OUR ORGANIZATION

Our goal is to improve the quality of life of individuals with acute disseminated encephalomyelitis, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis, including acute flaccid myelitis.

Founded in 1994

A team of 10 staff & officers

Advocating for people in 111 countries

With the support of over 8,000 donors & volunteers

OUR MISSION

To support and advocate for individuals and their families diagnosed with acute disseminated encephalomyelitis, neuromyelitis optica spectrum disorder, transverse myelitis including acute flaccid myelitis.

To advance scientific understanding of and therapy development for these rare disorders by supporting the training of clinician-scientists dedicated to these rare diseases and by supporting basic and clinical research.

To promote awareness and empower individuals, families, clinicians and scientists through education programs and publications.

OUR COMMUNITY

We currently support and advocate for 12,035 members worldwide

740 New members in the past 12 months

Diagnoses

- 11.6% ADEM
- 72.4% TM (including AFM)
- 10.3% NMOSD or ON
- 3.9% No diagnosis
- 1.8% Other

Type of membership

- 2.3% medical professionals
- 3.5% other
- 61.2% people diagnosed
- 27.4% relatives or caregivers
- 4.8% unknown

Location

- 33.2% Rest of the world
- 66.8% United States
In 2016, The Transverse Myelitis Association offered education and support through our website, newsletters, podcasts and symposia. We provided information and access to resources to over 1,300 members. With the support from our members, donors, sponsors and partners, we awarded over $373,000 in research and training grants.

1. QUALITY OF LIFE FAMILY CAMP

In 2016, 30 families, ten medical professionals, and eight volunteers and staff from across 17 states in the US and from Canada, India, and Australia joined the 2016 TMA Annual Quality of Life Camp.

2. REGIONAL RARE NEURO-IMMUNE DISORDERS SYMPOSIUM

75 people diagnosed with a rare neuro-immune disorder and their families attended the first regional rare neuro-immune disorder symposium held at the University of Colorado Denver. Symposium recordings were viewed 1,299 times.

3. JAMES T. LUBIN FELLOWSHIP

In 2016, we approved funding for two TMA James T. Lubin Fellowships to Dr. Cynthia Wang and Dr. Elena Grebenciucova.

Total grants: $540,000 Fellows supported: 4

4. 2016 ASK THE EXPERT PODCAST SERIES

Number of podcasts: 12 Number of registrants: 824

For more information on the above projects, please visit https://myelitis.org/shaping-the-future/our-programs
MEMBER SUPPORT

Over 1,300 individuals and families living with ADEM, NMOSD, TM, including AFM connected with our staff for education and support via email, phone and social media.

23 TMA support group meetings were held in 2016. Montana is the most recent state to have a support group leader.

We launched the Myelitis Help Line to provide direct access to information and support.

FUNDRAISING & AWARENESS CAMPAIGNS

Four TMA Walk-Run-N-Roll awareness events were held in 2016.

**FL Walk-Run-N-Roll, Dinner, and Auction**
Amount raised: $57,500
Participants: 400

**MA Walk-Run-N-Roll**
Amount raised: $25,407
Participants: 130

**NJ Walk-Run-N-Roll**
Amount raised: $14,500
Participants: 100

**OH Walk-Run-N-Roll**
Amount raised: $17,420
Participants: 93

Every day for 100 days, the myelife. my hope. campaign featured a story of a person touched by a rare neuro-immune disorder to honor those fighting every day for a better quality of life, to remember those we’ve lost and to recognize our dedicated researchers, medical professionals and industry leaders.

WHERE DOES YOUR DONATION GO?

In 2015*, the TMA expended a total of $480,000, of which $414,000 was spent on research, education and support programs.

Your fundraising efforts have supported strategic program spending in 2016. We are truly grateful for the sacrifices made by our community and appreciate your generosity.

We are mindful of every dollar spent and continue to utilize thousands of hours of volunteer time to manage the organization.

* 2015 990 tax form and audit are available on the TMA website.

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Research</td>
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<tr>
<td>Education &amp; Support</td>
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<td>General &amp; Administrative</td>
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<td>Camp</td>
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<tr>
<td>Fundraising</td>
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RESEARCH UPDATES

ONGOING TMA FUNDED RESEARCH

We awarded $75,000 in research grants:

Validation of biomarkers in transverse myelitis  
Site: Johns Hopkins University

Pediatric rare neuroimmunology biorepository  
Site: University of Texas Southwestern and Children's Health Dallas

Developing research strategies for assessment and improvement of the specificity of etiological clinical diagnosis  
Site: Johns Hopkins University

Utilizing brain imaging to understand cognitive dysfunction in transverse myelitis  
Site: University of Texas Southwestern and Children's Health Dallas

UPCOMING TMA FUNDED RESEARCH

Experiences with vaccination before and after a rare neuro-immune disorder

The TMA Registry in partnership with The NIH/NCATS GRDR® Program (Global Rare Diseases Patient Registry Data Repository)

ACTIVE CLINICAL TRIALS

11 clinical research studies are actively enrolling members of the community.  
For more info go to: myelitis.org/shaping-the-future/research/clinical-studies-trials

TMA RESOURCE LIBRARY

Our Resource Library is growing. We have over 200 educational resources, which include symposium videos, newsletters, podcast recordings, published literature summaries, information sheets and relevant external resources. To access our resource library go to: myelitis.org/living-with-myelitis/resources/resource-library

MYELITIS HELP LINE

We launched a new program, the Myelitis Help Line, on September 23, 2016 to provide our community with direct access to information and help. To access the Myelitis Help Line go to: www.myelitis.org/mhl

SOCIAL OUTREACH

<table>
<thead>
<tr>
<th>TWITTER</th>
<th>FACEBOOK</th>
<th>YOUTUBE</th>
<th>BLOG</th>
<th>INSTAGRAM</th>
</tr>
</thead>
</table>
| Tweets in 2016: **75**  
Followers: **687**  
Engagement: **123** | Posts in 2016: **111**  
Fans: **7,500**  
Engagement: **11,000** | Videos in 2016: **33**  
Subscribers: **1,826**  
Total Views: **550,851** | Blogs in 2016: **37**  
Subscribers: **594**  
Open rate: **46%** | Posts in 2016: **56**  
Followers: **101** |
THANK YOU

To all our sponsors, including the 2016 Florida, Massachusetts, New Jersey, Ohio Walk-Run-N-Roll campaigns and the myelife. my hope. campaign sponsors.

Dixie Crossroads
Sysco Foods, Inc
Kelly's Kustom Kurtains
Terry Hopkins Designs
Linda and Robert Malecky
Ryan Reporting, Inc.
Communications Concepts, Inc.
Creative Cakes
Entertainment Generations of Creations
Bush Ross
Edible Art Catering
Burger 21
Bizzarros Italian Restaurant
CORE Rehabilitation

Chick-Fil-A
Krispy Kreme Donuts
Law Office of Jason S. Robbins
PA Huddleston, Robbins and Riddle
PA Imperial Cleaners, LLC
Everyday ABA, LLC
Georgianna United Methodist Church
High Stack Gordon & Kirby, LLC
Thorne and Associates
PA Pediatrics in Brevard
Kennedy Krieger Institute
Rebound Physical Therapy
Carrabbas Italian Restaurant
iHeart Radio
Designer's Press, Inc

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Ingrained
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The Andersons
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