



Series 2

Volume 4 June, 2023



The Lambert-Eaton
LEMS Family Association

Awareness from the Heart

DONATE



June 14, 2022, we were incorporated as a nonprofit serving LEMS patients!

FROM THE BOARD

We are so excited to celebrate the first year birthday, today, June the 14th. The nonprofit was incorporated on this date in 2022 in Texas.

So much has been done in this first year and you can see some of the highlights below in this newsletter. It's been and continues to be a learning experience as we head into our second year, working for LEMS patients, caregivers, and our LEMS family.

Our promise to you is that we will continue on in our work and improve upon what we've just started in one year. We appreciate your support. Please follow our Facebook page. Please follow us on social media on Twitter and Instagram. Please donate if you can.

We already have initiatives planned for the remainder of 2023 and into 2024. The goal of everything we do is increase awareness of LEMS, encourage medical and academic research, and bring our LEMS family closer together.

Onward we go, and we can't wait to celebrate our 2nd Birthday with you next year!

August, 2022

LONDC Event

Board Member Kristina participated in the inaugural Late Onset Neuromuscular Disease Consortium (LONDC) in Nashville, Tennessee.



October, 2022

NORD Rare Summit

Board member Price attended the National Organization of Rare Diseases, Rare Summit in Washington, DC, to meet and develop relationships with other rare disease organizations working for the same goals.



2023

Rare Disease Day Events for Rare Disease Day



February 28, 2023

Rare Disease Day On the Hill



February 28, 2023

NASDAQ Closing Bell

We participated in ringing the CLOSING BELL of the NASDAQ Exchange in Manhattan, New York, recognizing Rare Disease Day 2023 and all rare diseases.

LEMS was specifically recognized at this event..

Advocacy Director Desiree attended Rare Disease Day On the Hill activities in Washington, DC, and the remainder of the week. She was there advocating for all LEMS patients, family, and caregivers.



March, 2023

Muscular Dystrophy Association Clinical & Science Conference

LEMS volunteers manned an information table at the MDA conference to increase the awareness of LEMS to doctors, researchers, and within the MDA itself.



Planned Upcoming Events

2023

American Neurological Association Annual Meeting 2023

Late Onset Neuromuscular Disease Consortium Meeting

2024

Rare Disease Day On the Hill

Muscular Dystrophy Association Science & Clinical Conference

American Academy of Neurology Annual Meeting

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