

# A support organization for persons with Transverse Myelitis and their family members

## What is Transverse Myelitis?

TM is a rare neurological disorder, part of a spectrum of neuroimmunologic disorders of the central nervous system. Other disorders in this spectrum include, Acute Disseminated Encephalomyelitis (ADEM), Optic Neuritis, and Neuromyelitis Optica (Devic's disease).

These conditions all involve inflammatory attacks in the central nervous system. They are differentiated primarily by the location of the attack, and by the attacks being either monophasic (single occurrence) or multiple episodes. These disorders have many common symptoms and the strategies to treat them are similar.

There is tremendous variability in the presentation of symptoms, which are based on the level of the spinal cord affected and on the severity of the damage to the myelin and the neurons

in the spinal cord. The symptoms of TM include muscle weakness, paralysis, parasthesias or uncomfortable nerve sensations, neuropathic pain, spasticity, fatigue, depression and bladder, bowel and sexual dysfunction.

TM can be acute or slow developing. There are several variations of TM diagnosis as well.

## Causes of Transverse Myelitis

TM may occur in isolation or in the setting of another illness. When it occurs without apparent underlying cause, it is referred to as idiopathic. Idiopathic TM is assumed to be a result of abnormal activation of the immune system against the spinal cord. TM often develops in the setting of viral and bacterial infections.

Approximately one third of patients with TM report a febrile illness (flu-

like illness with fever) in close temporal relationship to the onset of neurological symptoms. Vaccination is well known to carry a risk of the development of acute disseminated encephalomyelitis (ADEM) which is an acute inflammation of the brain and spinal cord.

## What Treatments Are Available?

Corticosteroid drugs are typically used as a treatment for spinal cord inflammation with TM patients. Plasmapheresis is also used as a treatment to suppress the immune system. Rehabilitation, especially physical therapy, is essential. Patients should expect to follow a rehabilitation regime typical for spinal injury. Long-term treatment for TM is focused on the management of symptoms.

## Who gets TM and what are the chances for recovery?

Age of onset of this condition can be from infancy to older adult (5 months to 80 years). The peak ages for a TM

diagnosis appear to be between 10 to 19 years and after 40 years of age. Both males and females seem to be equally diagnosed. Literature suggests that the annual incidence rate of a TM diagnosis is 1.34 per million population.

Recovery may be absent, partial or complete and generally begins within one to three months. Significant recovery is unlikely if no improvement occurs by three months. Most patients with TM show good to fair recovery. One-third of those diagnosed make a good recovery, one-third have only a fair recovery and one-third show no recovery after the initial onset period.

TM is generally a monophasic illness (one-time occurrence); however, a small percentage of patients may suffer a reoccurrence, especially if there is a predisposing underlying illness.

## Contact The Transverse Myelitis Association

If you are interested in becoming a member of The Transverse Myelitis Association, receiving information

about TM, or contributing to the efforts of the TMA, please contact Sandy Siegel, President of The TMA:

The Transverse Myelitis Association  
Sanford J. Siegel, President  
1787 Sutter Parkway  
Powell, OH 43065  
Phone: (614)766-1806  
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Your tax-deductible contributions to the TMA are greatly appreciated. Please send contributions to:

The Transverse Myelitis Association  
Paula Lazzeri, Treasurer  
10105 167th Place NE  
Redmond, WA 98052

The TMA is a registered not-for-profit organization with tax-exempt status under section 501(c)(3) of the IRS tax code.

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

**[www.myelitis.org](http://www.myelitis.org)**



## The Transverse Myelitis Association

### What is The Transverse Myelitis Association?

The Transverse Myelitis Association (TMA) is a not-for-profit and international organization started in 1994 by family members and persons with the Transverse Myelitis diagnosis. The TMA currently has over 5600 members from more than 80 different countries.

### Our Mission

The mission of the TMA is to facilitate support and education for persons diagnosed with Transverse Myelitis and other rare neuroimmunologic disorders of the central nervous system and to support improved treatment and research efforts.