



Leigh Syndrome Global Patient Registry Update

Our poster "[Leigh Syndrome Global Patient Registry - Cure Mito Foundation](#)" has been presented at the Mitochondria-Targeted Drug Development conference in February and can be seen and downloaded here: <https://www.curemito.org/results>

The next set of results will be based on data collected by April 30, 2022, and will be published in a paper. Our next enrollment goal is 250, all who enroll and respond to 2 surveys between now and April 30, 2022, will be entered into a raffle - 2 winners will be drawn randomly by our registry partner [Sanford Cords](#) - winners will win a \$150 VISA gift card

Please participate and share so that we can build a strong and active community! More information and enroll at: <https://www.curemito.org/cords>

If you're interested in surveys in Spanish or Portuguese please reach out to us!

Podcast!

We have recently joined CoRDS team to talk about Leigh Syndrome patient registry! To hear the podcast please visit:

<https://anchor.fm/cords-cast/episodes/Episode-41---Cure-Mito-Foundation-elf59ol/a-a7gnr3o>



Allstripes update

67 patients are now enrolled in [Allstripes](#), we are almost at our recruitment goal of 70 patients!!!

Allstripes collects medical records on behalf of patients, removing all

burden from patients and caregivers to connect their health portal accounts or upload their files.

Allstripes digitizes, structures and abstracts information from the records, including handwritten notes from doctors that may contain valuable insights.

Allstripes looks at data from the entire medical history since pre-diagnosis and updates data each year to create a much more complete picture.

For more information and to enroll: <https://www.curemito.org/allstripes>

NEW - Birthday Club

If you or your loved one have Leigh Syndrome, please join Cure Mito Birthday Club and get a special birthday surprise from us!

To join please complete the form: <https://www.curemito.org/birthdays>



Ukraine RELIEF efforts

Mark and Daniel Leukhin are 4-year old twins and both have Leigh Syndrome. Together, with their mom Katerina and older brother Ilya, they had to flee their home in Kharkov, Ukraine amid bombings and travel to Lviv, Lutsk, Poland, finally arriving safely in Frankfurt Germany. We have started a fund to help them rebuild. To donate please click

here, all money will be transferred to the family:

<https://www.classy.org/campaign/help-cure-mito-ukrainian-family/c396844>



There are other mito and rare disease families in Ukraine who need help. If you're able to help please reach out to us at info@curemito.org

Clinical trial updates

If you or your child has confirmed mitochondrial disease diagnosis with associated epilepsy you may qualify for MIT-E study by [PTC Therapeutics, Inc.](#) The study is currently open and enrolling patients. Please note that the study inclusion criteria has been expanded to include men and women up to 20 years of age.

More information can be found at:

www.themit-estudy.com or

<https://clinicaltrials.gov/ct2/show/NCT04378075?term=NCT04378075&rank=1>

With questions please contact MitoStudy@ptcbio.com.

Children 6 months-17 years old with genetically confirmed pyruvate dehydrogenase complex (PDC) Deficiency may qualify for a Trial of Dichloroacetate in Pyruvate

Dehydrogenase Complex Deficiency: (DCA/PDCD).

More information can be found at:

[Trial of Dichloroacetate in Pyruvate Dehydrogenase Complex Deficiency - Full Text View - ClinicalTrials.gov](#)

To search complete list of clinical trials please visit: <https://clinicaltrials.gov/>

Partner with us!

Families are invited to partner with us. As a partner family you will:

Have an opportunity to participate and have a voice in Cure Mito initiatives as well as propose new ones

Participate in Facebook group for partner families

And more!

For more information please reach out to use at info@curemito.org

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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