The Transverse Myelitis Association Newsletter

The organization advocating for children and adults with acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis

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New address for TMA Donations

The Transverse Myelitis Association
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The Transverse Myelitis Association will have one address to be used for donations and for all correspondence with the Association. We hope that this consolidation will make correspondence and donations to the TMA easier for everyone. Paula has moved to Southern California, so this address change is taking effect immediately. Please do not send any donations to the Redmond, Washington address. If you have remittance envelopes that you would like to use, feel free to cover the Washington address with a label and write in the Ohio address. Paula will receive all donations that have been sent prior to this notification. The address forwarding will be in effect until at least December 2011. The receipt of your donation will be acknowledged by a letter from Debbie Capen, so you can be assured that your checks have been received by the TMA and that we are always grateful for your generous support.

Plasma Exchange for Treating Neurologic Disorders: American Academy of Neurology Guideline

The American Academy of Neurology is an association of more than 22,500 neurologists and neuroscience professionals. A neurologist is a doctor with specialized training in diagnosing, treating and managing disorders of the brain and nervous system such as Alzheimer's disease, stroke, migraine, multiple sclerosis, brain injury, Parkinson's disease and epilepsy.

A new guideline from the American Academy of Neurology recommends using plasma exchange to treat people with severe relapses in multiple sclerosis (MS) and related diseases, as well as those with certain kinds of nerve disorders known as neuropathies. The guideline is published in the January 18, 2011, print issue of Neurology, the medical journal of the American Academy of Neurology. ***Evidence-based guideline update: Plasmapheresis in neurologic disorders; Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology***, I. Cortese, MD, V. Chaudhry, MD, Y.T. So, MD, PhD, F. Cantor, MD, D.R. Cornblath, MD, A. Rae-Grant, MD, **Neurology** 2011;76:294–300.

The objective was to reassess the role of plasmapheresis in the treatment of neurologic disorders. The authors evaluated the available evidence based on a structured literature review for relevant articles from 1995 through September 2009.

Plasma exchange, also known as plasmapheresis, is the process of taking blood out of the body, removing constituents in the blood's plasma thought to be harmful, and then transfusing the rest of the blood (mainly red blood cells) mixed with replacement plasma back into the body. Plasma is the liquid part of blood. The solid parts are white and red blood cells. In plasma exchange, blood is drawn from the person. The plasma is separated from the solid parts of the blood. It is then replaced with plasma from a plasma donor. The donor plasma is pumped into the person. A machine sends the plasma through a tube into the body. If no donated plasma is available, albumin solution can be used. Albumin is an important protein in plasma. Like any medical procedure, plasma exchange poses some risks. It is invasive. This means it involves an object—in this case, a tube—entering the body. Side effects of plasma exchange include infection and blood-clotting issues. You should discuss the benefits and risks of this treatment with your doctor.

The guideline recommends doctors consider using plasma exchange as a secondary treatment for severe flares in relapsing forms of MS and related diseases. The treatment was not found to be effective for secondary progressive and chronic progressive forms of MS. According to the guideline, doctors should offer plasma exchange for treatment of severe forms of Guillain-Barré syndrome and for temporary treatment of chronic inflammatory de-

myelinating polyneuropathy. Plasma exchange may also be considered for treatment of some other kinds of inflammatory neuropathies. These types of neurologic disorders occur when the body's immune system mistakenly causes damage to the nervous system. Plasma exchange helps because it removes factors in the plasma thought to play a role in these disorders. The guideline authors also looked at the use of plasma exchange for other neurologic disorders, including myasthenia gravis and pediatric autoimmune neuropsychiatric disorders (PANDAS), but there was not enough evidence to determine whether it is an effective treatment.

New studies show that plasma exchange can help treat certain inflammatory diseases of the central nervous system. This system is made up of the brain and spinal cord. These diseases involve demyelination. This is when the protective coating around certain nerves is damaged. The diseases also involve inflammation (swelling).

Multiple sclerosis (MS) is an autoimmune disease. This means it results from the immune system attacking the body. The nerve damage from MS worsens over time. MS takes different forms. In relapsing forms of MS, symptoms come and go. In other forms of MS, the condition often gets steadily worse. The cause of MS is unknown. In relapsing forms of MS, there is good evidence that plasma exchange can help treat some severe acute flares. However, the treatment should be used only for a short time. In inflammatory diseases that come on suddenly, weak evidence shows plasma exchange may help when high-dose steroid treatments have failed. Examples of these diseases are transverse myelitis and neuromyelitis optica. Their cause often is not known. Strong evidence shows that plasma exchange is not effective for treating chronic progressive or secondary progressive MS. There are no studies comparing plasma exchange to other treatment methods in MS.

After the experts review all of the published research studies, they describe the strength of the evidence supporting each recommendation:
Strong evidence = more than one high-quality scientific study.
Good evidence = at least one high-quality scientific study or two or more studies of a lesser quality.
Weak evidence = the studies, while supportive, are weak in design or strength of the findings.
Not enough evidence = either different studies have come to conflicting results or there are no studies of reasonable quality.

The results of the AAN Guidelines for the efficacy of plasmapheresis in the treatment of CNS demyelinating disease are summarized as follows:

Strong evidence: Plasmapheresis should not be offered for chronic progressive or secondary progressive multiple sclerosis (MS).
Good evidence: Plasmapheresis should be considered for the adjunctive treatment of exacerbations in relapsing forms of MS.
Weak evidence: Plasmapheresis may be considered in the treatment of fulminant CNS demyelinating diseases that fail to respond to high-dose corticosteroid treatment.
Clinical context: No studies on the efficacy of plasmapheresis compared to other treatment options in MS are available.

The evaluation, conclusions and recommendations in regard to CNS demyelinating disorders, other than MS, are based exclusively on the 1999 Weinshenker Study. (Weinshenker BG, O'Brien PC, Petterson TM, et al. A trial of plasma exchange in acute central nervous system inflammatory demyelinating disease. Ann Neurol 1999;46:878–886). The following discussion, conclusions and recommendations are quoted directly from the AAN report in regard to the Weinshenker study of PLEX (p. 297):

Since the previous TTA report, there has been an additional Class II, randomized, double-blind, shamcontrolled trial which included 22 patients with acute, severe attacks of CNS demyelination who had failed to improve after at least 5 days of high-dose parenteral steroids.

Patients were included in the trial if they had clinically definite or laboratory supported MS or if they had idiopathic inflammatory demyelinating CNS diseases (confirmed by biopsy when necessary) and acute neurologic deficit affecting consciousness, language, and brainstem function, or spinal cord function with impairment in one or more of the targeted neurologic deficits (coma, aphasia, acute severe cognitive dysfunction, hemiplegia, paraplegia, or quadriplegia). While the inclusion criteria are clearly defined, they are broad and encompass a heterogeneous group of inflammatory conditions with potentially diverse underlying pathogenic mechanisms. For this reason, this study is considered Class II rather than Class I. In all, the study included 12 patients with MS, 4 patients with transverse myelitis (TM), 1 patient with acute disseminated encephalomyelitis (ADEM), 1 patient with Marburg variant, 2 patients with neuromyelitis optica (NMO), 1 patient with recurrent myelitis, and 1 patient with focal cerebral demyelination. The primary outcome measures were evaluated by masked assessment by 2 neurologists (A and B) based on changes on standardized clinical scales for the targeted neurologic deficits. Treated patients showed a 42.1% response rate vs a 5.9% response rate in controls (p _ 0.032 according to Neurologist A and p _0.011 according to Neurologist B).

Conclusions. Based on a single Class II study, plasmapheresis is possibly effective for acute fulminant CNS demyelinating diseases (including MS, ADEM, NMO, and TM) that fail to respond to high-dose corticosteroid treatment. Because the study included subgroups of patients with demyelinating diseases, it is not possible to determine if plasmapheresis is more or less effective in patients with different demyelinating diseases.

Recommendations. Plasmapheresis may be considered in the treatment of fulminant CNS demyelinating diseases that fail to respond to high-dose corticosteroid treatment....

The AAN report makes the following critically important recommendations for future research as focused on the CNS demyelinating disorders other than MS.

1. For all indications, the optimal plasma exchange protocol (number of exchanges and volumes exchanged) remains to be established through future research.

6. The role of plasmapheresis in fulminant demyelinating CNS disease that has not responded to first-line treatment with corticosteroids will need to be confirmed. Individual demyelinating diseases (e.g., NMO, MS, TM) should be addressed separately in future studies to clarify the role of plasmapheresis in each (p. 298).

The AAN included the following disclaimer in their materials. *This is an educational service of the American Academy of Neurology. It is designed to provide members with evidence-based guideline recommendations to assist the decision making in patient care. It is based on an assessment of current scientific and clinical information and is not intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, and are based on the circumstances involved. Physicians are encouraged to carefully review the full AAN guidelines so they understand all recommendations associated with care of these patients.*

Recruiting for Studies

Volunteers with transverse myelitis or multiple sclerosis or NMO needed: CNS Growth Factor Release and Changes in the Inflammatory Environment in Response to Electrical Stimulation in Subjects with Inflammatory Myelopathies. Principal Investigator: Daniel Becker, MD
The International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute

This research is being done to study the effect of Functional Electrical Stimulation (FES) cycling on factors in blood and spinal cord in people with history of spinal cord inflammation as seen in TM, MS, and NMO (non-traumatic spinal cord injury). FES cycling is a method of applying low level electrical currents to the leg and buttock muscles to cause the weakened or paralyzed muscles to contract and produce a cycling motion of the legs. The FES cycling in this study will be done through a device called the RT300-SL Cycle Ergometer (RT300). The goal of this study is to determine which amount of FES biking is the optimal dose to result in the best recovery. There is no monetary compensation. There is no cost to the participants. No medical insurance is required.

The study requires adults (18 or older) with TM or MS or NMO at any level who are willing and able to come to Baltimore for 3 weeks to enroll and participate in this trial. People would be randomized into 1 of 4 groups receiving differing amounts of FES biking per week and with and without electrical stimulation. Spinal fluid and blood will be taken at the beginning of the study and at the end of the 3 week period.

For additional information or to enroll in the study, please call the ICSCI Clinical Research Coordinator at (443) 923-9235 or email clinicaltrials@spinalcordrecovery.org. Please be prepared to leave a detailed message, including the name of the study you are interested in and your contact information so that you can receive a confidential message in response. You may also visit the ICSCI website at www.spinalcordrecovery.org. The specific link to the study description is: www.spinalcordrecovery.org/NA_00041441.php

Risk Factors for Acute Idiopathic Transverse Myelitis

Johns Hopkins is currently enrolling new and recently diagnosed patients with idiopathic acute transverse myelitis (IATM) to study risk factors for the disease. This is a study conducted in collaboration with investigators at the Johns Hopkins Bloomberg School of Public Health, the Johns Hopkins Transverse Myelitis Center, and U.S. Food and Drug Administration, under the auspices of the Centers for Disease Control and Prevention.

In this exploratory study, patients will be asked to complete a questionnaire detailing demographic, socioeconomic data, information regarding illness and underlying diseases, medications, immunizations, travel history and other physician visits in the preceding 24 months prior to the onset of idiopathic acute TM.

Interested patients should contact the study coordinators: Yandong Qiang (301-827-1087), Mari Griffioen (410-955-2955), Mr. Howard Choi (410-502-5202), and Ms. Maureen Mealy (410-502-8672). Principal Investigator, Neal Halsey MD (410-955-6964).

