

# An international organization dedicated to the support of persons with acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis, and transverse myelitis

the central nervous system; to promote awareness and to empower patients, families, clinicians and scientists through education programs and publications; to advance the scientific understanding of and therapy development for these rare diseases by supporting the training of clinician-scientists dedicated to these rare diseases and by supporting basic and clinical research.

*Our goal is to...improve the quality of life of individuals with these rare neuroimmunologic disorders.*

We provide numerous services for our members. Our web site offers a tremendous amount of information and creates a support network between persons with these disorders, including the development of local support groups. Our goal is to advance a comprehensive network dedicated to the care of our members through the development of professionals specializing in these rare disorders, centers of excellence focused on these disorders around the world, and our international community support system. Additionally, we are developing strategic research priorities with our Board of Directors and Medical Advisory Board to further the understanding of the causes of TM, ADEM, ON and NMO, and to develop new acute

and regenerative therapies. To attract new clinicians and researchers into the rare neuroimmunologic disorder discipline, we have established the James T. Lubin Fellowship. We publish newsletters to update the community on current research and various community outreach events and opportunities.

We support and conduct various educational events through symposia and workshops involving clinicians, scientists, and individuals affected by these disorders for the exchange of information regarding research and treatment strategies. We also sponsor a family camp for children with these disorders and their family members.

## The Rare Neuroimmunologic Disorders of the Central Nervous System

ADEM, NMO, ON and TM are immune-mediated disorders of the central nervous system (brain, spinal cord and optic nerves). Each of these disorders occurs when a person experiences an inflammatory attack at some location in their central nervous system. The immune system functions to protect the body from foreign invaders, such as bacterial, viral, or fungal infections. For

people with these neuroimmunologic disorders, the immune system becomes dysfunctional and mistakenly attacks some part or multiple parts of the central nervous system. These inflammatory attacks are also referred to as demyelinating attacks because the immune system attacks and destroys myelin, the insulating material that surrounds nerves. The attacks can also damage axons. Axons are the threadlike extension of the nerve cell that transmit the electro-chemical impulses outward from the cell body.

Very little is understood about the disease mechanisms for these disorders. It is believed that a person who develops one of these rare neuroimmunologic disorders likely has a genetic predisposition to autoimmunity, and that there are environmental factors that interact with these genetics to trigger the disease. The specific genetics in each of these disorders is not understood and environmental factors have not been identified. The central nervous system is separated and protected from foreign agents by the blood brain barrier. For the immune system to attack anywhere in the central nervous system, cells from the immune system have to pass through this barrier. Thus, in the case of these disorders, not only does the immune system become confused, it also has to find a way to cross this protective bar-

rier to get to the brain, the spinal cord and/or the optic nerves. These mechanisms are not very well understood.

There is a great deal of information about each of these disorders on the TMA web site. We urge you to learn as much as you possibly can about these disorders and believe that this will help you to become the most effective advocate for your medical care, as well as for the rare neuroimmunologic disorder community.

## Contact The Transverse Myelitis Association

If you are interested in becoming a member of the TMA, or contributing to our efforts, please contact us at the information below. The efforts of the TMA are supported largely by our members and through charitable contributions and fundraising events. Your support to help advocate for and bring awareness to these rare neuroimmunologic disorders through the TMA is greatly appreciated.

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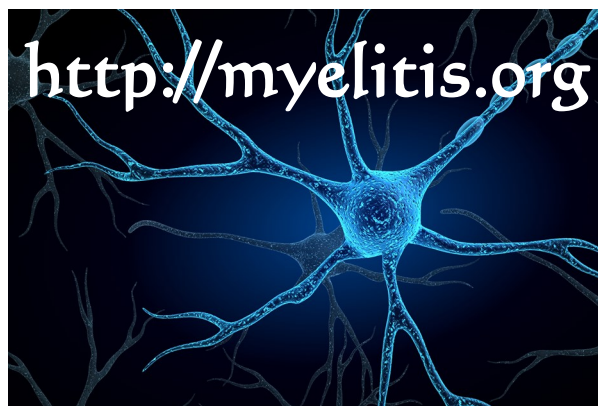
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For more information please log onto The Transverse Myelitis Association Web Site:



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[facebook.com/myelitis](https://www.facebook.com/myelitis)

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## The Transverse Myelitis Association

The Transverse Myelitis Association (TMA) is a not-for-profit international foundation dedicated to the support of children, adolescents, and adults with a spectrum of rare neuroimmunologic disorders, including Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON), and Transverse Myelitis (TM). Founded in 1994 by family members and persons with these diagnoses, the TMA was incorporated on November 25, 1996 in the state of Washington and we became a 501(c)(3) organization on December 9, 1996. Membership of the TMA includes individuals with these rare disorders, their family members and caregivers, and the medical professionals who treat individuals with these disorders. The TMA currently has approximately 9,000 members from more than 80 different countries and has a large number of support groups across the United States and around the world. There are no membership fees.

### Our Mission and Programs

Our mission is to support and advocate for individuals and their families diagnosed with rare neuroimmunologic disorders of