



228 participants from 34 countries have joined "Empower and Inspire: Understanding and Accelerating Research for Leigh Syndrome" conference. Thank you to all who joined us for speaking, moderating, listening, asking questions, giving us your time, knowledge, and passion. Special appreciation to the parents who shared their personal stories - thank you for your courage. Here's some feedback that we have received after the conference:

- EVERY presentation I attended was excellent, rich with knowledge and information and valuable.
• With the efforts you are taking, I am very optimistic that very soon we will have treatment options for Mito diseases.
• I enjoyed the mix of scientific talks and stories/experiences.
• Bringing high quality science in a way that everyone can understand!
• I did appreciate the broad range of topics, from research to caregiver care. It was really informative without feeling too packed.
• Short mini talks are a good format to help audience stay engaged. Program was well organized and coordinated, thank you
• I love that it was targeted to an international audience and leveraged technology so well to strengthen those global connections
• It brings more awareness and knowledge about Leigh syndrome in the world where many pediatricians are still unaware of the disease.
• You are providing an important base of knowledge to many who will help unite an educated base of passionate people. I am certain this will result in new discoveries and care models.
• Beautifully organized and very high level science and speakers. Congratulations for arranging this great conference!
• Thank you for your hard work in the endeavor to meet the challenge of Leigh's in better ways.
• Bravo - so well done - the Cure Mito vision was on full display here!

To share your feedback with us please fill out a short form:
https://forms.gle/6Pa1rB1aBXA7jNPd9

To view recordings of all presentations please click here:
https://www.youtube.com/channel/UCxdl5j3l8ads-cS9QySzuIQ

Leigh Syndrome Families - Have You Joined the Patient Registry?

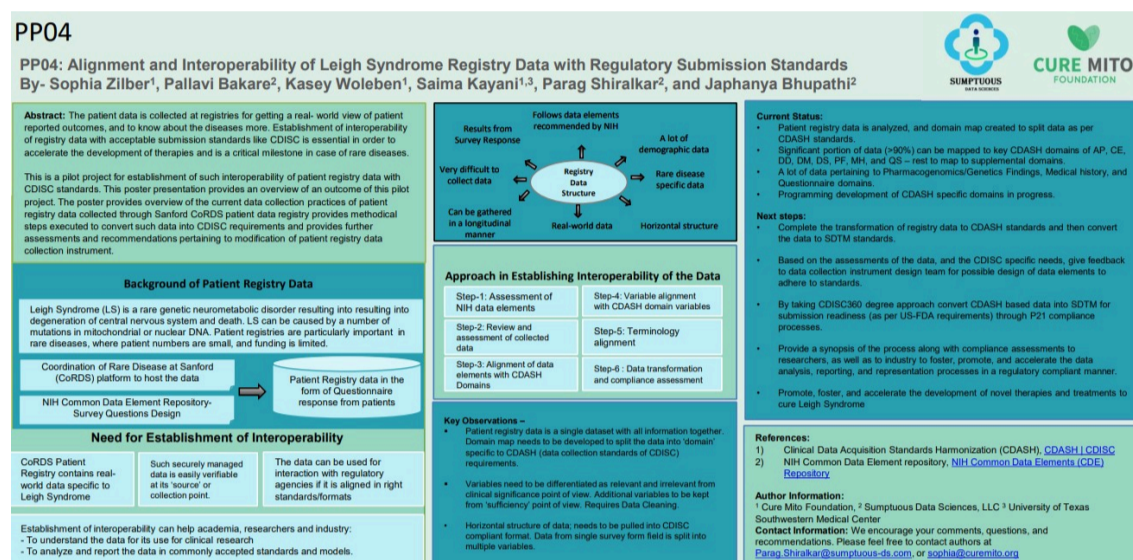
Largest LS patient registry with over 200 participants from at least 32 countries

Accessible and available data

Results are always reported back to the community

LEARN MORE

Latest Patient Registry news: Over 90% of Leigh Syndrome data that we have collected could be mapped to an existing CDISC domain, as required by FDA and PMDA. Results of a pilot project on Alignment and Interoperability of Leigh Syndrome Registry Data with Regulatory Submission Standards as well as next steps have been presented at PHUSE/FDA Computational Science symposium. Our poster is shown below, to see in full size please visit: https://www.curemito.org/results



To view patient registry timeline, updates, and activities, please visit: https://www.curemito.org/leighsyndromeregistry

If you see a Mito specialist, please download and share our printable IRB-approved flyer with your medical team: https://www.curemito.org/leighsyndromeregistry

Surveys in Spanish and Portuguese are available. All translations are certified, and IRB approved. If you have an interest in additional languages, please reach out to us!



Attention to all families in UK, US and Canada: Your stories can help improve understanding patient experiences with mitochondrial disease and in turn can help develop better treatments

You can help by participating in 3 15-minute video diaries followed by a phone interview - please see details in the flyers below. A modest honoraria will be provided to compensate you for your time.

If you are interested in participating please fill out short form below:

To participate please fill out a short form:

UK: https://community.just-worldwide.com/newdesign/site/justworldwide/indexrid_nbr?surveyID=69jvvaRengnb

US/Canada: https://community.just-worldwide.com/newdesign/site/justworldwide/indexrid_nbr?surveyID=nt6ngysan430

For any questions please contact Tom@just-worldwide.com.

Just Worldwide Opportunity to share your experiences with Mitochondrial Disease. WHO: Just Worldwide, a global market research firm, is looking to understand the journey and experiences of patients and caregivers of patients living in the UK, US, or Canada and diagnosed with various types of Mitochondrial Disease... WHAT: We are looking for patients/caregivers of patients in the US, UK, and CA living with Mitochondrial Disease to share their story with us... WHERE: We are looking to have folks do a 45-minute pre-task (3 days x 15 minutes each day) video diary... WHEN: Interviews will be scheduled through the next few months, our team is flexible so we are happy to find a time that works best for you.

Helpful links
Newly diagnosed patients guide
https://www.curemito.org/newly-diagnosed
Birthday club
https://www.curemito.org/birthdays
Support
https://www.curemito.org/support
Books about finding resilience, hope, and courage
https://www.curemito.org/recommended-books
Just for kids
https://www.curemito.org/for-kids

Get in touch and join us!
Please visit our website to learn about our research projects, resources, and more:
https://www.curemito.org/
We invite you to join us in our efforts! For ways to get involved please visit:
https://www.curemito.org/get-involved

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