Approach to acute or subacute myelopathy

William F. Schmalstieg and Brian G. Weinshenker

Neurology 2010; 75; S2

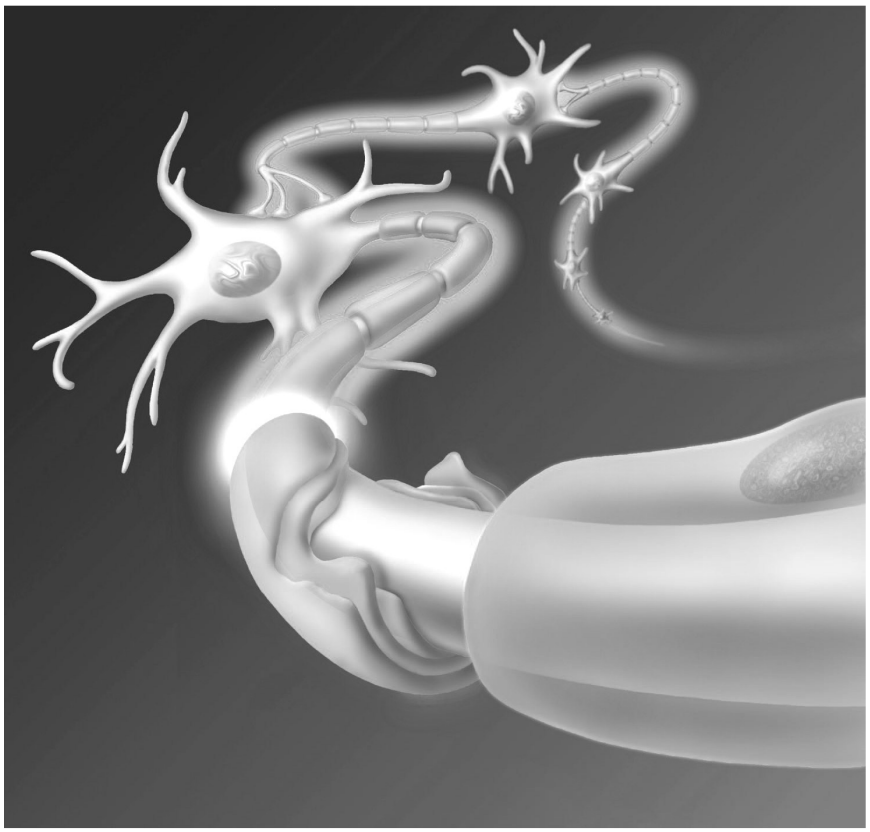

Illustration by Amy P. Collins

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Improved understanding of the differential diagnosis and improved investigative techniques, particularly neuroimaging and serologic testing, have facilitated the diagnosis of patients with acute and subacute myelopathy and reduced the proportion of patients who are labeled as having "idiopathic transverse myelitis." Additionally, these advances have identified subgroups of patients in whom progression of deficit or future relapses are anticipated, allowing intervention and prophylaxis as appropriate. However, early management remains empiric and consists of high-dose corticosteroids for most patients. In the event of an inadequate response to corticosteroids or a subsequent atypical course, further investigations to detect diagnoses other than "transverse myelitis" should be considered and additional treatments, such as plasmapheresis, may be appropriate. Individualized diagnosis and treatment is more feasible now than in the past.

IS IT AN ACUTE MYELOPATHY? Localizing an acute neurologic process to the spinal cord is often, but not always, straightforward (table 1). The ascending sensory symptoms of acute inflammatory demyelinating polyradiculoneuropathy (AIDP) may confuse the diagnosis, as this complaint is also highly associated with acute myelopathy. Unequivocal upper motor neuron signs exclude AIDP, but are often not apparent in the early stages of a spinal cord insult. Although not invariably present, an unequivocal sensory level on the torso, sensory loss indicating involvement of spinal tracts (e.g., spinothalamic modality impairment contralateral to motor findings), or urinary retention localize to the spinal cord. Myopathy or neuromuscular junction disorders may be mistaken for myelopathy, particularly if the lower limbs are predominantly affected, but the absence of any sensory abnormality should suggest the correct localization. Bilateral mesial frontal lobe lesions (e.g., bilateral anterior cerebral artery distribution infarcts) could mimic a myelopathy, although abulia or other signs of frontal lobe dysfunction typically coexist. Autoimmune or paraneoplastic muscle stiffness syndromes, such as stiff-person syndrome associated with glutamic acid decarboxylase or amphiphysin autoantibodies, may be confused with spasticity and erroneously lead one to suspect myelopathy.

Occasionally patients with chronic myelopathy may present a history that mistakenly suggests an acute process. For example, patients with primary progressive multiple sclerosis (MS) may experience acute, transient worsening (pseudoexacerbation) in the setting of an underlying infection or heat exposure. In such cases, careful history will uncover symptoms that have been insidiously progressive over a longer interval than first

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Table 1 Distinguishing acute myelopathy from mimics

Signs strongly indicating myelopathy
Sensory level on torso
Spinal tract crossed findings (e.g., unilateral pyramidal signs with contralateral spinothalamic findings)
Spinal tract-specific sensory findings (e.g., selective spinothalamic findings with preserved dorsal column findings; suspended band of spinothalamic sensory loss)
Urinary retention
Signs consistent with but not diagnostic of myelopathy
Glove-and-stocking sensory loss (consider peripheral neuropathy)
Hyporeflexia/hypotonia (consider peripheral neuropathy)
Unilateral or bilateral upper motor neuron signs (consider brain or brainstem disorders)
Signs suggesting alternative diagnosis
Spasms, rather than spasticity (consider stiff-person syndrome)
Paratonic rigidity (consider frontal lobe disorder)
Cognitive impairment (consider frontal lobe or diffuse brain disorder)
Dysarthria and dysphagia (consider brainstem disorder, such as motor neuron disease)

suspected. Patients with myelopathy who have no clear lesion on spinal MRI or multiple chronic-appearing lesions should be questioned to uncover subtle previous symptoms of chronic myelopathy and examined to detect cognitive or bulbar impairment localizing elsewhere in the nervous system.

WHEN IT IS AN ACUTE MYELOPATHY, WHAT CAUSES SHOULD BE CONSIDERED? In patients with recent onset symptoms, particularly ones that evolve rapidly, the initial priority is to exclude a surgical emergency such as epidural metastasis or abscess. When the index of suspicion for an acute compressive lesion is high, immediate imaging is required, ideally with MRI of the entire spine. If imaging demonstrates spinal cord compression due to an acute lesion such as epidural metastasis, definitive management (i.e., surgery) should be pursued without delay to prevent rapid and irreversible worsening.

Often the cause of an acute or subacute myelopathy is inapparent after an initial evaluation. In a recent French series of patients presenting with acute noncompressive myelopathy, 101/170 (59.4%) were of uncertain cause initially, although 55/101 (54.4%) patients were ultimately diagnosed with a demyelinating or inflammatory disorder. After average follow-up of 73.2 months, 49/170 (28.8%) had a final diagnosis of myelopathy of uncertain etiology. The most commonly identified causes were demyelinating disorders (MS and neuromyelitis optica), spinal cord infarction, parainfectious myelitis, and systemic inflammatory disorders (e.g., Sjögren syndrome and lupus).[1]

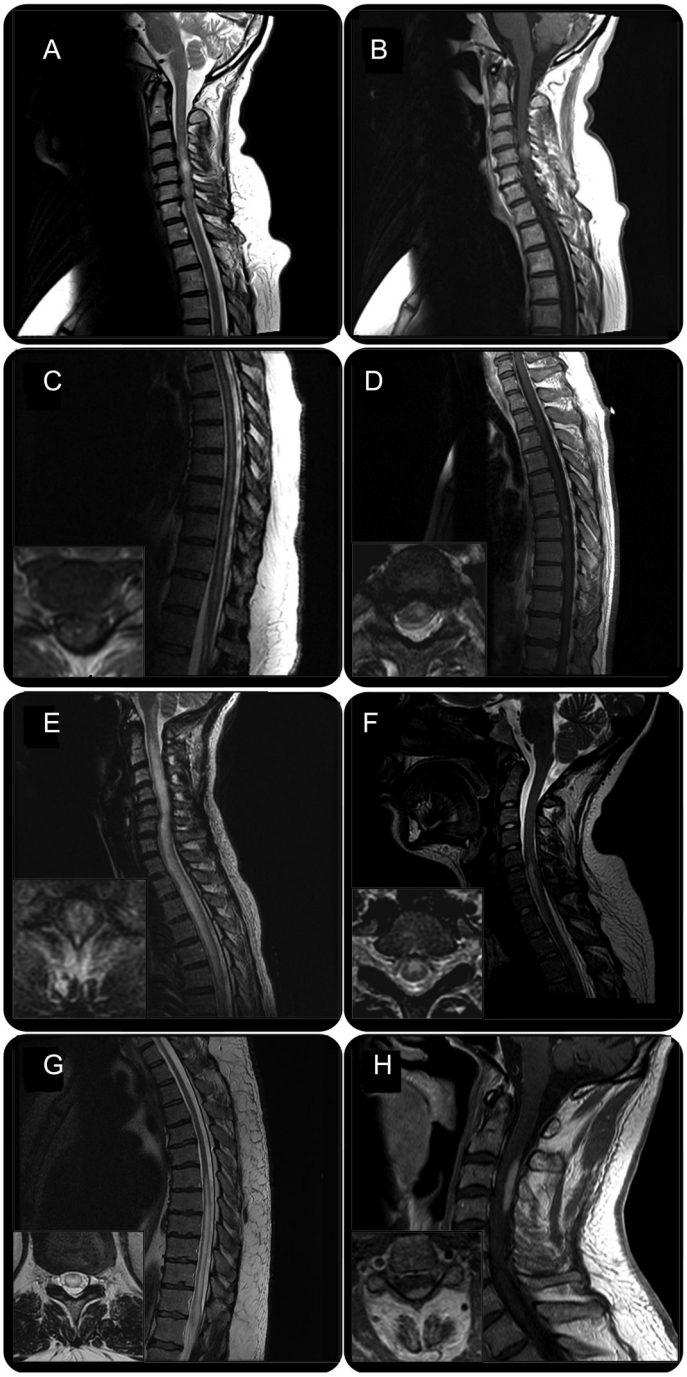
Transverse myelitis is the default diagnosis for an unexplained myelopathy evolving over the course of days to 3 weeks with subsequent stabilization or improvement. In practice, there are no satisfactory ways to distinguish among idiopathic transverse myelitis, parainfectious myelitis, and postvaccinial myelitis. When a viral illness occurs in close temporal association, parainfectious myelitis is often diagnosed, but the causal role of the associated infection is difficult to determine for an individual patient. One can confidently link the two only when myelitis occurs concurrently or within days of an infection known to be associated with myelitis (e.g., zoster) or when investigation such as CSF PCR demonstrates unequivocal evidence of CNS infection.

Nevertheless, serologic evidence of recent infection with pathogens known to be associated with myelopathy (e.g., enteroviruses, *Chlamydia, Mycoplasma*) may limit the need for further diagnostic investigations in an otherwise unexplained myelopathy. Features suggesting an infectious etiology include fever, rash (zoster, enterovirus, Lyme disease), meningismus, a history of recent travel (tuberculosis, parasitic infections such as schistosomiasis with travel to endemic regions), suspected rabies exposure, or immunosuppression (herpes zoster, cytomegalovirus). It is particularly important to consider treatable infections such as syphilis, HIV, tuberculosis, Lyme disease, and herpesviruses.

