We are so grateful to all who supported us and continue to support us on this journey!

We hope you find this newsletter interesting and useful! If so, 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

*"How wonderful it is that nobody needs to wait a single moment before starting to improve the world."*

-Anne Frank

### We are celebrating 2 years since Cure SURF1 Foundation expanded its mission to form Cure Mito Foundation!

We have been incredibly busy for the past 2 years, and would like to highlight some of what we have accomplished:

- Partnered with and funded promising research with Dr. Michal Minczuk (University of Cambridge, UK), Dr. Alessandro Prigione (University of Dusseldorf, Germany), Dr. Eitan Perlestein (Perlestein, US), and Rarebase. We also continued partnership with Dr. Steven Gray at UT Southwestern Medical Center and contributed to the Hope for Families travel fund at Children's Hospital of Philadelphia.
- Held a first virtual Leigh syndrome symposium and looking forward to the 2nd one coming up in September! Our first conference was attended by over 200 participants from 34 countries. Live translation to 30+ languages will be available this year.
- Launched Leigh syndrome global patient registry and published 4 posters presented at 9 conferences, written 2 papers (both are currently under peer review), as well as established data interoperability with CDISC standards. Data has been shared with researchers and industry as well as utilized to contact potential study participants multiple times.
- Created a Corporate Advisory Council that currently has 7 member organizations. The corporate advisory council's (CAC) goal is to unite mitochondrial disease stakeholders across different organizations with a common goal to accelerate the development and delivery of treatments, and ultimately a cure, for Leigh syndrome and mitochondrial disease.
- Launched a birthday club that currently provides birthday gifts for more than 100 children living with Leigh syndrome. Seeing kids smiles in the photos we get back is priceless!
- Created multiple informational resources for patients and healthcare providers, including a newly diagnosed guide, family planning guide, parental well-being guide, and much more.
- Launched [aboutleighsyndrome.com](http://aboutleighsyndrome.com) - a new informational website about Leigh syndrome with resources and support for both families and healthcare professionals.

*"We are beyond grateful to all who believe in our vision, partner with us, and support and encourage us on this journey. Together we will change the world."* - Kasey Woleben, Cure Mito co-founder

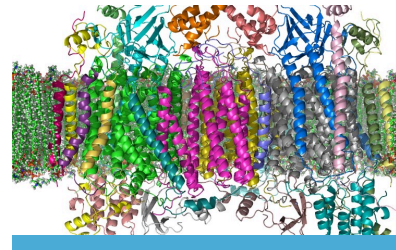
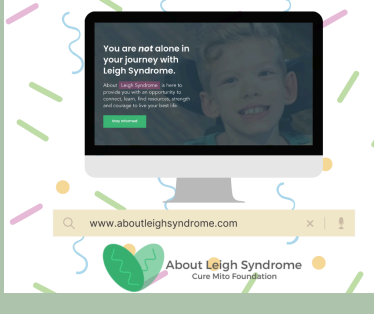
### NEW WEBSITE ABOUT LEIGH SYNDROME IS NOW LIVE

[AboutLeighSyndrome.com](http://AboutLeighSyndrome.com) is a new website and a landing place for patients, families, providers, and the entire global Leigh syndrome community.

The goal and vision behind the project was to create a website that provides accurate and reliable medical content, along with an appealing layout, colorful design, user-friendly features, engaging graphics, and pictures of families and children. It's dedicated to being a platform where individuals can find support, resources, and feel seen (not just as patients, but as people).

Please find more information in the press release: [Cure Mito Foundation releases the first-of-its-kind online resource about Leigh syndrome \(news-medical.net\)](https://www.curemito.org/news-media/2023/06/01/cure-mito-foundation-releases-the-first-of-its-kind-online-resource-about-leigh-syndrome/)

### New Website is Now Live!



### Drug repurposing update

The high-throughput drug screens and dose response studies in yeast are completed. Next up: validating hits in SURF1 patient fibroblasts and Complex IV yeast avatars. Please learn more: <https://www.curemito.org/news-media/2023/06/01/cure-mito-foundation-releases-the-first-of-its-kind-online-resource-about-leigh-syndrome/>

We are honored to have [Mytolife Therapeutics](http://MytolifeTherapeutics) join our Corporate Advisory Council! The corporate advisory council's (CAC) goal is to unite mitochondrial disease stakeholders across different organizations with a common goal to accelerate the development and delivery of treatments, and ultimately a cure, for Leigh syndrome and mitochondrial disease. If your company is interested in joining or has questions please reach out to us at [info@curemito.org](mailto:info@curemito.org).

### Corporate Advisory Council member organizations



### 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

#### What you can expect:

- Research and clinical care updates
- Patient registry and data sharing updates
- Updates from our industry partners
- Parent story and perspectives

LIVE TRANSLATION TO 30+ LANGUAGES WILL BE AVAILABLE

[REGISTER NOW](#)

Full agenda will be available soon. To learn more, including confirmed speakers and sponsorship opportunities, please click [HERE](#)

### 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

We have contributed data that we have collected to RDCA-DAP platform by [C-path](#). Please stay tuned for a press release coming soon!

#### POSTER WITH OUR LATEST REGISTRY RESULTS PRESENTED AT EUROMIT!

Kasey travelled to Euromit this month where she represented our latest patient registry poster!  
You can view the poster in full size [HERE](#)  
You can find all of our previously published results [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 more 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](mailto:info@curemito.org) to learn more.

[DONATE NOW](#)

#### Follow Us:

