

Patient Registry Update

We're thrilled to share that our poster "Leigh Syndrome Global Patient Registry - Cure Mito Foundation" is now available!!!

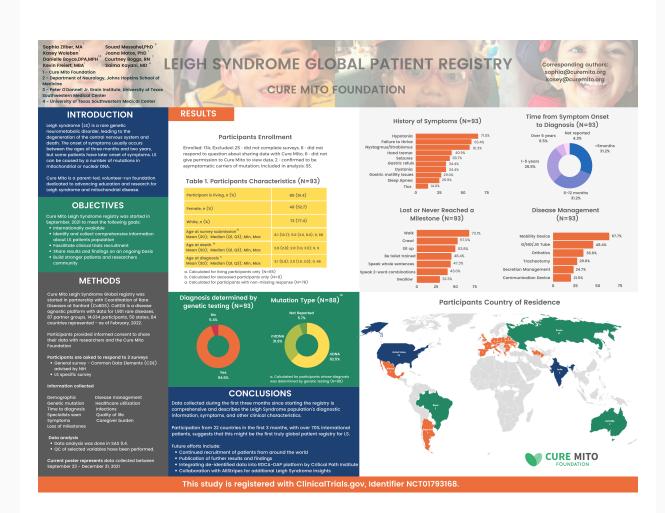
We are grateful to the patients for their support and participation, to our registry partner Sanford Health, and to our incredible patient registry team for their expertise, time, and dedication to this effort and to Cure Mito.

You can see poster below and also download the PDF in full size and listen to the audio recording at the Mitochondria-Targeted Drug Development conference website: https://mitochondria-targets.com/poster-exhibition-page/

After that we're planning a bigger, more detailed publication. If you or your loved one has

Leigh Syndrome and have not enrolled into the registry yet, please enroll soon to contribute to
the results! Register here: https://www.curemito.org/registry

If you're interested in collaborating with us, please reach out to us at info@curemito.org



Finding Your Family Path - Webinar this Friday

Insights and perspective from other parents and resources from Courageous Parents Network

Please join us on <u>February 25th, 12 pm EST</u>, for a discussion with Blyth Lord, founder of <u>Courageous Parents Network</u> exploring the spectrum of the parent experience grounded in qualitative research about parent beliefs, values, and priorities when caring for a medically complex child.

Register: https://us02web.zoom.us/meeting/register/tZckcOCtpzMiEt02BBgqcHYmdCz2gfDsZ

<u>DyC</u>



Courageous Parents Network is a non-profit organization and educational platform that orients, empowers and accompanies families and providers caring for children with serious illness.

PTC Clinical trial update

We would like to update our patient community that participation in the MIT-E study by PTC

Therapeutics is now expanded to include men and women is now <u>up to 20 years of age</u>.

More information can be found at:

www.themit-estudy.com

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

With any questions, please email <u>MitoStudy@ptcbio.com</u> for an immediate response

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

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

And 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

DONATE

Copyright © 2021 Cure Mito Foundation, All rights reserved.

Want to change how you receive these emails? You can <u>update your preferences</u> or <u>unsubscribe from this list</u>.



Copyright © *|CURRENT_YEAR|* *|LIST:COMPANY|*, All rights reserved. *|IFNOT:ARCHIVE_PAGE|* *|LIST:DESCRIPTION|*

Our mailing address is:

|HTML:LIST_ADDRESS_HTML| *|END:IF|*

Want to change how you receive these emails?

|IF:REWARDS| *|HTML:REWARDS|* *|END:IF|*

You can <u>update your preferences</u> or <u>unsubscribe from this list</u>.