Occasionally patients with chronic myelopathy may present a history that mistakenly suggests an acute process

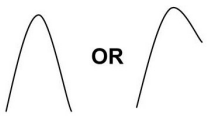
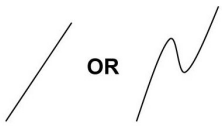
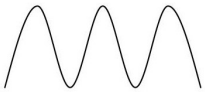
Other diagnoses that may be made confidently in most instances include cord compression, vascular disorders, toxic/metabolic syndromes, neoplasm, paraneoplastic syndromes, and sarcoidosis. Although compression is often obvious as the cause of myelopathy on MRI, spinal stenosis may cause impressive and occasionally longitudinally extensive T2 signal abnormalities (≥3 vertebral segments) on spinal MRI that may lead one to suspect an inflammatory myelopathy. Circumscribed gadolinium enhancement at the point of maximal stenosis and a history of progressive symptoms over many weeks to months are consistent findings in such cases (figure 1, A and B).[2] Vascular myelopathies include those due to infarction resulting from arterial embolism or hypoperfusion, hemorrhage, or vascular malformations associated with venous hypertension. Dural arterio-

Figure 1 MRI of representative cases of acute and subacute myelopathies



(A, B) Sagittal T2 and gadolinium-enhanced T1 MRI showing longitudinally extensive cord signal change (A) and focal signet ring gadolinium enhancement (B) due to severe spinal stenosis. (C) Sagittal T2 and axial gadolinium-enhanced T1 (inset) MRI demonstrating longitudinally extensive, tract-specific lateral column enhancement due to paraneoplastic disorder in a patient with renal cell carcinoma. (D) Sagittal gadolinium-enhanced T1 and axial T2 (inset) MRI demonstrating focal enhancement and T2 signal change in the periphery of the cord in a patient with partial transverse myelitis due to multiple sclerosis. (E) Sagittal T2 and axial gadolinium-enhanced T1 (inset) MRI showing longitudinally extensive transverse myelitis extending rostrally into the medulla and central cord enhancement due to neuromyelitis optica–associated myelitis. (F) Sagittal and axial T2 (inset) MRI showing anterior cord signal change due to anterior spinal artery infarct. (G) Sagittal and axial T2 (inset) MRI, longitudinally extensive signal change extending to the conus and flow voids (eccentric to the left side of the cord) characteristic of dural arteriovenous fistula. (H) Sagittal and axial gadolinium-enhanced T1 (inset) MRI demonstrating nodular and subpial enhancement due to sarcoidosis.

Figure 2 Differential diagnosis of acute myelopathy: Time course and MRI findings

Clinical course	T2 hyperintense signal < 3 vertebral segments in length	T2 hyperintense signal ≥ 3 vertebral segments in length
 OR (nadir 3 weeks from onset)	• Idiopathic/ parainfectious TM • MS-associated TM • Spinal cord infarct	• Idiopathic/ parainfectious TM • NMO spectrum disorder* • ADEM • Spinal cord infarct • Paraneoplastic myelitis (often tract specific) • Myelitis due to SD*
 OR	• Cord compression • Chronic infection** (HIV, HTLV, syphilis, etc.) • Intrinsic cord tumor • Sarcoidosis*	• DAVF • Sarcoidosis* • Cord compression • Intrinsic cord tumor • SCD** • Copper deficiency**
	• MS • Sarcoidosis*	• NMO • Sarcoidosis* • Myelitis due to SD*

*Relapses upon withdrawal of corticosteroids/immunosuppression. **MRI may be normal. ADEM = acute disseminated encephalomyelitis; DAVF = dural arteriovenous fistula; HTLV = human T-lymphotropic virus; MS = multiple sclerosis; NMO = neuromyelitis optica; SCD = subacute combined degeneration; SD = systemic disease; TM = transverse myelitis.

venous fistula (DAVF)–associated myelopathies may be distinguished by the distinctive history of stepwise progression or transient worsening precipitated by walking or prolonged standing. This myelopathy can be successfully treated by obliteration of the fistula and should not be missed. Toxic myelopathy due to nitrous oxide abuse is a consideration in younger patients and medical professionals; patients with underlying vitamin B12 deficiency are particularly vulnerable. Vitamin and trace metal deficiencies usually cause chronic myelopathies, but as these etiologies are readily treatable, vitamin B12 and copper levels should be tested in unexplained steroid nonresponsive myelopathy. Spinal cord tumors may present subacutely or with apoplectic onset in the case of hemorrhage into tumor and are usually readily identifiable on MRI, although rarely they may be mistaken radiologically for myelitis. Screening for serum paraneoplastic autoantibodies including collapsin response mediator protein-5 (CRMP-5) antibody[3] should be considered in patients with known cancer, constitutional symptoms, smoking history, or suggestive neuroradiology with isolated, tract-specific involvement. Sarcoidosis may present as isolated myelopathy. Definitive diagnosis requires biopsy evidence of noncaseating granulomatous inflammation, either from the nervous system or other involved organs. A high serum angiotensin-converting enzyme level is suggestive but nonspecific. A diagnosis of isolated CNS sarcoidosis should be suspected when subacute myelopathy is accompanied by patchy, asymmetric, slowly evolving, and persistently enhancing gadolinium cord lesions. A satisfactory therapeutic response to empiric, long-term (months to years) corticosteroid treatment provides a reasonable basis for a tentative but usually correct diagnosis.

WHAT CLINICAL FEATURES SUGGEST A PARTICULAR DIAGNOSIS? The time course (figure 2), specific spinal cord syndrome, and symptoms other than those referable to the spinal cord may provide useful clues as to the diagnosis. Apoplectic onset suggests a cord infarct or spinal hemorrhage, both of which may worsen over hours to days. Parainfectious or idiopathic myelitis, myelitis related to inflammatory demyelinating diseases, and some paraneoplastic

Table 2 Utility of diagnostic tests in evaluation of myelopathy

	Test used to evaluate for:	Sensitivity[a]	Specificity[a]
Imaging studies			
Spinal MRI	Rule out compression, define etiology	+++	++
Brain MRI	MS	++	+
CT myelogram	Cord compression	+++	+
Spinal angiogram	DAVF	++	+++
CSF studies			
Oligoclonal bands	MS	++	++
IgG index	MS	++	++
PCR for herpesviruses	CNS herpesvirus infection	++	+++
Cytology	Intramedullary neoplasm	+	+++
Serologic and other blood tests			
NMO IgG	NMO	++	+++
Antinuclear, SS, anticardiolipin antibodies	Systemic inflammatory disease, NMO	+	+
Angiotensin converting enzyme	Sarcoidosis	++	+
Serologies for infectious agents	Parainfectious or infectious myelopathy	+	++
Electrodiagnostic studies			
EMG	Myelopathy associated with peripheral neuropathy (e.g., sarcoid, Sjögren, paraneoplastic)	++	+

Abbreviations: DAVF = dural arteriovenous fistula; IgG = immunoglobulin G; MS = multiple sclerosis; NMO = neuromyelitis optica; SS = Sjögren syndrome.
[a] The symbols +, ++, and +++ indicate low, intermediate, and high sensitivity/specificity, respectively.

syndromes evolve over days to weeks, but generally reach a nadir within 3 weeks, after which there is either improvement or stability.[4] When a myelopathy develops insidiously or continues to progress after 3 weeks, transverse myelitis becomes unlikely and the differential diagnosis includes an intrinsic cord tumor, compressive lesion, DAVF, metabolic derangement, sarcoidosis, or a degenerative process.

The clinical syndrome of spinal cord involvement may suggest a particular etiology, although none are specific. Incomplete Brown-Séquard syndrome (loss of pain and temperature sensation contralateral to weakness) may be associated with either compression or an intrinsic cord lesion such as demyelination. An anterior spinal cord syndrome with bilateral corticospinal and spinothalamic involvement sparing dorsal column function is typical of anterior spinal artery distribution infarction, but may also occur in MS. A complete spinal cord syndrome with bilateral involvement of all spinal tracts is rarely caused by an MS relapse or infarct, but may occur in idiopathic or neuromyelitis optica (NMO)–associated transverse myelitis or cord compression. NMO-associated myelitis more commonly presents with clinical and imaging signs of central cord involvement than does MS-associated myelitis, which more commonly affects the periphery of the cord. Highly selective tract involvement (e.g., pure corticospinal tract involvement), especially when confirmed by MRI evidence of highly localized enhancing tractopathy, is characteristic of a paraneoplastic disorder (figure 1C).

Neurologic or constitutional symptoms not referable to the spinal cord focus the differential diagnosis, but may be irrelevant and distract one from the true diagnosis. Optic neuritis or a prior diagnosis of intermediate uveitis may suggest MS. Severe optic neuritis and an episode of unexplained intractable nausea or hiccoughs are characteristic of NMO.[5] Coexisting peripheral neuropathy can occur in sarcoid, Sjögren syndrome, lupus, metabolic disorders (e.g., subacute combined degeneration), and paraneoplastic syndromes.

WHAT INVESTIGATIONS SHOULD BE PERFORMED? MRI scan of the spinal cord with and without gadolinium contrast is the initial investigation of choice in the evaluation of acute myelopathy. Contraindications are limited to MRI-incompatible ferromagnetic medical devices or foreign bodies and incompatibility with the scanner due to habitus. With careful coordination between cardiologists and radiologists, MRI can be performed in selected patients with cardiac pacemakers who are not entirely pacemaker-dependent. For patients unable to undergo MRI, CT myelography may be considered when cord compression is suspected. CSF evaluation including cell count, glucose, protein, oligoclonal bands, immunoglobulin G (IgG) index, and cytology is appropriate unless imaging, history, and examination already suggest a clear diagnosis. The results of spinal MRI and clinical suspicion should guide the selection of additional investigations (table 2).

For noncompressive myelopathy, the results of MRI can be broadly subdivided into 3 categories:

1. Short T2 hyperintensity (<3 vertebral segments in length).

   Focal, discrete lesions that do not occupy the entire cord in axial cross-section are highly suggestive of MS (figure 1D), although remote, sometimes forgotten trauma can occasionally produce such lesions. MRI scan of the brain may help to clarify the cause; detection of 1 or more brain lesions typical of MS (discrete periventricular, juxtacortical, or infratentorial T2 hyperintense foci) correlates with at least an 85%–90% future risk of developing MS.[6] Oligoclonal bands and elevated CSF IgG index help to confirm a suspected MS diagnosis, but CSF analysis may be

superfluous if other clinical and radiographic features are highly suggestive.

2. Longitudinally extensive T2 hyperintensity (≥3 vertebral segments in length).

   Longitudinally extensive transverse myelitis occurs in idiopathic transverse myelitis, NMO (figure 1E), acute disseminated encephalomyelitis, cord infarction, and myelitis associated with systemic diseases such as systemic lupus erythematosus. Serum NMO IgG testing is indicated before assigning a diagnosis of idiopathic transverse myelitis.[7] Brain lesions on MRI eventually occur in the majority of patients with NMO, but usually NMO does not lead to the discrete Dawson finger pattern of periventricular lesions characteristic of MS. However, confluent and linear lesions encircling the ventricles may occur in NMO. CSF oligoclonal bands are usually absent in NMO.

   Certain patterns of signal abnormality on MRI predict a vascular disorder. Anterior and central cord signal change and swelling with sparing of the posterior columns suggest infarct, particularly in patients with a suggestive history (figure 1F). Posterior flow voids on spinal MRI representing dilation of the epidural venous plexus are a fairly specific but less sensitive indicator of DAVF, whereas longitudinally extensive gadolinium enhancement and T2 hyperintensity often extending to the conus are typical but nonspecific findings (figure 1G). Magnetic resonance angiography may help to visualize a DAVF, but spinal angiography is required for definitive diagnosis and treatment.

   If symptoms suggestive of recent infection or CSF pleocytosis (>50 leukocytes/μL) are present, CSF PCR testing for herpesviruses (e.g., herpes simplex, cytomegalovirus, varicella zoster) and serologic testing for HIV, syphilis, and Lyme disease should be considered. Prominent CSF pleocytosis and occasionally neutrophilic pleocytosis may occur in myelitis associated with NMO. Symptoms and signs of systemic inflammatory disease such as polyarthritis should prompt autoimmune serologic testing (i.e., antinuclear antibodies, SS-A, SS-B antibodies). In the absence of clinical indications of these diseases, positive serologic tests may be unimportant, although they may indicate NMO; a quarter of NMO spectrum disorder patients have nonspecific serologic evidence of autoimmunity, usually in the absence of clinical signs of other autoimmune disorders.[8] Indiscriminate use of autoantibody testing in all patients with myelitis is not recommended. MRI findings including nodular and persisting (>2 months) gadolinium enhancement or meningeal and nerve root enhancement suggest sarcoidosis (figure 1H) or, rarely, lymphoma.

