



2023 IMPACT REPORT

2023 In Review

2023 was a truly notable year for The Myositis Association (TMA). We celebrated our **30th year of service** to the worldwide myositis community.

Our Mission

To improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

Patient Education Impact

383 attendees, including 37 scholarship recipients, gathered in San Diego, Calif., for TMA's 28th **International Annual Patient Conference**, Sept. 7-10, 2023. Brig. Gen. (Ret.) Bob Gaylord delivered the inspiring keynote, "Myositis is Your 100-Miler." Conference content also included 34 breakout

sessions and medical advisor panels. 864 attendees participated in TMA's virtual programs in 2023, including more than 30 **Ask the Doc, Empowerment Clinic, and Research Insights webinars**. We hosted the "Beyond Limits" virtual summit during **Myositis Awareness Month**. On Feb. 11, 2023, TMA and the Kansas Univ. Medical Center partnered on a **virtual Regional Conference** for Myositis Patients.



Patient Support Impact

TMA's 36 regional Support Groups and 8 virtual Affinity Groups welcomed 3,118 patients and care partners to group meetings in 2023. **Plus!**

- TMA Illinois marked an amazing **25 years** in 2023! Now known as TMA Missouri & Illinois, the group combined with TMA Missouri and Southern Illinois, which Jean Nolan started in 2016. Key volunteers are Dave Volk, Bill Simeral, Denise Antonucci, Ed Arnold, and Barbara Shaw.

- **TMA Myositis Africa** was established in 2023, with support from the TMA Women of Color Affinity Group. Group leaders are Cynthia Ikediashi and Eniyome Onoviran.
- **TMA Michigan IBM** launched in 2023, as TMA Michigan East & West evolved. Michigan leaders include Jim Mathews, Jim Anderson, Deb Grutter, Christie Chapin, Deborah Keller, Veronica Fatura, and Louise Hartung.



Research Impact: Grants

Since 2002, TMA has awarded **66** research grants totaling nearly **\$8 million**. Funding has been in all forms of myositis to advance research, clinical trials, pilot projects, fellowship grants, and myositis registries. Together, we will find better treatments – and one day, a cure.

Twelve grants were active in 2023. Two new grants were approved:

- **Julio Huapaya, MD, Myositis Fellowship:** Application of Quantitative Autoantibody Levels and Proteomic Endotypes in Myositis-associated Interstitial Lung Disease
- **Merrilee Needham, MBBS, PhD, Pilot Project:** Identifying Muscle Antigens Recognized by Autoreactive T Cells in IBM Patients using Deep-learning Based Predictive Modelling.

Two investigators with funded projects concluded their studies last year:

- **Yves Allenbach, MD, PhD, Pilot Project:** MYOTOXICI - Study of the Pathomechanisms in Immune Checkpoint Inhibitor-induced Myositis
- **Erin Wilfong, MD, PhD, Pilot Project:** Pathological Role of B cells in the Idiopathic Inflammatory Myopathies

Research Impact: Career Outcomes

Investigators who receive TMA grants report that our support is instrumental to their ongoing successes. Congratulations to these former grantees for their career accomplishments in 2023!

- **Begum Horuluoglu, PhD**, promoted to Assistant Professor, Karolinska Institutet
- **Tom Lloyd, MD, PhD**, appointed Chair of Neurology and Professor of Neurology, Neuroscience, and Human and Molecular Genetics at Baylor College of Medicine



Awareness Impact

In 2023, TMA presented **Three Heroes In The Fight** awards.

- Peter Frampton, legendary musician and Grammy winner living with IBM, received TMA's Patient Ambassador Award.
- Rohit Aggarwal, MD, received TMA's Heroes in Research Award.
- The Neuromuscular Center at University of California, Irvine received TMA's Heroes in Healthcare Award.



Member Impact

In 2023, TMA's members numbered more than 13,000. More than 5,000 members resided outside the U.S., living in **108 other countries**.

Learn More

Follow us on social media and visit our website at www.myositis.org. You can donate securely online, and view our audited financial statements and federal tax disclosures.

2023 Expenses by Program

Total Expenses \$1,909,206



- Patient Conference
- Patient Support
- Clinical Education
- General and Operations
- Advocacy and Awareness
- Research
- Fundraising

Our 2023 Impact Report is dedicated to the 1,631 donors, families, and Legacy Society members who supported TMA's mission last year. Thank you!

Our Team

Thank you to all who worked **toward a world without myositis** in 2023, including Marek Blaszkiewicz, Webmaster; Rachel Bromley, Patient Education, Support, and Advocacy Senior Manager; Rhonda Buckley-Bishop, Interim Executive Director; Dogwood Event Strategies; Linda Kobert, Research & Communications Specialist; Aisha Morrow, Operations Senior Manager; One Degree Financial; Sapphire Consulting; Sasse Agency; Quist & Associates; and many others whose efforts are sincerely appreciated.

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