



THE MYOSITIS ASSOCIATION

## 2018 Annual Report

**TMA's Mission: To improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy**

**In 2018, TMA achieved the following:**

- TMA's 25th Anniversary was celebrated with a year-long recognition of this significant milestone, which included three member-funded campaigns in its honor.
- Members celebrated TMA during the 25th Anniversary Gala held at the Muhammed Ali Center in Louisville, KY during our Annual Patient Conference.
- In honor of our 25th anniversary, TMA recognized three myositis researchers for their significant contributions to increasing the understanding of myositis diseases and treatments. Kanneboyina Nagaraju, PhD, DVM was recognized for Outstanding Accomplishments in the last 5 years; Lisa Rider, MD was recognized for Outstanding Accomplishments in the last 15 years; and Ingrid Lundberg, MD, PhD was recognized for Outstanding Accomplishments in the last 25 years.
- The Annual Patient Conference was held in Louisville, KY, attracting more than 450 individuals with myositis, care partners, and family members.
- For the seventh consecutive year, TMA held a day-long Myositis Symposium for myositis researchers and TMA's Medical Advisory Board to share insights and findings from their research. Seven members of the MAB and one TMA-funded fellow presented on current projects.
- The Medical Advisory Board was expanded to 23 members, adding three new myositis specialists who brought diversity to this body with specialties that have previously never participated on the MAB. These include pulmonologist Sonye Danoff, MD, PhD and physical medicine and rehabilitation specialist Tae Hwan Chung, MD, both from Johns Hopkins Myositis Center, and occupational therapist Malin Regardt, PhD, OT from Karolinska University in Sweden.
- Research funding totaling \$220,000 was awarded for two pilot projects and one fellowship grant; projects focused on inclusion body myositis, dermatomyositis, and juvenile myositis.
- A newly redesigned and upgraded website was unveiled during Myositis Awareness Month, featuring mobile device accessibility and completely revised and updated myositis content.
- In its third year, TMA's Visiting Professors Program supported members of our Medical Advisory Board to travel to medical schools across the US and Canada to educate medical students about myositis. To date, more than 40 medical schools have participated in this program.

- Together with our local support groups, TMA continued to support regional mini-conferences to provide a more accessible option for members to gather for support and patient education. Seven of these half-day or day-long programs have taken place in the three years of this program, often in geographic regions where TMA has not held Annual Patient Conferences.
- TMA introduced a new support service for care partners called Talking Circles. This virtual group provides a network of myositis care partners who connect by phone or email as a way to give and receive emotional support.
- TMA's publication *Myositis 101*, a lay person's guide to myositis diseases, was fully revised and distributed to all TMA members.
- The Bob Goldberg Annual Conference Scholarship Fund was initiated to raise funds to provide support for those experiencing financial hardship to allow them to attend TMA's Annual Patient Conference.

**Other significant milestones:**

- TMA Executive Bob Goldberg retired after leading the organization for 16 years.
- Mary McGowan joined TMA as our new Executive Director.
- Tricha Shivas joined TMA as the new Director of Development and Strategic Partnerships.

**Financials**

**2018 Financial Results from financial statements audited by GRF:**

<b>Total Revenue:</b>		<b>\$ 1,625,374</b>
<b>Program Expenses:</b>		<b>\$ 1,634,003</b>
<b>Communications:</b>	<b>\$223,702</b>	
<b>Member Services:</b>	<b>\$506,831</b>	
<b>Grants:</b>	<b>\$355,473</b>	
<b>Fundraising Expenses:</b>		<b>\$ 238,595</b>
<b>Administrative Expenses:</b>		<b>\$ 309,402</b>
<b>End-of-the-year Net Assets:</b>		<b>\$ 2,417,593</b>
<b>Corporate Contributions:</b>		<b>\$ 316,968</b>

## 2018 Board of Directors

**John McClun**, *Chair*

Williston, FL  
(Retired Navy)

**James Mathews**, *Vice-chair*

Grand Haven, MI  
(Healthcare)

**Renee Lantner**, *Secretary*

Western Springs, IL  
(Physician)

**John Suttle**, *Treasurer*

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**Terry Anderson**, *Immediate Past Chair*

Severna Park, MD  
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**Steven Ytterberg, MD**, *MAB Liaison to the*

*Board of Directors*  
Rochester, MN  
(Physician)

**Martha Arnold**

Lower Gwynedd, PA  
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**Laurie Boyer**

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Wasilla, AK  
(US Air Force)

**Owen "Wayne" Mortenson, DMD**

Louisville, KY  
(Dentist)