3. Normal MRI.

   Patients with suspected myelopathy and apparently normal MRI should undergo careful review of the images for subtle findings of cord signal change, atrophy, or extrinsic compression by uncommon causes (e.g., epidural lipomatosis). If examination demonstrates unequivocal evidence of a spinal cord process and the MRI is normal, consider and test for degenerative, infectious, and metabolic causes of myelopathy. EMG and nerve conduction studies occasionally help to identify a primary peripheral process (e.g., AIDP) or myelopathy associated with concomitant peripheral neuropathy as can be seen in sarcoidosis and subacute combined degeneration.

HOW SHOULD AN ACUTE MYELOPATHY BE TREATED? Controlled studies of treatment of acute myelitis are lacking. In myelitis due to demyelinating, inflammatory, or undetermined cause, expert consensus favors high-dose IV corticosteroids, typically 1 gram of IV methylprednisolone daily for 5 days. This treatment should not be withheld in the case of suspected recent viral infection; the role of steroid treatment in patients with definitive evidence for direct viral infection of the cord (e.g., myelitis occurring simultaneously with or within days of a zoster eruption) is unclear. Plasmapheresis should be considered in patients who continue to have significant impairment after high-dose corticosteroids. In a sham-controlled trial of plasma exchange in patients with an acute relapse of demyelinating disease unresponsive to corticosteroid treatment, many of whom had acute myelitis, 8 of 19 (42.1%) treated patients experienced moderate to marked improvement vs 1 of 17 (5.9%) who received sham treatment.[9] There are no established treatments for patients with cord infarction.

Long-term treatment to reduce recurrent attacks or progression of deficit is required for patients with NMO, neurosarcoidosis, and systemic inflammatory disorders. Options to be considered for NMO include azathioprine, mycophenolate mofetil, mitoxantrone, and rituximab. Sarcoidosis is usually treated with prolonged high-dose oral corticosteroids (e.g., prednisone 1 mg/kg/day for 6–12 months). Oral steroids and steroid-sparing immunosuppressive agents are also typically prescribed when systemic inflammatory processes involve the nervous system. Immunomodulatory treatment should be considered in patients who are at high risk for developing relapsing-remitting MS by virtue of having additional lesions on MRI of the head.

Ongoing clinical observation is an important part of the care of patients with an unexplained myelopathy. Subsequent appearance of new neurologic or systemic symptoms may reveal a demyelinating or systemic inflammatory disorder. Patients with relentlessly progressive symptoms despite appropriate empiric treatment may require spinal cord biopsy for definitive diagnosis, particularly when follow-up imaging demonstrates worsening.

DISCUSSION Acute and subacute myelopathies require urgent medical evaluation. Imaging, preferably by MRI, should be performed without delay to exclude a compressive lesion. Subsequently, history and physical examination should guide subsequent investigations to reach a definitive diagnosis. As the etiology is often unclear at initial presentation, empiric treatment should be provided while conducting further investigations to determine the etiology of myelopathy. A thorough evaluation often reveals evidence of a treatable disorder or one that may relapse without preventive treatment.

DISCLOSURE

Dr. Schmalstieg reports no disclosures. Dr. Weinshenker has served on data safety monitoring boards for Novartis and Biogen Idec; serves on the editorial boards of *Multiple Sclerosis*, the *Canadian Journal of Neurological Sciences*, and the *Turkish Journal of Neurology*; receives research support from the Guthy-Jackson Charitable Foundation; and receives license royalties from RSR Ltd. and may receive royalties from Mayo Medical Ventures for a patent/intellectual property re: Aquaporin-4 associated antibodies for diagnosis of neuromyelitis optica.

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The Transverse Myelitis Association

The membership of The Transverse Myelitis Association includes persons with the rare neuroimmunologic disorders of the central nervous system, their family members and caregivers and the medical professionals who treat people with these disorders. The Transverse Myelitis Association was established in 1994 as an organization dedicated to advocacy for those who have these disorders.

The TMA was incorporated on November 25, 1996 in the state of Washington and became a 501(c)(3) organization on December 9, 1996. The TMA has more than 8,500 members from every state in the United States and from more than 80 countries around the world. There are no membership fees. The TMA is registered with the California Department of Justice, the Maryland Secretary of State, the Ohio Attorney General's Office, and the Washington Secretary of State. The TMA has a large number of support groups across the United States and around the world. Some of our international support organizations have been formally recognized by their governments, including the United Kingdom, Germany, Ghana, Australia and Canada.

The TMA has been registered with the National Organization of Rare Disorders since 1994. The TMA is a member of or has a partnership with the following organizations: Cody Unser Firststep Foundation, the Johns Hopkins TM and NMO Centers and Project RESTORE, the University of Texas Southwestern TM and NMO Centers, the Accelerated Cure Project, the Center for Courageous Kids, Spinal Injuries Association – Australia, Christopher and Dana Reeve Foundation, National Family Caregivers Association, American Autoimmune Related Diseases Association, Genetic Alliance, Kakkis Everylife Foundation, Unite2Fight Paralysis, and the Guthy-Jackson Foundation.

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Idiopathic acute transverse myelitis in children: an analysis and discussion of MRI findings

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Abstract

Background: There is lack of reported magnetic resonance imaging (MRI) studies of idiopathic acute transverse myelitis (ATM) in children.

Objective: To describe the imaging features of idiopathic ATM in children.

Methods: We retrospectively analyzed the spinal MRI findings of children diagnosed with ATM. The anatomic regions, vertebral segmental length, gray or white matter involvement, cord expansion and gadolinium enhancement were examined.

Results: A total of 27 children were diagnosed with isolated monophasic ATM with a mean follow-up of 5.2 years. Two children later diagnosed with neuromyelitis optica were excluded from the pediatric ATM cohort. None of the patients had a subsequent diagnosis of multiple sclerosis. The mean age of onset was 9.5 years (0.5–16.9 years). Spinal MRIs were abnormal in 21 (78%). The mean interval between symptom onset and the MRI was 1.7 days (0–19 days). Central cord hyperintensity involving gray matter was seen in all patients. A majority (67%) of the patients demonstrated long segment lesions with a mean segment length of 6.4.

Conclusions: We conclude that central cord inflammation extending over three or more segments is the most common finding of idiopathic monophasic transverse myelitis in children. The risk of multiple sclerosis in children who experience isolated transverse myelitis as a first demyelinating event is low.

Keywords

acute transverse myelitis, demyelinating disease, MRI, pediatric-onset multiple sclerosis, spinal cord inflammation

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Introduction

Acute transverse myelitis (ATM) represents a major subset of acute non-compressive myelopathies. Possible causes of acute non-compressive myelopathies include vascular, infectious, autoimmune, inflammatory, neoplastic and metastatic disorders. The term 'acute transverse myelitis' denotes the inflammatory etiology excluding non-inflammatory causes.

ATM can occur as an isolated inflammatory disorder, or as part of a multifocal central nervous system (CNS) demyelinating disease such as acute disseminated encephalomyelitis (ADEM), multiple sclerosis (MS) or neuromyelitis optica (NMO); it can also be associated with systemic rheumatological disorders. As many features overlap, these disorders can be encompassed under the umbrella term of ATM on first presentation. After such recognizable associations are excluded, a group of patients remains in whom no causes can be identified. In this study, the term 'idiopathic ATM' is used to define those patients who remain isolated and monophasic during a longitudinal follow-up and not found to be associated with another disease. Current diagnostic criteria for idiopathic ATM have been proposed by the Transverse Myelitis Consortium Working Group (TMCWG).[1]

The incidence of ATM is reported as 1400 cases per year in the United States; 20% of these cases involve individuals younger than age 18.[2] ATM occurred in

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10 22% of children with acute demyelination reported from pediatric demyelinating cohorts.[3–5] Long-term neurological deficits have been reported in 30 62% of children.[2,6–7]

We retrospectively evaluated the magnetic resonance imaging (MRI) findings in children with ATM of the idiopathic type. Defining the MRI patterns of monophasic ATM would help to distinguish other phenotypes associated with multiphasic relapsing diseases.

Patients and methods

Patients and inclusion criteria

Patients diagnosed with ATM at Children's Hospital of Pittsburgh during the period 1985 2008 and under the age of 18 at clinical presentation were studied. Patients who fulfilled the criteria proposed by the TMCWG (definite ATM) and patients who met all criteria with the exception of 'objective documentation of inflammation within the spinal cord' (possible ATM) were included.[1] Excluded were patients who had symptoms outside the spinal cord (polyfocal presentation), MS-like brain lesions or symptoms suggesting meningoencephalomyelitis and initial imaging data performed beyond the 4 weeks of disease onset.

The patients were identified from the pediatric demyelinating cohort registry at Children's Hospital of Pittsburgh. This cohort has two types of patients: 1) those patients identified with retrospective chart review who have then been followed yearly via phone contacts by the principal investigator; and 2) those patients registered at the onset of acute demyelination and followed prospectively.

Data were collected on clinical features, neuroimaging, cerebrospinal fluid (CSF) examination and other laboratory findings. All patients underwent extensive evaluations to investigate for infectious and connective tissue disorders. As the study spans a time period of approximately 20 years, there was some variation of laboratory data in addition to differences determined by the individual clinical features. In general, routine laboratory tests included blood cell count, electrolytes, liver enzymes, creatinine, urea, glucose, viral serology, Lyme titer, mycoplasma pneumonia, meningoencephalitis panel, rheumatoid factor, antinuclear antibodies, anti-neutrophil cytoplasmic antibodies, Sjogren's syndrome antibody A and B, anti-cardiolipin and anti-phospholipid antibodies, angiotensin-converting enzyme, complement levels, thyroid antibodies and B12 level. NMO-IgG antibody was included in patients diagnosed after the test become available. On rare occasions paraneoplastic antibodies were sent and West Nile virus was added to infectious work-up. CSF examinations included cell count, protein, glucose, gram stain, bacterial cultures, oligoclonal bands by isoelectric focusing, IgG index, polymerase chain reaction for varicella zoster virus, Epstein-Barr virus, enterovirus, humanherpesvirus 6 and 7, cytomegalovirus and Lyme disease. CSF cytology was obtained if clinically indicated. Patients with suspected infectious myelitis had additional CSF and systemic investigations. These studies are obtained immediately after admission. Vascular investigations were performed on selected patients if CSF examination was lacking the evidence for inflammation and if there was no better explanation. Ophthalmology consults were obtained at admission and visual evoked potentials were performed in some patients. Consultation with rheumatology was obtained either as inpatient or outpatient, particularly in children with significant family history of other autoimmune disorders.

In addition to detailed neuroimaging analysis, we included the following clinical characteristics in this study: demographic features (age at clinical onset, gender), preceding infections or immunizations (4 weeks prior to clinical onset), family history of autoimmune disease, time to first MRI, distribution of motor deficits (mono/para/tetraparesis), CSF white cell count, protein, oligoclonal bands, IgG index, serum NMO- IgG antibody results and duration of follow-up.

The study was approved by University of Pittsburgh Institutional Review Board.

Imaging analysis

Spinal and brain MRIs obtained at clinical onset were reviewed. Two experienced neuroradiologists (KAP, CRF) retrospectively reviewed the studies while blinded to the specific clinical findings at onset. Any differences in assessment were resolved by consensus.

