

ACUTE FLACCID
MYELITIS

TRANSVERSE
MYELITIS

OPTIC
NEURITIS

ACUTE DISSEMINATED
ENCEPHALOMYELITIS

NEUROMYELITIS OPTICA
SPECTRUM DISORDER

RARE NEURO-IMMUNE DISORDERS
CAN AFFECT
ANYONE

TMA 2015 ANNUAL UPDATE



THE TRANSVERSE MYELITIS
ASSOCIATION

www.myelitis.org

November, 2015

Dear members and friends,

2015 was another incredibly productive year for the TMA. We offered many different programs and opportunities to accelerate education, research and awareness of rare neuro-immune disorders. We are entirely indebted and grateful for all that you, your families and friends have done to make this happen. The enclosed brochure updates you on our programs and offers information on an exciting new fundraising challenge, the **ASAP Dollar-4-Dollar Challenge**.

The TMA Board has made the James T. Lubin Fellowship a funding priority. Fellows are trained to provide clinical care to address both acute and long-term effects of these disorders. These rare neuro-immune disorders can affect anyone at any time. **In the early stages, time is crucial and early recognition can make the difference in long term outcomes.** Our first graduate, Dr. Allen DeSena, established his practice at the University of Cincinnati, and our second fellow, Dr. Michael Sweeney began his training at the University of Utah. Through the generosity of The Madison Charitable Foundation, **we are looking forward to funding not one, but two new Fellows in 2016. Please join our ASAP Dollar-4-Dollar Challenge.**

People seek and find us at a most critical time in their lives. Receiving a diagnosis of acute disseminated encephalomyelitis, optic neuritis, neuromyelitis optica spectrum disorder or transverse myelitis begins a journey filled with tragedy, loss, pain and suffering. The TMA offers a pathway of hope. We provide emotional support to those who feel isolated and alone in their experience with a rare disorder. We provide guidance to those seeking acute and long term medical care. We provide critical resources to the medical community, including medical training and research opportunities. With your help we can continue to raise awareness and train more clinicians in the diagnosis and treatment of these devastating disorders.

We appreciate all that you do for our cause and for your cause and look forward to your continued support.

Thank you.

Sanford J. Siegel

Sandy Siegel
President

Chitra Krishnan

Chitra Krishnan
Executive Director

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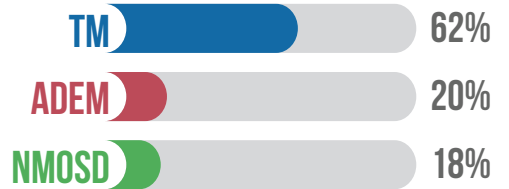
2015 IN NUMBERS...

SERVING OVER **11,400** MEMBERS

& **410** MEDICAL PROFESSIONALS



756 NEW MEMBERS
SINCE NOV 2014 DIAGNOSED WITH...



21% DIAGNOSED AS
CHILDREN

1 entirely redesigned, intuitive and mobile-friendly website that includes a searchable resource library specific to all rare neuro-immune disorders.

150

participants attended the **2015 Rare Neuro-immune Disorders Symposium** on Oct 23-24, 2015. Sessions were recorded to share with our members who could not join us in person.

1,500

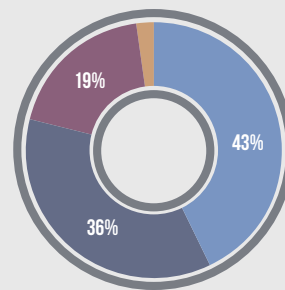
patients, caregivers and relatives were provided with **direct support and education** from The TMA staff by phone or email.

28 EXPERT PHYSICIANS AND RESEARCHERS

from all over the world joined The TMA supported **International Myelitis Working Group Meeting** in October 2015 to update diagnostic criteria.

2014 FINANCIALS

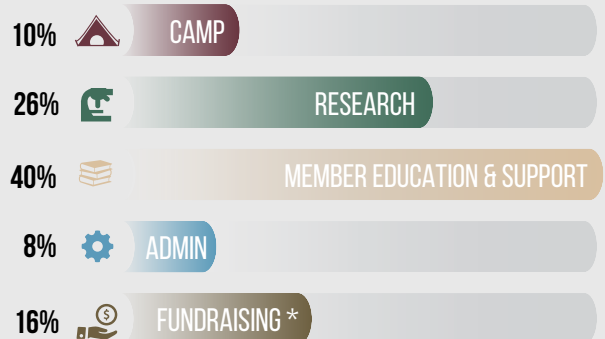
Revenues



COMMUNITY DONATIONS – 43%
MEMBER EVENTS – 36%
GRANTS – 19%
OTHER – 2%

TOTAL: \$619,000

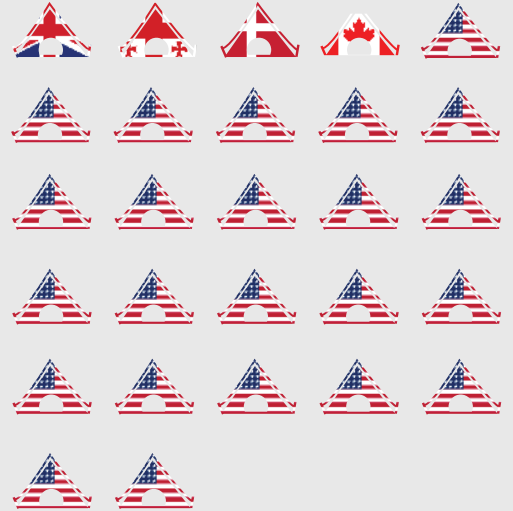
Expenses



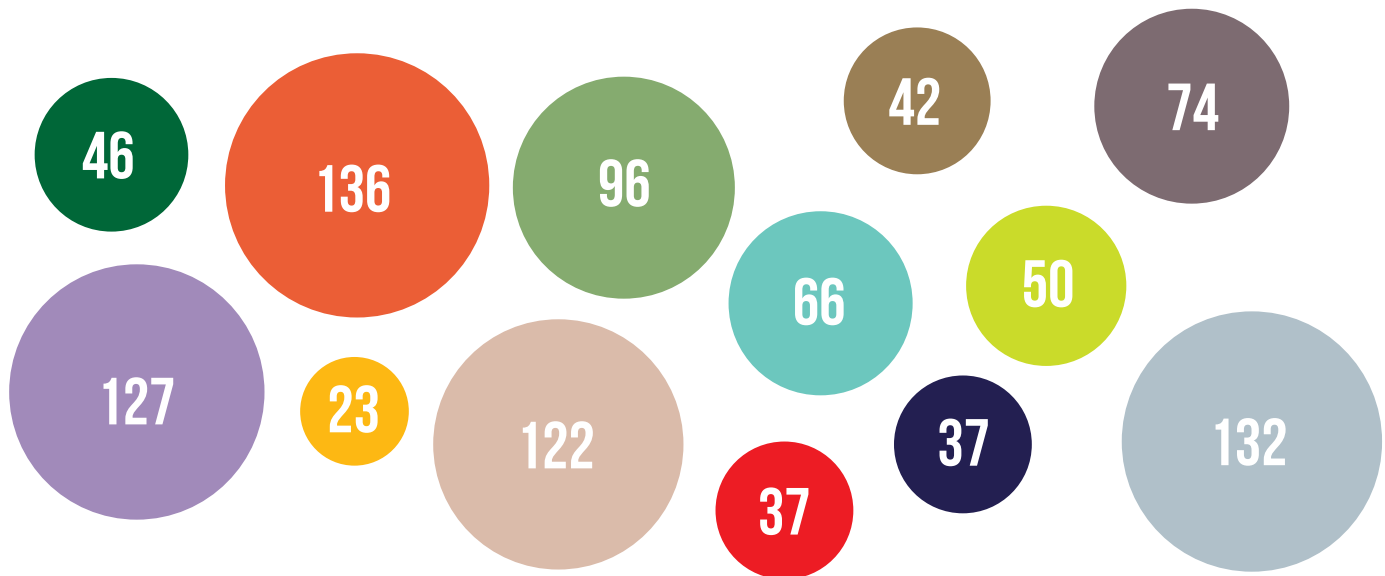
* Includes new fundraising and awareness events.
Donations increased 55% over 2013.



