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The Myositis Association Hosts Patient Stories on Rare Disease Day—a Virtual Event

Rare Disease Day Summit highlights myositis and the 7000 other rare diseases affecting one in ten Americans

COLUMBIA, MD, UNITED STATES, February 27, 2025 /EINPresswire.com/ -- The Myositis Association (TMA), in collaboration with the Myositis International Health and Research Collaborative Alliance (MIHRA) and Nori’s Fight, will host, We Care for Rare Summit: Celebrating Myositis Science and Rare Patient Stories, on Friday, February 28, 2025, from 1:00–3:00 PM ET, followed by a virtual happy hour from 3:00–4:00 PM ET.

> My journey with rare disease has taught me that the challenges we face don’t just affect our health—they impact every aspect of our lives.”
>
> *Lindsay Guentzel, keynote speaker*

This interactive virtual event will bring together medical experts, researchers, advocates, and patients to highlight groundbreaking research, share personal experiences, and discuss the impact of rare diseases on healthcare. Discussions will focus on rare diseases collectively and their impact on research and broader healthcare advancements.

Event Highlights:
- Welcome & Group Photo – Laurie Boyer, TMA Board Chair
- Pride in Rare Disease & Science – Insights from top myositis researchers
- Flash Talks: Rapid presentations on new therapies, clinical trials, and patient-driven research
- Flash Talks: Myositis Science and Myositis ILD Patient Story
- Keynote: Lindsay Guentzel – The Full-Time Job of Living Rare

“My journey with rare disease has taught me that the challenges we face don’t just affect our health—they impact every aspect of our lives,” said Lindsay Guentzel, keynote speaker. “I’m honored to share my story and to amplify the voices of others in our community who are redefining what it means to live with a rare disease.”
- Virtual Happy Hour – A celebration of the rare disease community

"Especially on Rare Disease Day, TMA celebrates the resilience of the myositis community and proudly supports the clinicians, scientists, and research teams who are bringing us closer to more and better treatments in myositis," says TMA Executive Director Paula Eichenbrenner.

"Ongoing innovation is desperately needed, with approximately 95% of the 7,000 known rare diseases having no treatment."

How to Attend: RSVP here

About The Myositis Association (TMA)
Myositis is a group of rare autoimmune diseases that cause muscle weakness, severe pain, and life-threatening complications. The Myositis Association is a global nonprofit dedicated to patient support, awareness, and funding research to advance treatment and find a cure.

We Care for Rare Summit: Celebrating Myositis Science and Patient Stories on Rare Disease Day

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