All MRIs were performed on 1.5T magnets. Since this was a retrospective analysis, the patients had not been imaged under a standardized protocol; however, all spinal MRIs included the minimum of sagittal and axial T1-weighted (T1W), sagittal and axial fast spin-echo, or spin-echo T2-weighted (T2W), as well as post-contrast sagittal and axial T1W sequences.

The following imaging characteristics were recorded on spinal MRIs: 1. Anatomic region(s) were classified as cervical, thoracic and lumbar spine (distal cord / conus). A lesion involving more than one anatomic region was defined as multiregional. If more than one discrete lesion were found, it was defined as multifocal; 2. Vertebral segmental length (one segment = one vertebra body height); the cephalocaudal extension of each abnormality estimated on sagittal T2W sequences were expressed in a number of segments for each involved region; 3. Cord expansion was determined on sagittal

T2W images; 4. Gray or white matter involvement was assessed on axial T2W images; 5. Enhancement was assessed on both the sagittal and axial planes. Presence of hemorrhage and syrinx assessed on T1W and T2W sequences were recorded.

Statistical analysis

Statistical analyses were performed with SAS, version 9.1 under the alpha level of 0.05. Descriptive statistics were presented as counts and percentages for categorical variables, and mean ± standard deviation or median with range for continuous variables.

Results

Thirty-five patients had isolated transverse myelitis at first presentation that included the cases with definite and possible ATM by TMCWG criteria. Six patients were excluded from this analysis as initial MRIs were not obtained within the 4 weeks of disease onset or imaging data were not available to review. Two patients who later developed multiple relapses of both myelitis and optic neuritis had positive NMO-IgG antibodies and were diagnosed with NMO; they were excluded from the idiopathic ATM cohort.

None of the other patients had relapses during the follow-up. None had a subsequent diagnosis of MS or systemic rheumatological disorder. A total of 27 patients with isolated monophasic ATM and with available imaging data at clinical onset were analyzed in this study. The mean follow-up period was 5.2 years (SD; 4.6, range; 0.04 13.1 years). Fourteen patients fulfilled the TMCWG criteria for definite ATM, and 13 had possible ATM. In possible ATM patients, the clinical course was not suggestive for vascular myelopathy, and extensive evaluations did not reveal any other etiologies. The mean age of onset was 9.5 years (SD; 5.7, range; 0.5 16.9 years). Male to female ratio was 1.07 (14/13). Most of the patients (74%) presented with paraparesis. Table 1 summarizes the clinical and CSF characteristics of patients. Only five subjects were tested for NMO-IgG antibody since test has become available in recent years.

Table 1. Clinical and laboratory characteristics in ATM

Characteristics	*n*/Total	%
Preceding infection	10/26	38.5
Preceding immunization	2/25	8.0
FH of autoimmune disease	7/27	25.9
Monoparesis	4/27	14.8
Paraparesis	20/27	74.1
Tetraparesis	3/27	11.1
CSF pleocytosis (median: 52 cells/mm^3; range:6–205)	10/27	37.0
Elevated protein (median: 57 mg/dl; range: 45–77)	12/27	44
Elevated IgG index	2/21	9.5
Oligoclonal bands positive	0/22	0.0
NMO-IgG antibody	0/5	0.0

CSF: cerebrospinal fluid, FH: family history.

Spinal MRI results

MRIs were performed on admission or shortly after admission on most of the patients. The mean interval from symptom onset to initial MRI study was 1.7 days (SD; 4.3, range; 0 19 days). Spinal MRIs were abnormal in 21 (78%) patients, while six patients had normal results. A total of 30 lesions were analyzed. Seven patients (33%) had multifocal lesions. The cervico-thoracic cord was the most frequently involved region. Characteristics of abnormal MRI are shown in Table 2.

In all patients, centrally located high signal intensity involving gray matter was seen on axial T2-weighted

Table 2. Characteristics of abnormal MRI findings in childhood ATM ($n=21$)

		n	%	Total
Region	Only cervical	3	14.3	21
	Only thoracic	6	28.6	
	Only lumbar	1	4.8	
	Multiregional	11	52.3	
Multiregional	Cervical and thoracic	7	63.6	11
	Thoracic and lumbar	1	9.1	
	Cervical, thoracic and lumbar	1	9.1	
	Cervical, thoracic, lumbar and conus	2	18.2	
Involvement at axial plane	Gray matter only	14	66.7	21
	White matter only	0	0.0	
	Both gray and white matter	7	33.3	
Segment length	<3	7	33.3	21
	≥3	14	66.7	
Gadolinium Enhancement	Yes	4	19.1	21
	No	17	80.9	
Swelling/cord expansion	Yes	9	42.9	21
	No	12	57.1	

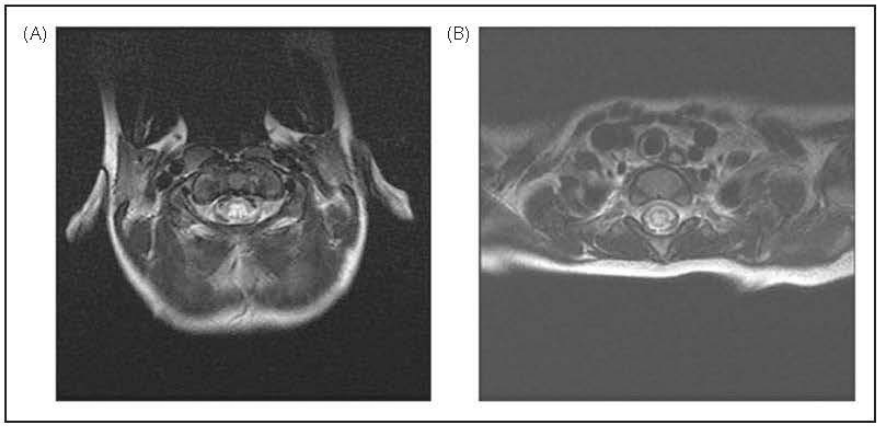

Figure 1. Central cord inflammation. Axial fast spin-echo T2W sequences reveal increased signal intensity in the center of the cord with variable intensity (A and B).

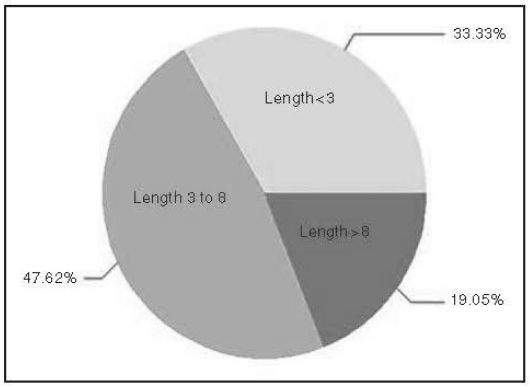

Figure 2. Segment length distribution. Distribution of segment length in children with idiopathic acute transverse myelitis.

images (Figure 1). This central cord abnormality involved gray matter and nearby surrounding white matter in seven patients. No patient, including those with short segment lesions, had only peripheral white matter abnormality.

Seven out of 21 patients revealed lesions less than three segments, while 14/21 patients had lesions with a length equal to or more than three segments. The mean segment length was 6.4 ± 6.1 (0.5–21.0), and the median segment length was 5.0 (0.5–21.0). Figure 2 shows the distribution of segment length. In patients with multiple lesions, the longest lesion was analyzed. To be consistent with the current literature and relevant to discussions of 'longitudinally extending transverse myelitis' (LETM) in MS and NMO, long segment is defined as $\geq$3 vertebral segments.[8] A majority (67%) of patients demonstrated long segment lesions (Figure 3). None of the patients had hemorrhage or syrinx on the initial MRIs.

Brain MRIs

Brain MRIs were performed in 25/27 patients at onset. In one patient, MRI showed asymptomatic patchy T2 hyperintensities at bilateral periatrial regions, which resolved 1 month later and remained normal at 1-year follow-up. NMO-IgG was negative. This patient has been followed for 2 years, and remains monophasic. Two patients had lower brainstem lesions contiguous to cervical cord lesion; these were not considered as brain lesion. In two children, brain MRIs were not available at clinical onset. These patients had symptoms and findings only attributable to spinal cord with clearly defined sensory levels. They were followed for 11.5 and 12.8 years and remained monophasic.

Discussion

The diagnosis of ATM is usually made from a combination of history, laboratory tests and imaging. MRI has been the most useful diagnostic tool; despite its non-specificity, the constellation of changes in the appropriate clinical setting can offer a strong presumptive diagnosis of ATM.

There is lack of reported MRI studies of ATM in children.[9] The radiological features of ATM have been described mainly in adult patients. As ATM is a diagnosis of heterogenic etiology, results of the some studies provide information on a mixed population, including both idiopathic and disease-associated myelitis. Involvement of longer segments extending over three to four segments is a common finding of ATM in adults (reported in between 53–71%) after excluding

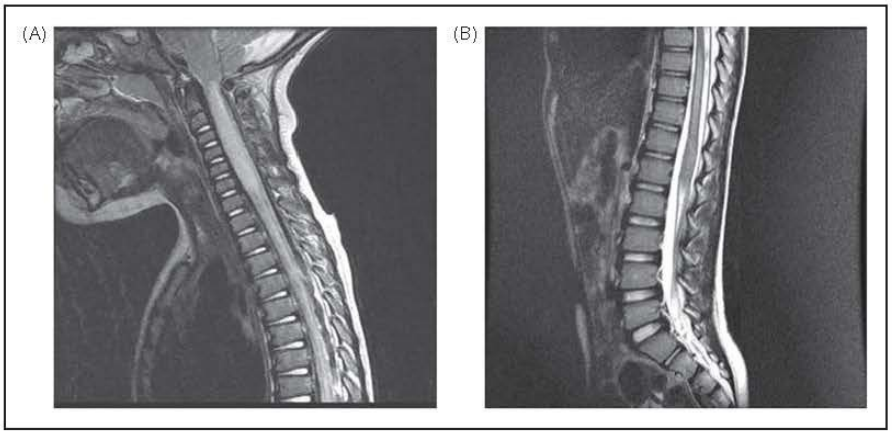

Figure 3. Longitudinally extending transverse myelitis. Sagittal fast spin-echo T2W images demonstrate long segment lesions, A) along with cord expansion, B) not associated with cord expansion.

the ATM secondary to identifiable causes.[10–12] Other important features described in adult patients include cord expansion, no enhancement, or diffuse and inhomogeneous, peripheral or slightly nodular (small focus) enhancement.[10,13–14] Variable presence of cord expansion was seen in 47% of patients,[10] and found in 43% in the present study.

The most striking result of this study is the presence of central cord hyperintensity involving the gray matter and nearby surrounding white matter. Gray matter involvement has not been previously reported in childhood ATM. Centrally located lesions occupying more than two-thirds of the cross-sectional area have been reported in adults as well.[10] Our radiological results demonstrate that lesions do not clearly demonstrate a predilection to the white matter in isolated monophasic transverse myelitis.

Similar to adult patients, idiopathic ATM in children involves long segments; the lesion tends to be vertically extensive. In a recent study, LETM was reported in 9 out of 12 children who were seronegative for NMO-IgG antibody and had monophasic ATM.[15] Andronikou et al. reported long segment involvement in three children.[16] These results support our observation that LETM, defined as lesions spanning over two segments, is a common radiological feature of acute isolated monophasic transverse myelitis in children and is not unique to NMO.

In adult patients with MS, spinal lesions are usually less than a two-segment length,[12–13,17–20] and are usually located in the posterolateral aspect of the spinal cord;[12] cord swelling is rare in MS.[20,21] The detailed features of the ATM associated with polyfocal CNS demyelination (ADEM and MS) are yet to be studied in children. In adult cohorts, the reported risk of MS is higher when partial forms are considered or included only the patients with short segment lesions.[22–24] Acute partial transverse myelitis is known as the major spinal expression of MS, with complete transverse myelitis being extremely rare.[23,24] TMCWG criteria do not distinguish between the partial and complete myelitis. While some adult studies find this classification as a useful outcome parameter, we avoided the clinical definition of 'partial myelitis' as there were many patients falling into gray areas. It is even less applicable to younger children, in whom the extension of sensory deficits would be more difficult to determine.

