CURE MITO FOUNDATION

Upcoming events

November 29th 12:30 PM ET/11:30 AM CT - please join us for a webinar with CEO of Taysha Gene Therapies, RA Session II and Chief Medical Officer Dr. Suyash Prasad, to discuss status and progress of a clinical trial for SURF1 gene therapy and SURF1 Natural History study. Please click HERE to register.

December 1st, 12 PM ET/11 AM CT - please join us for a Facebook Live event with Chief Medical Officer of PTC Therapeutics, Dr. Matthew Klein to discuss the history of PTC 743 drug and Mit-E clinical trial. Join us live on Cure Mito or Mitoaction Facebook pages.

Giving Tuesday

#GivingTuesday2021 is on November 30! There are over 100+ genes that are associated with Leigh syndrome. Our goal is to research ALL mutations and we need your help! Please consider giving to Cure Mito and helping to accelerate research for this terminal life-limiting disease that was discovered OVER 70 YEARS ago. It's time for a treatment/cure!

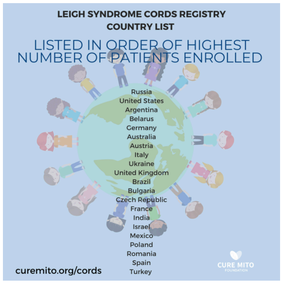
You can make a tax-deductible donation our Facebook fundraiser or our webiste!

Patient registry news and updates

Worldwide Leigh Syndrome Patient registry

In September, 2021, we have opened a Worldwide patient registry for Leigh Syndrome in partnership with Coordination of Rare Diseases at Sanford (CoRDS). Participants are asked to fill out two surveys describing their demographic and general information as well as their experience related to Leigh Syndrome. Two months later, we have met our initial recruitment goal of 100 patients - we now have over 120 participants enrolled and over 90 who completed both surveys.

Our registry is truly INTERNATIONAL as can be seen in the image below. Congratulations to RUSSIA for the most enrolled patients so far!



We are now analyzing all data and preparing a first set of reported results to be widely shared with mito patient and medical community.

For more information and to register please visit: https://www.curemito.org/cords

Medical Records

In September, 2021 we have also started a program in partnership with Allstripes and Mitoaction to enable medical records collections for patients with Leigh Syndrome in US, Canada, and UK.

Allstripes collects all medical records on behalf of patients and digitizes, structures and abstracts information from the records. De-identified data can then be used to advance research. Patients can also access all their medical records in one place. Our initial recruitment goal is 50 patients.

For more information and to enroll please visit: https://www.curemito.org/allstripes

Please click HERE to download one-page IRB-approved printable registry flyer to share with patients and clinicians

Data sharing and Collaboration

Critical Path Institute (C-Path) and Cure Mito Foundation (Cure Mito) announced a joint collaboration to significantly promote data sharing and accelerate Leigh syndrome and other rare mitochondrial disease data incorporation into C-Path's Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®). To read a full press release, please click HERE.

For more information please visit: https://www.curemito.org/cpath

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

DONATE