

Welcome Back!

Welcome to the third issue of Neuromuscular Connections. Included is the latest in news, events, and advancements in the neuromuscular community. As always, we encourage you to keep in touch with us by sending your experiences, updates, photos, questions, and concerns to advocacy@catalystpharma.com. We look forward to hearing from you soon!

Catalyst News

Bringing the LEMS Community Together at Our First Meetup in NYC!

Catalyst hosted our first regional meetup – A Look at LEMS: Listen. Engage. Meet. Share. – Jul. 29 in New York City. The event gathered people with Lambert-Eaton myasthenic syndrome (LEMS), caregivers, healthcare providers, and other experts for an interactive discussion on topics ranging from information on the condition to tips on living well with a rare neuromuscular disease. While together, we made new friends and shared insights on managing a disease that can be hard to understand and diagnose. Attendees learned useful ways to work with their doctors to figure out how to best manage LEMS. This event was also a great way for us to hear directly from the community about topics that concern them the most so we can work on potential solutions. We look forward to more events in 2020 – stay tuned for more information to be shared on our Facebook page at Facebook.com/CatalystPharma/!

If you're interested in having us come to your area, please email us at: advocacy@catalystpharma.com.



Join the Conversation

Catalyst launched our Facebook page this past summer! Located at Facebook.com/CatalystPharma/, the page is a great way for people living with LEMS and other neuromuscular conditions to connect with Catalyst and each other to learn about the latest news, activities, events, and resources. We hope our page will become not just a place for information, but also an active forum for discussion and participation among the community. Check for new posts often.

Follow up and join the conversation [@CatalystPharma!](https://twitter.com/CatalystPharma)

Catalyst Supports Spinal Muscular Atrophy (SMA) Awareness Month

In August, Catalyst supported SMA Awareness Month, which featured activities worldwide spotlighting the work the SMA community does year-round to raise awareness and research funds for this debilitating and potentially deadly disease. SMA is a genetic disease that affects the part of the nervous system that controls voluntary muscle movement. Learn more about SMA by visiting CureSMA.org.

“We are proud to be part of the global movement to raise awareness and contribute to developing new evidence-based medicines to improve the lives of individuals, families, and caregivers impacted by SMA.”
—Patrick J. McEnany
Chairman and CEO of Catalyst

Out of every 10,000 births, one baby is born with SMA. It is caused by malfunctioning genes that affect how nerve cells and muscle cells communicate across the neuromuscular junction—the place where nerve cells meet muscle cells. People living with SMA can have severe muscle weakness in the upper arms, legs, and shoulders. In some instances, SMA may lead to paralysis or death. Read more about Catalyst’s commitment to the SMA community at CatalystPharma.com or by clicking [here](#).

Guide to Talking to Your Doctor About LEMS

We are excited to share a discussion guide we created to help people with LEMS prepare for visits with doctors other than their neurologist – doctors who may not be as familiar with the condition. We worked directly with people who have LEMS to tailor this guide to help them articulate their symptoms, share general information, and keep track of questions they’d like to ask their doctor. We hope the LEMS community finds this to be a useful tool to enable meaningful conversations with all of their doctors.

To gain access to the guide and print a copy before your next doctor appointment, please contact your Catalyst Pathways Patient Access Liaison, or email advocacy@catalystpharma.com.

Catalyst is Committed to Supporting YOU!

Catalyst Pathways™, our free, personalized support program offers patients and families one-on-one support throughout their treatment journey with LEMS. Several specialists make up the dedicated team of experts focused on helping people understand their medicine and how to get it, insurance coverage, and how to identify additional financial support programs, if needed. The team includes **Care Coordinators, Patient Access Liaisons (PALs), and Insurance Navigators.**



New & improved site!

To learn more about Catalyst Pathways™, how to enroll, and view videos of real patient experiences, visit our new, improved site at YourCatalystPathways.com or call 1-833-422-8259.

Meet Our Team



In every issue, we will introduce you to one of our team members who is working hard to help the neuromuscular disease community. In this issue, we're delighted to introduce Pete Curry, Catalyst's senior national sales director.