Some questions remain about the low ratio of lesion enhancement in our ATM cohort. No data are available correlating the presence of enhancement and timing of the study in children. In an adult study Choi et al. found greater frequency of positive enhancement in patients with subacute stage than those in acute stage.[10] Most of our patients underwent imaging studies on admission, and the short interval from symptom onset to MRI study (mean; 1.7 days) may be an explanation for lack of enhancement. Normal spinal MRIs were also reported in other pediatric series.[2,3,6,25]

Inflammatory transverse myelitis in the absence of a specific cause is the most common cause of acute myelitis.[26] However, idiopathic nature is a diagnosis of exclusion, and other causes need to be excluded. Acute infectious myelitis is usually diagnosed by prominent CSF inflammation (pleocytosis above the usual post-infectious range with neutrophilic predominance and significantly elevated protein), presence of systemic infectious symptoms (fever, rash, meningeal signs, concurrent infectious illness), and finally with the confirmation of microorganism in CSF. Connective tissue disorders (systemic lupus erythematosus, Sjogren's syndrome, mixed connective tissue disorders, Behcet's disease) and sarcoidosis may present with acute myelitis,

but it is rare for myelitis to be a presenting symptom.[26] Until more autoimmune biomarkers are identified, some causes of ATM can be proved only by 'time', therefore long-term follow-up information is crucial. Vascular etiologies and fibrocartilaginous embolism are very rare in children, but should be considered in the presence of hyperacute presentation (time to nadir less than 4 h), and normal CSF. History of trauma or lifting heavy weight should be carefully documented in the history. Clinical and radiological evidence of anterior cord syndrome should raise the suspicion for anterior spinal artery occlusion.

It is well known that ATM may occur as part of a multifocal CNS demyelination. LETM is reported in association with ADEM;[15] however, ADEM is characterized by multifocal involvement (cerebral, cerebellar, optic nerve and spinal cord), therefore isolated spinal cord syndrome is not consistent with ADEM by definition.[27] NMO, as one of the relapsing CNS diseases, may present with isolated transverse myelitis and characteristically involves long segments. NMO, both clinically and radiologically, may not be distinguishable from idiopathic ATM at onset. Therefore, obtaining NMO-IgG antibodies is crucial for distinguishing the two entities. On the other hand, isolated ATM is not likely to be an initial manifestation of MS in children. Only 1 of 47 children with transverse myelitis was diagnosed with MS after a mean follow-up of 8 years,[2] and none (0/24) reported by Defresne et al. after a mean duration of 7 years.[6] Among patients with a final diagnosis of MS, 2 out of 29 were considered to have had a focal episode of transverse myelitis at the first event.[3] The presence of oligoclonal bands in ATM has been associated with a higher risk of an MS diagnosis;[28] none of our patients had oligoclonal bands, a result that supports the observations of previous studies.

Although a variety of conditions should be considered, our results showed that the disease presenting with non-compressive acute spinal cord syndrome in children is most likely inflammatory in origin and not associated with another CNS or systemic disease process. Long-term follow-up in this study demonstrated that this acute inflammatory disease limited to spinal cord is not likely to relapse and thus become monophasic in the majority (94%) of children. Disease-associated ATM was found in only 6% of patients in this cohort, with NMO being the most likely diagnosis. The risk of MS in children who experience isolated spinal cord syndrome as a first demyelinating event appears to be low. Future studies in pediatric patients comparing initial spinal cord lesions of idiopathic ATM with those who are subsequently diagnosed with MS and NMO would be critical.

This study provides a comprehensive analysis of MRI findings of idiopathic ATM in children. In summary, lesions are located in the central cord involving gray and nearby surrounding white matter. Most of the lesions are longitudinally extending, characterized by involvement of three or more segments. Childhood ATM typically has a monophasic course and remains a major subset of acute inflammatory CNS disorders.

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Conflict of interest statement

None declared.

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The TMA Newsletter and Journal Archives

The TMA is currently publishing a journal (winter) and a newsletter (summer) every year. When people sign up for membership in the TMA, they receive a packet of information which contains the most recently published TMA Journal or Newsletter. We encourage people to read the previously published newsletters and journals. They are an excellent source of information about the neuroimmunologic disorders, both through articles written by medical professionals and by people with these disorders and their family members, which describe their personal experiences. Through these publications, you can also learn about research and clinical trials, the TMA, awareness and fundraising efforts, and the support groups around the country and around the world.

All of the newsletters and journals are archived on our web site; you can find them under the link 'newsletters' on the main page of our web site or you can type www.myelitis.org/newsletters/index.html into your web browser. You can view the newsletters and journals as they were published by selecting the PDF files from the column on the right, or you can view them in html format from the column on the left. The html files include an index which makes it very easy to find articles covering specific subjects. Additionally, Jim has installed a search engine for the entire TMA web site, which allows searching for specific subjects. Topics may be searched in the newsletters and journals by using the search engine.

If you have difficulty in finding information about any topic on our web site, and the search engine does not provide you with the results you were seeking, you should always feel free to contact Jim for assistance. You can send Jim a question or a request for help at jlubin@myelitis.org

Neuromyelitis Optica

NMO

S

Multiple Sclerosis

WHAT YOU NEED TO KNOW...

WHAT IS NMO?

NMO is Neuromyelitis Optica. Originally known as Devic's disease, NMO is a rare spectrum disease of the central nervous system that usually affects the optic nerves and/or the spinal cord. **Until recently, NMO was thought to be a type of Multiple Sclerosis (MS). However, recent discoveries indicate that NMO and MS are distinct diseases. Traditionally spinal cord lesions seen in NMO are longer than MS but this is not always the case.**

WHAT ARE THE SYMPTOMS?

NMO symptoms can vary from person to person and may resemble MS symptoms in many ways. NMO is most commonly characterized by inflammation of the spinal cord and/or optic nerves, causing any of the following symptoms:

>> Rapid onset of eye pain or loss of vision (optic neuritis).

>> Limb weakness, numbness, or partial paralysis (transverse myelitis).

>> Shooting pain or tingling in the neck, back or abdomen.

>> Loss of bowel and bladder control.

>> Prolonged nausea, vomiting or hiccups.

>> Sometimes these symptoms are temporary, and resolve on their own. In any case, it is important to discuss these symptoms with your doctor to help consider NMO in your diagnosis.

WHY IS IT IMPORTANT TO KNOW ABOUT NMO?

With so many symptoms in common, NMO can sometimes be confused with MS or other diseases that are treated in different ways. Early detection ensures best outcomes.

In addition to MS, NMO shares symptoms with:

>> Unexplained Transverse Myelitis (TM)

>> Acute Disseminated (ADEM)

>> Unexplained Optic Neuritis (ON)

Some patients with NMO also have other autoimmune diseases like:

>> Sjögren's Syndrome

>> Systemic Lupus Erythematosus (SLE)

>> Mixed Connective Tissue Disease (MCTD)

WHERE DO I START?

The Guthy-Jackson Charitable Foundation funds research and sponsors Spectrum, an online NMO community, where you can...

>> Learn the latest research and clinical studies of NMO.

>> Connect with NMO patients, clinicians, researchers.

>> Share your experience of NMO, and follow the journeys of other patients and caregivers.

Join us at www.spectrum.guthyjacksonfoundation.org

>> Volunteer to become a member of our NMO Advocacy Network by emailing us at **advocate@guthyjacksonfoundation.org**

>> Locate NMO clinicians worldwide.

GUTHY JACKSON *Charitable Foundation*

NMO NEUROMYELITIS OPTICA *No More Orphan Diseases*

REPOSITORY FOR NMO

We need NMO blood samples to make our Repository an invaluable resource to scientists and doctors who are uncovering new insights into NMO every day. If you know an NMO patient who is willing to **donate blood** to our cause, please contact our **Repository Nurse** at **858.333.1704** or **repository@guthyjacksonfoundation.org**. It's easy and **free of charge!** Currently we only accept blood donations within the continental United States. Our worldwide Repository is in development. Please visit our website for updates.

WHAT CAN I DO?

Good communication with your doctor is one way to help. The discovery of an antibody in the blood of individuals with NMO gives doctors a reliable way of determining if you have NMO.

- **Ask your doctor about NMO, and whether an NMO antibody test is right for you.**
- **If you have NMO, volunteer to take part in important new NMO research and give us all the best chance for discovering a cure.**
- **Donate your blood to our Repository for NMO.**

ABOUT US

The Guthy-Jackson Charitable Foundation is dedicated to funding basic science research to find answers that will lead to the prevention, clinical treatment programs and a potential cure for NMO.

CONTACT US

Email: info@guthyjacksonfoundation.org
Phone: 858.638.7638

JOIN US AT

www.guthyjacksonfoundation.org

NMO and TM Centers

University of Texas Southwestern and Children's Hospital (Dallas)

To make an appointment for an adult, please call (214)645-8800 and ask to speak to the Multiple Sclerosis and Transverse Myelitis Clinic for a new patient appointment.

For an appointment for a child, please call (214)456-5214 and ask to set up a new patient visit with Dr. Greenberg or Dr. Graves.

Johns Hopkins

The Transverse Myelitis Center
600 N. Wolfe Street
Pathology 627
Baltimore, Maryland 21287

Phone: (410) 502-7099 (option 2)
Fax: (410) 502-6736
Email: hopkinsTMcenter@jhmi.edu
Website: www.hopkinsmedicine.org/jhtmc

If you are a patient or the relative of a patient interested in consultations at the JHTMC, you may expedite scheduling of appointments by sending **ALL** of the following: MRIs (CDs or films), MRI reports, laboratory reports (blood and cerebrospinal fluid), and hospital admission/office notes to the above address or fax. A pre-visit assessment of needs and review of records allows a match of each patient to specific doctors and provides the best opportunity to get the absolute most out of a visit to the Center. This process also allows for patients with more urgent needs to be seen in a timely fashion. For some patients, their visit to the JHTMC may be in conjunction with a several week stay with the rehabilitation team either at Johns Hopkins or at Kennedy Krieger Institute for intensive therapy.

Save the Date

2011 NMO Patient Day

Living with NMO[3]

November 9, 2011

Location The Hilton LAX
5711 West Century Boulevard
Los Angeles, CA 90045

Transportation Free Hilton/LAX shuttle

Donate to the
GJCF Repository for NMO
at our
Repository Blood Draw
Available On:
Nov. 8,9,10

Register to attend:

www.guthyjacksonfoundation.org/patient-day-2011/

If you are a physician or health provider interested in urgent referrals or consultations, please contact the phone or e-mail above or call the Hopkins Access Line and request to speak with the neurologist on call (800) 765-5447.

We have established a system to facilitate a comprehensive assessment that involves not only the neurological evaluation, but other types of consultations in an effort to provide patients with long-term plans for management of all health problems associated with TM. These consultations may include specialists in rehabilitation, neuroradiology, neuropsychiatry, neuro-ophthalmology, urology, and spinal neurosurgery at Johns Hopkins Hospital and its affiliates at the Kennedy-Krieger Institute (KKI) International Center for Spinal Cord Injury. Our team at KKI possesses a focused interest in TM.

Because of the complexities of transverse myelitis, the JHTMC consists of a team of neurologists within the Neuroimmunology Division, as well as other specialists who have a focused knowledge of this rare and oftentimes difficult disorder. Our neurological team includes:

Dr. Carlos Pardo-Villamizar, Director of the JHTMC, focuses on acute idiopathic transverse myelitis, as well as sub-acute and chronic myelopathies associated with neurosarcoidosis and other etiologies.

