



THE TRANSVERSE MYELITIS ASSOCIATION 2016 ANNUAL UPDATE



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.








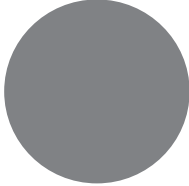




To **advance scientific understanding** of and therapy development for these rare disorders by supporting the training of clinician-scientists dedicated to these rare diseases and by supporting basic and clinical research.

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



Diagnoses	Type of membership	Location
 11.6% ADEM	 2.3% medical professionals	 33.2% Rest of the world
 72.4% TM (including AFM)	 3.5% other	
 10.3% NMOSD or ON	 61.2% people diagnosed	 66.8% United States
 3.9% No diagnosis	 27.4% relatives or caregivers	
 1.8% Other	 4.8% unknown	

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.



OUR EDUCATION AND RESEARCH PROGRAMS

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

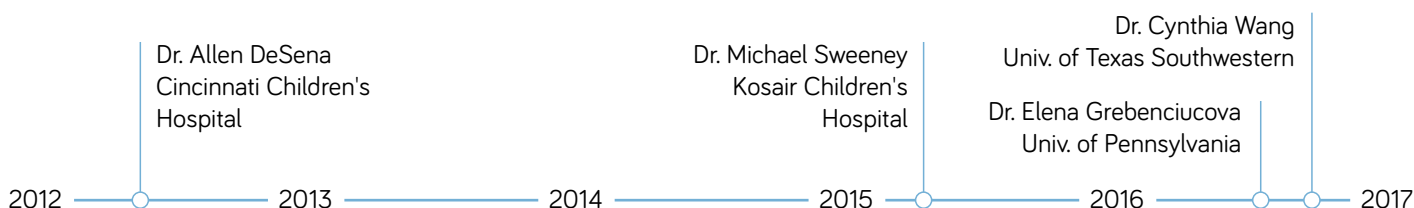
75 people diagnosed with a rare neuro-immune disorder and their families attended the first regional rare neuro-immune disorder symposium held at the University of Colorado Denver. Symposium recordings were viewed **1,299** times.

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.



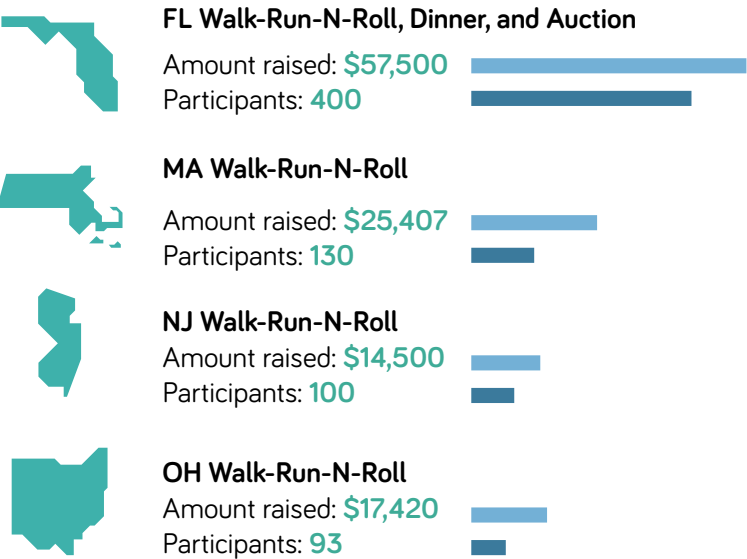
23 TMA support group meetings were held in 2016. Montana is the most recent state to have a support group leader.



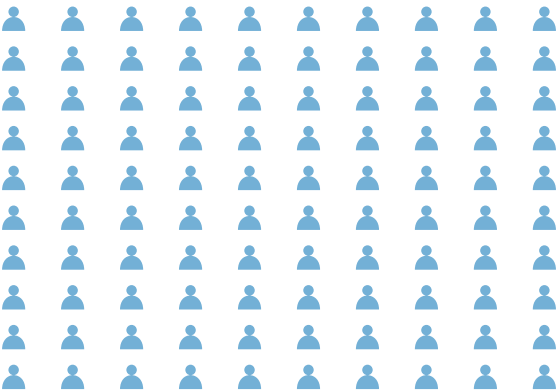
We launched the **Myelitis Help Line** to provide direct access to information and support.

FUNDRAISING & AWARENESS CAMPAIGNS

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



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.



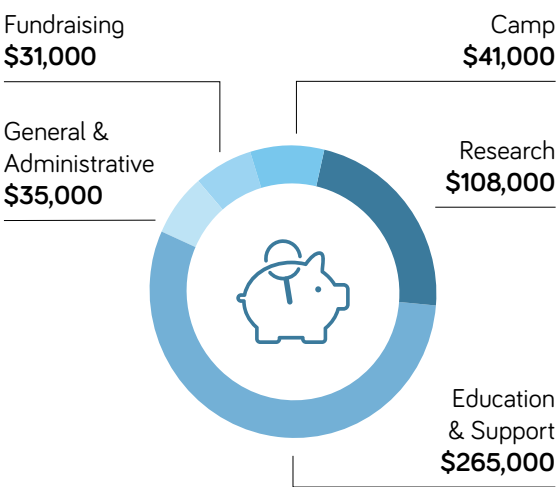
WHERE DOES YOUR DONATION GO?

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.



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

TWITTER

Tweets in 2016: **75**
Followers: **687**
Engagement: **123**

FACEBOOK

Posts in 2016: **111**
Fans: **7,500**
Engagement: **11,000**

YOUTUBE

Videos in 2016: **33**
Subscribers: **1,826**
Total Views: **550,851**

BLOG

Blogs in 2016: **37**
Subscribers: **594**
Open rate: **46%**

INSTAGRAM

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.



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