Pete Curry leads Catalyst's small team dedicated to educating physicians around the country about LEMS. Prior to joining Catalyst, Pete spent more than 20 years at pharmaceutical companies both large and small, but it wasn't until 2004 when he got his first taste of working in the rare disease space. "It was like a breath of fresh air," he says. "I loved getting up in the morning, knowing that my work had a real impact on peoples' lives."

Based in West Virginia, Pete spends a lot of his time on the road visiting physicians to make sure they know about the latest developments in

neuromuscular disease, including LEMS research, diagnostic tests, and treatment options. Pete stays motivated and gets satisfaction from knowing that his outreach may help doctors diagnose LEMS and ultimately bring treatment to people who may not have known any existed. "It's like finding a needle in a haystack," he says. In fact, Pete recently participated in a Catalyst lunch symposium at the annual American Association of Neuromuscular and Electrodiagnostic Medicine in Austin, TX, where associate professor Dr. Perry Shieh from UCLA, a key thought leader in neurology, presented approaches and common challenges with diagnosing LEMS to other neurologists.

Pete's advice to people living with rare neuromuscular disorders is to "stay connected and be active within the patient organization for their specific condition. It's the best way to learn, share information, and support each other."

Events

AAN 2019 Annual Meeting: The American Academy of Neurology (AAN) held its 71st annual meeting on May 4 - 10, 2019 in Philadelphia, PA. Catalyst exhibited onsite and engaged in meaningful conversations with leaders in the neuromuscular disease community to promote LEMS awareness and education.

2019 AANEM Annual Meeting: The annual meeting of the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM) took place on Oct. 16 - 19, 2019 in Austin, TX. This year's meeting focused on "The Present and Future Role of Technology in the Lives of Patients with NM Diseases." Catalyst was pleased to attend and share real patient stories, their experiences with Catalyst Pathways, and offer a presentation that provided a detailed overview of LEMS, its challenges, and potential treatments.

2019 NORD Summit: The National Organization for Rare Disorders (NORD) held its annual Summit on Oct. 21 - 22 in Washington, D.C., bringing together patient advocacy groups, government, industry, and academia to discuss current, important topics in rare disease. This year's theme, "The Time is Now," reinforced the urgent need for innovation, collaboration, advocacy, and research. While at the Summit, Catalyst met with advocacy groups and patients and attended educational sessions to learn from thought-leaders about the latest policy updates and issues.

2019 RARE Patient Advocacy Summit: Held Sept. 18 - 20 in San Diego, CA, Global Genes' RARE Patient Advocacy Summit is the largest gathering of rare disease patients, caregivers, and thought leaders in the world. It presented an opportunity for rare advocates to connect, exchange ideas and information, and take home actionable tools and strategies to help accelerate change. While onsite, Catalyst met with the advocacy leaders in the LEMS community to discuss their needs and how Catalyst can help address potential gaps in support and information.

Connections Corner



Welcome back to the Connections Corner, where you lead the discussion! Please see below for common questions in the LEMS community. We encourage you to submit your answers to one or more of these questions to advocacy@catalystpharma.com. We might print your answers in the next issue!

- Is there anything you do to help make living with LEMS easier?
- What is one piece of advice you have for caregivers?
- What is one piece of advice you have for people newly diagnosed?
- What are some of your favorite resources to go to for information about LEMS?

If you have a question about LEMS or neuromuscular diseases, it's likely that others do too. Please feel free to submit your questions to advocacy@catalystpharma.com. Additionally, if you are interested in being contacted by Catalyst for opportunities to share your stories, please let us know via email.

Community Q&A

Q: What do you wish your doctor knew about LEMS?

A: "I wish my doctor was familiar with myasthenic disease symptoms as well as the unusual symptoms of LEMS, testing available to identify LEMS, possibilities available to treat the disease, and the rareness of the disease. I'd also like my doctor's help making connections with other patients or organizations."

- Betty Ann, living with LEMS

To learn more about other patient stories, visit the Catalyst website at catalystpharma.com/lems-stories and catalystpharma.com/cms-stories.

If you have comments or questions about anything in this bulletin, write to us at advocacy@catalystpharma.com and we will do our best to respond, either directly or in future issues.