27 FAMILIES and 10 medical professionals joined the **2015 TMA Annual Quality of Life Camp** at The Center for Courageous Kids in Scottsville, KY. Through the generosity of the Roles Family Foundation, The TMA provided camp travel grants that allowed 4 families to attend who would otherwise not have been able to participate.



988 REGISTERED TO JOIN 13 ASK THE EXPERT PODCASTS



Nov'14 - Support for Caregivers | **Dec'14** - TM-101 | **Jan'15** - Understanding Vaccinations and Autoimmune Diseases | **Feb'15** - Hablemos de Mielitis Transversa y Neuromielitis Óptica | **Mar'15** - NMO/SD-101 | **Apr'15** - Understanding Depression and Cognitive Dysfunction | **May'15** - NMO Studies and Clinical Trials | **Jun'15** - Living with a diagnosis as an adolescent and young adult | **Jul'15** - Navigating Life, School, College, Work and Beyond | **Aug'15** - Developing a Cardio and Strength Training Program at Home | **Sep'15** - CAPTURE study | **Sep'15** - Alternative Therapies and Lifestyle Management | **Oct'15** - Understanding IEPs and 504 Plans

NEWS AND UPDATES ON THE TMA BLOG

We've published 191 blog posts on...

COMMUNITY
STORIES

EDUCATION &
AWARENESS

CLINICAL CARE
& RESEARCH

GUIDES, SUPPORT
& RESOURCES

OVER 27

published research articles and presentations have been supported in part by grants from The Transverse Myelitis Association.

\$90,000

has been committed to support **academic centers of excellence** focused on research and clinical care of rare neuro-immune disorders.

THE JAMES T. LUBIN CLINICIAN SCIENTIST FELLOWSHIP AWARD

established in 2008, supports clinical care and research training of clinicians committed to careers in academic medicine specializing in rare neuro-immune disorders. Our goal is to **build future leaders in medicine focused on these disorders.**

“ Through this unique opportunity, I will have a once in a lifetime chance to train with leaders in the field. I hope to gain knowledge and skills from mentors across the country in order to better serve patients with immune-mediated neurologic disorders. I am excited to also become involved in areas of research, which will further the field and ultimately lead to better care and outcomes. ”

Dr. Michael Sweeney, University of Utah
Recipient of the 2015 Fellowship Award



Dr. Michael Sweeney at 2015 TMA Camp



THE **ASAP**
DOLLAR-4-DOLLAR
MATCHING
CHALLENGE



RARE NEURO-IMMUNE DISORDERS CAN AFFECT **ANYONE. ANYTIME.**

25-30% OF THOSE DIAGNOSED WITH TM, AFM, NMO/D, ON AND ADEM ARE CHILDREN
MORE THAN **50%** ARE INITIALLY MISDIAGNOSED

TIME IS CRITICAL AND EARLY RECOGNITION CAN MAKE THE DIFFERENCE IN LONG TERM OUTCOMES
TREATMENT BY TRAINED PHYSICIANS CAN IMPROVE LONG TERM **QUALITY OF LIFE**

ARM SCIENTISTS AND PHYSICIANS TO FIGHT RARE NEURO-IMMUNE DISORDERS

JOIN THE ASAP CHALLENGE

NOW

www.myelitis.org/asap

Your contribution will be doubled thanks to the support of the Madison Charitable Foundation

THANK YOU!



2015 FL, IL, MD, MI, NJ WALK RUN-N-ROLL CAMPAIGNS & 2015 ANNUAL GOLF OUTING



The Transverse Myelitis Association

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