Dr. Michael Levy focuses on Neuromyelitis Optica and Neuromyelitis Optica spectrum disorders, including recurrent TM and longitudinally-extensive TM. Dr. Levy is the Director of the NMO Clinic at Hopkins, a clinic that is not only dedicated to the diagnosis and management of NMO, but also focuses its efforts on research into this TM-related disorder.

Dr. Daniel Becker, a neurorehabilitation specialist and also faculty at the Kennedy Krieger Institute International Center for Spinal Cord Injury focuses on evaluation and treatment of long-term effects of TM and neurorehabilitation.

Drs. John Ratchford and Daniel Harrison focus on myelitis, myelopathies, and demyelinating disorders that can present as TM. Both are neuroimmunologists with expertise in clinical trials and neuroimaging technology in neuroimmunologic disorders.

Drs. Peter Calabresi (Director of the Johns Hopkins MS Center) and Scott Newsome focus on assessment of those patients suspected of having demyelinating syndromes that can present as TM. They are also interested in the assessment of novel technologies, such as ocular coherence tomography (OCT), a new non-invasive technique used in the assessment of axonal and retinal damage produced in neuroimmunologic disorders.

Drs. Justin McArthur, Avindra Nath and Arun Venkatesan focus on patients with TM as a result of an infectious disorder. They have a longstanding interest in neuroinfectious disorders, including those that are associated with TM, such as herpes infections or other viruses.

Dr. Julius Birnbaum has the unique expertise of rheumatology and neuroimmunology as he was trained in both specialties. He focuses on patients who have TM as a result of an underlying rheumatologic condition, such as Sjogren's disease or systemic lupus erythematous.

The Neuropsychiatry clinic for TM and MS was established through the pioneering work of Dr. Adam Kaplin. Dr. Kaplin's work continues to be one of the most important facets of the JHTMC. Dr. Kaplin focuses on the assessment and treatment of issues related to depression and cognitive problems in patients affected by TM.

Referrals are facilitated through The Transverse Myelitis Association, the JHH Hopkins Access Line (HAL, which facilitates inpatient admission to JHH from other hospitals), the JHTMC website, JH Access Services (which facilitates scheduling of outpatients to JHH), and the JH International Office. Additionally, there is an on-call neuroimmunologist to facilitate triage and admission, as well as to offer advice for the management of TM inpatients outside of the JHH system, in conjunction with the JHH HAL Attending. This allows for prompt attention to meet acute management needs.

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Tips for the Traveling mobileWOMAN

Melissa Male and Cheryl Price

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If you are a mobileWOMAN, then you have an inner desire to explore the world around you. This thirst for adventure most often requires air travel. With new airline regulations, as well as the need to bring along personal supplies, medical equipment, and your ever-important wheelchair, traveling may seem like an overwhelming endeavor. Relax! We are here to provide you with some tips to help your trip run smoothly so that you have even more time for adventure!

Booking

When booking your flight, you should immediately make the airline aware of your disability and your needs. Many times, you can reserve a seat close to the front of the plane, or even in the first row – bulkhead -- which is easiest for both you and the staff who may help you on-board.

If you want, you can get assistance immediately when you arrive at the airport. They will escort you through security and to your gate. You will also have assistance getting on and off the plane, picking up your luggage and helping to get transportation.

When booking a flight, also pay close attention to the times for layovers and make certain that you have enough time for a bathroom break as well as getting to your next gate. A direct flight is always best if possible, so that you have less chance of missing the next one or losing your luggage.

You may be asked how much your chair weighs without you in it. Figure this out before heading to the airport. They ask in order to find out if they can carry it from the jetway down a flight of stairs to cargo, which saves them time ... but, it can be risky. If

there isn't an automatic lift to lower the chair from the jetway, say "it's very heavy" or tell them NOT to take it down the stairs. They have other options, which take more time, but will give you more peace of mind.

Service dog: If you have a service dog with you, let the airline know when you're booking the flight. Service dogs are allowed to be in the cabin with you. Legally, you should not have to provide paperwork, however it is a good idea to have certification papers and proof that the dog's shots are up to date. Some staff are not well-informed and it is much easier to give them paperwork than to argue and possibly miss your flight.

Medical insurance: Make certain that you have health insurance coverage while you are on a trip. If you don't have coverage, when you book your trip, be sure to talk to your airline representative about what medical insurance options they offer. Medical bills can be astronomical, so it is worth the investment to purchase this for your trip, especially for an international trip. Once on your trip, always keep on-hand your medical information, such as health insurance, list of special needs, and physicians' contact information.

Packing

Medication: When you are going out of town, make sure to bring extra prescriptions, especially if you're traveling out of the country, on a cruise or anywhere without access to a pharmacy. The last thing you want to do is try to get a prescription while you're away. Consult your doctor about which ones you should have on hand during your time away. If you are prone to urinary tract infections, bring antibiotics that have worked well for you in the past. These should be packed in your purse or carry-on because there is a strong possibility that your luggage may be lost and they can take days (or longer!) to get it back to you. Probably, the best philosophy is to assume your luggage will be lost so put all necessities in carry on, i.e. the "what can't you live without" bag.

If possible, pack at least a week extra in case you end up staying away longer than anticipated. Be sure to keep the pills in the original pharmacy bottle with the label still intact, in case airport security needs to check. If your medication needs to be stored in a refrigerator, be sure to keep that in mind with wherever you'll be staying on your trip; you may need to request a refrigerator at your hotel.

Medical supplies: The same tips apply when it comes to medical supplies. A few weeks in advance, go through your daily routine and make certain that you have all the necessary supplies. If not, you may need to order more supplies, which is why figuring this out in a timely manner will allow you the opportunity to have what you need shipped in time. Once you have everything, pack as much as you can in a carry-on. Check with your airline for allowable carry-on items and up-to-date policies.

Clothing: Oftentimes, people with disabilities have temperature-control issues. When you're traveling, this problem may be exacerbated because you are out in the elements all day and the weather may change quickly. To help prevent problems, it is best to dress in layers and make certain that your clothing is functional and comfortable. Always bring with you rain gear, a warm jacket, a hat, and any other garment or accessory that you can roll up and toss in your bag if you don't need it. For the plane, bring a warm sweater or fleece because it is usually cold on the plane and many airlines are no longer giving out blankets.

Wheelchair supplies: There's nothing more frustrating than getting a flat tire while on vacation. This may happen to you, so be prepared by taking with you repair tools (these will not be allowed in your carry on so put in your checked baggage) and a pneumatic tire repair kit. If you're traveling domestically and have access to a computer, you may want to print out and pack a list of any wheelchair or bike shop that may be near your travel destination. This way, if you have a wheelchair mishap while out and about, you don't have to scramble to figure out where to get repaired. To be most proactive, you can even service your wheelchair before you go on your trip!

Before Your Flight Departs

Remember that you will need to keep your passport or ID, boarding pass, custom papers, etc. within reach while you're in the airport, which isn't easy to do while pushing your wheelchair. You can purchase small traveling pockets that can hang around your neck, or keep a small pouch either on your lap or somewhere easy to reach. A coat pocket, purse, or even hardcover book works sometimes as well. Best solution, however, is something attached to you so you will not lose everything.

The airline will assist you through the airport if you need it. It is beneficial because you will often by-pass long lines at security. You will need to get physically patted down by a female member since you can't go through the metal detector. You can request a private area if you prefer.

Service dog: Some airports have designated areas for you to take the dogs to go to the bathroom. To be safe, take them before you go through security and restrict their eating and drinking prior to flight. Some dogs are extremely scared and agitated during flights so talk to your trainer regarding how to properly handle the dog for flights. In addition, ask your veterinarian about a possible sedative to keep your dog calm (but not completely knocked out

-- you don't want to be carrying an 80 pound dog through the airport!) For larger dogs, they will give you the bulkhead seat to allow for more space. Once you land, get the dog some water and find a place for a bathroom break as soon as possible.

Wheelchairs: If you have a manual wheelchair that is collapsible or folds, you may be able to take it on board and store in the closet. If not, it will go below the plane. Make certain that every loose part is tightened and securely fastened. It is even helpful to tape over any parts that may come loose or need protected, for example the side guards. You can at least remove your cushion and sit on it during the flight. If you have an air cushion, keep checking it during the flight because the cabin pressure can cause it to over-inflate! For chairs with power rims, remove the power rims and battery and bring those on board with you. Make certain that they tag your wheelchair and give you the receipt in case anything is lost. You can also write your name and address somewhere on the frame of your wheelchair or use a return address label with tape on it, in case the tag gets ripped or lost.

When you are traveling with a power wheelchair, there are several additional elements that you need to keep in mind when booking and getting on your flight. First and foremost, make sure you know what type of batteries you have. "Wet" batteries, which are not as common anymore, have to be removed from the chair and boxed up in special containers because of the risk of acid spillage. Check with your carrier to find out if you need to box up the batteries beforehand or if they will do that for you. "Dry" or gel batteries, which are common now, don't need to be removed from the chair. When you check in (which you must do at the gate even if you already did at the ticket counter), you will be asked what type of batteries you have so that your crew is notified in advance. Sometimes, although the batteries are not removed, they are unplugged during the flight. So, when you get your chair once you've arrived at your destination and the power doesn't work, check to see if the batteries are unplugged before having a panic attack!

Before your power chair leaves your sight and is taken away, double and triple check that your chair has a destination tag on it (and the CORRECT destination!) and a gate check tag; this means that they will bring your chair back up to the entrance of the plane when you've landed, so you don't have to pick it up at baggage claim. Also, make sure you've removed items from your chair you wouldn't want to have lost or damaged - your backpack, your seat cushion, and anything else. You may want to wisely remove the little rubber nob that easily comes off of the chair's joystick, as those suckers aren't cheap to replace if they fall off. Just remember - the crew treats your chair like a piece of luggage ... not always as gingerly as you would like!

Make sure you take your battery charger on the plane with you and stow it under your seat or in overhead. Just in case luggage should be lost, you do not want to get stuck for a few days without your charger. Most new chargers are fairly light and small - not like the old ones that weighed as much as you!

Whether you are using a manual or power chair, when you get to your gate, make sure whoever is working at the gate is aware you will be boarding the flight. You are always entitled to pre-board the plane to give you space and comfort to get to your seat and to allow the airline time to bring your chair down to cargo. Let whoever is at the gate know if you need any assistance boarding. Even if you are able to transfer into your seat with no assistance, you will more than likely not be able to fit your chair on the plane and transfer directly from the wheelchair to your seat. You might need to transfer into an "aisle chair" before boarding the plane, and then you will be buckled up and pushed onto the plane and to your seat. If you need assistance transferring, once again, don't be afraid to clearly tell those helping you what your needs are and the best way to assist you. Do not assume that they will understand balance issues or if you can't move your legs, for example, since they are dealing with a multitude of disabilities on a daily basis and are always in a hurry.

In The Air

While in flight, especially if you are flying alone, let the flight attendants know if you need help reaching your carry-on, which needs to be stored during take-off and landing. If you need help reclining your chair and taking out the tray to eat, they will also help you if you ask. Remember your feet may swell while flying, so you want to use a carry-on while in-flight to prop your feet up for some elevation! Wearing compression stockings is another great idea, especially for long flights.

Bladder: For some people, bladder problems prohibit them from any travel whatsoever. But remember, there are options! Don't let your bladder keep you from getting out there, having some adventure and enjoying yourself.

Those who use intermittent catheterization have a few options. One is to restrict your fluid intake for a couple hours prior to the flight and, if the flight isn't too long, wait until you land and get to a restroom to catheterize again. Keep in mind that you are the first one on board and the last one to get off the plane. This can be risky because you can end up dehydrated and should really drink a lot of fluid while flying. But you know your body best, so if you can handle not drinking a lot on board, then this may be the

easiest route to take.

