

Series 1 Volume 1

August 7, 2022



WELCOME to the first volume of our newsletter. We've been month's in the making. After incorporating as a nonprofit in Texas, we have now received our tax exempt 501(c)(3) designation and signed a contract to partner with a large group to develop and administer a LEMS Registry. It's been a big few weeks!

### OUR LOGO - THE ORIGINS STORY

When we decided to do a nonprofit, one of our first orders of business was to create our logo, our identity. Everyone knows how important a good logo is to establishing something that will always be associated with the organization. Starting out, we discussed the concept of 'family', that LEMS patients, caregivers, and family members truly do become our own 'LEMS family'. It's the nature of being so rare. From the idea of **'family'**, the first designs included a circular wreath design. Here are a few examples of early attempts to create a look for the logo.



We felt like these early attempts were on the right track, but weren't exactly what we wanted. Additionally, these were just quickly cobbled together with elements off the

internet and free-drawing, not worthy of a real nonprofit logo. An actual artist, Virginia Smith, from Arlington, Texas, was engaged to take these crude concept efforts and put her own interpretation on it. We loved the results! It's so important to give an artist your concepts and ideas and then see what they bring. After a few iterations back and forth with the artist, we developed this series of color test graphics to choose from.



## The Lambert-Eaton LEMS Family Association

Which one is your favorite? Interestingly, we had difficulty coming to an agreement ourselves. Everyone had their own favorite. Bouncing these samples around amongst ourselves, friends, and family, we got a winner. It's important to get input from disinterested parties, to get their first impression. When we did this the clear winner emerged. We had our logo!



**FROM THE DIRECTORS**

Each newsletter we plan to offer some brief comments from one of the members of the Board of Directors. As President of the Board it's my honor to kick this column off. In future you will also hear from Kristina, Julianna, and other members of the Board, as The Lambert-Eaton LEMS Family Association grows.

We've just gotten started! I incorporated the Association on Jun 14, 2022 in Texas where I live. It was done here primarily for convenience as the Agent of Record for the corporation must also be in the state. The Texas incorporation process is relatively easy.

After receiving our incorporation certificate from Texas, I quickly filed with the IRS for our tax-exempt status known as 501(c)(3). This in essence is the 'Golden Ticket' to becoming a viable nonprofit organization, recognized by other organizations, vendors, and others. We received that designation letter the last week of July. Now we are rolling!

This is just the beginning. We've just become a viable nonprofit as I type this, the first week of August. We are incredibly excited with what lies ahead. We have signed a contract with a large midwestern rare disease registry group and will announce the partnership when it is operational. We are developing a customized questionnaire for LEMS with the input from many sources. We are also preparing our application to join NORD, the National Organization for Rare Diseases. That may be done by the time you read this.

There's going to be so much more! We haven't even talked about on-line virtual meetings and webinars. I'll close by saying we appreciate your interest by signing up for this newsletter. There are many more to come! There will be more exciting reporting here in the months ahead as our activities launch. As always, we appreciate your financial support. No donation is too small, as we begin our work for the LEMS community. Onward!

Price Wooldridge

Board of Directors, President

## Meet the Team!

### Board of Directors

#### **Julianna Kustelski**

Julianna was born and raised in San Antonio, Texas. Since diagnosed with LEMS she has been a patient advocate and is currently the Administrator for the largest LEMS Facebook Group online since it's inception. She has worked with legislators, medical professionals, organizations, government institutions and the public. Her passion is advocating for LEMS.



## Board of Directors

### **Kristina Patafio**

Kristina, a diagnosed LEMS patient, has become a strong voice for LEMS, speaking with patients, family, and caregivers all over the U.S.

Born and raised in Staten Island, NY, she still lives there with her husband of 27 years and her 24 year old son. She is a highly successful Real Estate sales person in New York.



## Board of Directors

### **Price Wooldridge**

Price is a native Texan and also a diagnosed LEMS patient. With a background as a television producer, director, and production manager, he enjoys using his skills in communication as an amateur radio operator, voice over talent, and amateur photographer. He also manages to enjoy retirement in his native state, Texas.



## Director of Social Media

### **Ashley Gregory**

Ashley is a full time surgery nurse from Virginia. She is the lead Moderator on The Lambert Eaton News Forums for LEMS patients, hosted by a multimedia company focused on rare diseases. In her spare time she enjoys beach time on the Atlantic, modeling, and being a foster dog mom. Diagnosed with LEMS at an early age, she is a strong patient advocate for LEMS.



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The  
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**LEMS Family**  
Association

*Awareness from the Heart*

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