



## **Welcome to the January, 2023 Newsletter!**

Series 2 Volume 1

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## **Thanks for taking a moment to read the Newsletter!**

The nonprofit is starting off an exciting new year, 2023, and our first full year working for and representing LEMS patients and caregivers.

We have exciting plans for this year, which we will tell you about in this newsletter. All of our activities are focused on fostering research, improving the visibility and understanding of LEMS, and strengthening the bonds of our LEMS Family!

One of our Board members, Kristina, has her unique take on LEMS and having COVID, so please read her article!

We look forward to working together with you, our LEMS Family, in 2023. Please visit our website, and we appreciate any financial or volunteer support you may be able to give.

Thanks for reading our first Newsletter of the year!

- Price

## **Our First Event of the Year – Rare Disease Week on the Hill**



Desiree, our Director of Patient Advocacy, will be attending Rare Disease Week activities in Washington, DC, February 28th to March 3rd.

She will be there 4 days, filled with activities supporting you, our LEMS family, on the hill.

We'll have pictures and talk about it much more after the event!

# LEMS and COVID – Kristina Patafio

I wanted to share my experience as a LEMS patient and having COVID. When COVID hit and the severity of the cases were turning the world upside down I was fortunate enough to relocate to our summer home to quarantine. I have a heart condition as well as LEMS and we thought it would be best to take every precaution necessary to stay safe and my job completely shut down.

Once back to work and being exposed numerous times I never got COVID and thought wow maybe it is because my immune system is suppressed by the regimen I am on. It wasn't till recently in September 2022 that I officially came down with COVID.

I would said I had a more than mild case having fatigue and high fevers in the range of 103.5. It was suggested that I take the Paxlovid, which I personally had a hard time taking. It effected my stomach tremendously and effected my swallowing because my mouth and throat felt like cotton, but the risks could have been higher not taking it.

Before I came down with COVID I was doing extremely well, eating a very clean diet and on a great regimen. Taking back control of my life more the way I knew it pre LEMS and I was so proud that I was able to fight back through healthy eating and supplements.

It is now almost 2 months after getting COVID that I am still feeling a lot of weakness in the mornings and back to feeling more tired than I was. It has been very hard for me thinking I have been knocked down again after pushing for 5 years to get a lot of my life back. I don't like to ever complain, get depressed, or feel sad. Life is too short for that and I know if I was there once I can get there again. Doctors and people that have had COVID say it takes time for the inflammation to go away and for cellular regrowth as we get older is slower.

I wanted to share my experience so that others also know this is possible to take time and heal from having COVID. It is important for our rare community to share information on any level we can to help each other through hard and tough times.

## The Lambert-Eaton LEMS Family Association

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