CURE MITO FOUNDATION

Cure Mito Foundation - the beginning...

Cure Mito Foundation was originally formed in 2018 as Cure SURF1 Foundation. In 2021, after successfully blazing the trail for SURF1 gene therapy at UTSW we decided to expand our efforts and changed the name of our foundation to Cure MITO Foundation. Our primary focus is advancing research towards a cure for Leigh syndrome and eventually for mitochondrial disease as a whole. Cure Mito is a parent-led, fully volunteer foundation. 100% funds raised are used towards research.

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. A little over a month later, we have over 75 participants enrolled and over 50 who completed both surveys.

We are planning on starting data analysis soon and encourage patient families to join the registry and respond to surveys by **November 15th** for their data to be included in the first set of reported results to be widely shared with mito patient and medical community.

More information can be found at: 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.

More information at: https://www.curemito.org/allstripes

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

Upcoming events

November 30th - please save the date 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.

December 1st, 12 pm EST - please save the date for a webinar with Chief Medical Officer of PTC Therapeutics, Dr. Matthew Klein to discuss the history of PTC 743 drug and Mit-E clinical trial

For additional details on these webinars, please follow updates on our Facebook, Linkedin, or Twitter

Research updates

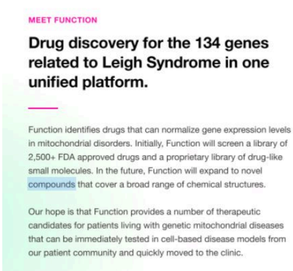
Drug Discovery Platform

We are collaborating with Rarebase, on Function - a drug discovery platform to enable drug discovery for all 100+ nuclear DNA mutations causing Leigh Syndrome.

Please click here to read the press release and learn more

We are relying on YOUR support for this and other research projects, to donate please click HERE. All donations are tax-deductible.

Rarebase + CURE MITO FOUNDATION



MT-ATP6 gene therapy

We are partnering with UT Southwestern Medical Center to develop gene therapy for the mutation in the MT-ATP6 gene. Please click HERE to learn more.

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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