Another option that is definitely not for the timid is to use Velcro or a zipper in the crotch of your pants and discreetly cath in your seat. You can get a steward or stewardess to help with getting neighbors to move and block the view for privacy. Blankets come in handy.

For long flights, you can also use an indwelling catheter while flying and then remove it once you are at your hotel. This is a great option because you can drink as much as you want and it is easy to empty at your seat, if necessary. For areas with very few accessible bathrooms, such as Europe, some even put one in every day while sightseeing and then remove it once in the hotel. Using an indwelling catheter makes things much easier, but can also cause bladder infections, so carefully weigh your options.

When it comes to bathroom issues, it is imperative to plan ahead. Discuss with your physician/urologist and see which options are best for you.

Some longer/international flights have on-board wheelchairs and bigger airplane bathrooms that fit this wheelchair so that you may use the restroom while in flight. Check with your airline before the day you fly to see if you have this option.

You've Arrived!

Wheelchair-users always de-plane last. It usually takes them a while to get your chair up to the jetway, and it's easier to maneuver around without hoards of anxious travellers and their luggage. BE PATIENT! You may get lucky and only wait a few minutes or have to wait for 15 minutes. But once you do get in your chair, thoroughly check your chair for damage. You might be in a hurry, but you need to take the time to make sure there aren't any new scrapes, nicks, gashes, dents, bent axles, broken spokes, missing pieces, or popped tires. If you find damage, however big or small, you need to go to customer service in baggage claim and fill out a damage claim form. Airlines are accommodating when it comes to paying for damage done to wheelchairs, but you need to take care of this right away if this happens to you. You may choose to photograph the damage while at the airport, as well.

The airline is available to help you in any way that you need to navigate through the airport and get to your baggage. Once again, it can be beneficial to use their assistance because they know where elevators are and can get you through customs quickly, if necessary. There are also people to help you take your bags outside. You will need tip money handy to pay them.

Once you are outside, keep in mind that if you are traveling by taxi, your chair will be folded and stuffed in a vehicle. You may have to guide either the taxi driver or whoever is with you so that everything is stowed away properly and safely. Depending on your travel destination, you may be able to request a mini-van or SUV taxi in order to optimize space or even a wheelchair accessible van with a lift and tie-downs so that you can stay in your chair. Make certain that you are secured properly before they start driving.

Hotel Accommodations

Depending on your destination and accommodations, finding a wheelchair-accessible room may or may not be easy. Choosing an American chain such as Marriott, Hilton or Westin will help to ensure that your room will be within the ADA Accessibility Guidelines. Sometimes, however, you may be traveling abroad or to a location where there are more boutique hotels than anything else. If this is the case, then you need to call up each hotel, explain to them your individual needs, and choose a hotel based on the information they provide you. You may need to tell them the width of your chair and have them check the width of their bathroom doors. Be sure to ask whether or not there is space in the bathroom for your wheelchair to fit and, at the same time, close that bathroom door. You may want to inquire about sink height, as well. Having your room on the first floor might also be an option you want to choose so that, in case of a fire drill or real emergency, you can evacuate without having to be carried down flights of stairs.

Getting Around

If you are traveling to an international destination where the terrain is rougher than just concrete and asphalt, for example if there's cobblestone or uneven pathways, you may want to consider an amazing product called the FreeWheel ™. This piece that fastens onto your wheelchair frame is also helpful for domestic trips that involve a lot of grass and hiking elements. As their website states: "This is a new product to use with your existing wheelchair that allows you to push over surfaces that would typically be impossible! The FreeWheel ™ Wheelchair Attachment is adjustable to fit your footrest (must be a fixed footrest). Clamp it on in seconds and you're ready to go! Lightweight and durable, strolling, exercising, hiking or just checking the mailbox is so much easier. Grass, curbs, rough road, etc. can be easily negotiated to help you in your quest of independence!" For photos and more information that can make your next trip safer and more efficient, visit http://gofreewheel.com/.

Do you feel prepared for your next trip yet? Zip up your suitcase, put your seat in its upright position, buckle up, and have a safe and memorable trip!

In loving memory of Daniel Tan January 22, 1989 - January 12, 2011

Daniel Tan passed away on January 12, 2011 after a six-year battle with Neuromyelitis Optica (NMO). Throughout his life, Dan was an incredibly positive spirit whose courage, determination, and vibrant sense of humor inspired those around him.

Dan was born on January 22, 1989 in Los Angeles, CA. He spent his early years in Surabaya, Indonesia before moving back to Los Angeles. When Dan was eight years old, he suddenly experienced some vision loss. Despite his new disability, Dan continued to live his life just the same. He played basketball both at Carlthorp and Windward schools and continued to excel in his academics.

At sixteen, after suffering from weakness in his limbs and additional vision loss, Dan was diagnosed with NMO. Over the next six years, Dan became completely blind and wheelchair-bound. Even still, he maintained his fierce positivity and determination. Dan continued to live the life of a typical teenager — he went to his high school prom, "watched" TV and attended concerts and sports events. He surprised us all when he won $1600 with his NCAA March Madness bracket. Dan also made every effort to continue cheering on his high school basketball team. He would sit at the bench at every game. During half time, he would join the players in the locker room and Coach Miguel Villegas would let him say a few words.

Dan's commitment to Windward basketball eventually led to the creation of the "Dan Tan Award" by the High School Academic All-American Classic. This award will honor student athletes who have overcome hardships, inspired others, and led from the heart.

Less known to others, Dan was also driven to continue with his academics. Last fall, he was looking forward to begin taking classes at Santa Monica College. Even after being out of school for three years, Dan surprised us all when he placed into Calculus. Being blind, Dan had to do all of the math in his head as a proctor read the test to him. He was so motivated to do well that he stayed for five hours and would have stayed longer if they didn't have to close the office. As always, Dan met every obstacle with a strong sense of determination; he never let his illness prevent him from continuing to live his life the way he wanted to live it.

Despite living a short life, Dan touched and inspired the lives of so many. We will never forget him and the brightness that he brought to all of us.

A Facebook page has been created in memory of Dan: http://www.facebook.com/InMemoryOfDanTan

October 6 - 9, 2011: Family Camp Weekend at Victory Junction

The TMA will be holding a family camp weekend at Victory Junction in Randleman, North Carolina, October 6 - 9, 2011. The camp is for families who have a child with TM, ADEM, NMO, or ON between the ages of six and sixteen and their siblings and parents or guardians. We are asking that only members of the immediate family apply to come to camp so that we are able to offer this opportunity to as many families as possible. There is a limited amount of space at camp.

The camp arrival for families will begin late afternoon, Thursday, October 6th and camp programming will begin at dinner time Thursday. The camp will end and camp departure will be at noon on Sunday, October 9th. Your travel plans should be coordinated with the beginning and end of camp. If you are going to be flying into Piedmont Triad Airport (GSO) in Greensboro, North Carolina you will need to coordinate your travel arrangements with Chris Foster, the Camp Recruiter at Victory Junction. Victory Junction is about 20 miles away from the airport and the camp will arrange to get you to and from the airport free of charge. For planning your flights, the best time to arrive at the airport will be early afternoon on Thursday, and the best time to depart would be midafternoon on Sunday.

There is no cost to attend this weekend of fun; however, you will need to provide your own transportation. The application process is described and the applications are available from the following link on the Victory Junction web site:

http://www.victoryjunction.org/parents/camper-application.php

There is a medical section of the application that will need to be filled out by your doctor. Please send in your portion of the application as soon as you have it completed. Do not wait for the physician section; that portion can be sent in later.

Your point of contact at Victory Junction regarding the application process and the TMA Family Camp Weekend is Chris Foster. Chris can be reached at: (336)495-2019; his email address is chris.foster@victoryjunction.org.

We are very excited about the physicians and medical specialists who are going to be attending from our community. They will be there to participate in the activities and to answer your questions. We will provide an education workshop for parents and older children who would like to attend on Friday and Saturday mornings during camp that will focus on research and short and long-term treatment and symptom management practices. While the emphasis is going to be on a weekend of fun and relaxation, you will have the opportunity to spend time with the physicians who have the best understanding of these complex disorders. The response we have received from our physician community has been outstanding. We are anticipating that the following people are going to be able to attend: Dr. Daniel Becker, Janet Dean, RN, Dr. Benjamin Greenberg, Dr. Adam Kaplin, Dr. Douglas Kerr, Dr. Michael Levy, Dr. Donna Graves and Dr. Allen Desena. Dr. Graves is a pediatric neuroimmunologist who practices with Dr. Greenberg at the University of Texas Southwestern. Dr. Allen Desena is completing his residency in neurology and is going to begin a fellowship next year to establish a pediatric specialization in the rare neuroimmunologic disorders. We are thrilled to have Drs. Graves and Desena attend our family camp weekend, and it will provide an opportunity for them to meet our wonderful families.

We are also very excited to announce that Cody Unser will be coming to camp to participate in our family camp weekend at Victory Junction.

Please visit the web site to learn more about Victory Junction: www.victoryjunction.org

Summer Camp for our Children and Families August 1 – 5, 2012 The Center for Courageous Kids

We have come to understand and appreciate just how important our summer camps have become to the children and families who participate in this wonderful program. Since 2006, our summer family camp has been held at Victory Junction in North Carolina. As arranging a summer camp has become increasingly difficult at Victory Junction, we began a search for a summer camp for our families. I was contacted by the Center for Courageous Kids shortly after it opened in 2008 and they requested my help in recruiting children for the camp from our community. As the camp was offering such a wonderful opportunity, I was thrilled to run an article about the Center for Courageous Kids in Journal Volume III in June 2008. When it came time for us to look for a new camp, the Center for Courageous Kids was the first choice on my list.

Pauline, Kazu and I made a trip to the Center for Courageous Kids in April. It was a beautiful spring day; a perfect time to tour this spectacular camp for children with medical conditions that make it difficult for them to participate in a traditional summer camp experience. We met with the camp CEO, medical director and the camp recruiter. They took us for a tour of their camp and they gave us so much of their time and attention. They clearly understood what kind of experience we were looking for and they were

very gracious about discussing all of the possibilities. We talked about our education program and the physicians and researchers who participate in our camps and we provided a great deal of information about ADEM, NMO, ON and TM. It was a great visit and Pauline and I left camp really hopeful about our community being accepted for a family camp beginning in the summer of 2012.

We are thrilled to announce that the TMA Family Camp will be held at the Center for Courageous Kids August 1 – 5, 2012. Children with ADEM, NMO, ON and TM who are 5 – 17 years old and their families will be eligible to apply to the TMA Family Camp. As space will be limited and we want to be able to include as many families as possible, we are asking that only immediate family apply to attend camp.

You may begin to apply online in October 2011 from the following link:

www.thecenterforcourageouskids.org/camperapp.html

Please do not procrastinate. We anticipate that we are going to have very high interest in this event from our families from all around the world.

Faith Cary is the Camp Recruiter and will be our point of contact for the Center for Courageous Kids. You can reach Faith at: (270)618-2912 or faith@courageouskids.org.

Our physicians will be attending camp and will offer an exceptional education program. You will also have access to these doctors during the entire time you are at camp.

Please visit the Center for Courageous Kids website to tour this wonderful camp for yourselves.

www.thecenterforcourageouskids.org

If you are an adult with TM, ADEM, NMO or ON and have an interest in volunteering at camp, please get in touch with me. The number of volunteers needed for our camp will depend on the numbers of families that apply. We won't know this number until early next summer, but I would like to begin compiling a volunteer list and have you submit an application to camp. You can reach me at (614)766-1806 or through email at ssiegel@myelitis.org.

The closest airport to the Center for Courageous Kids is in Nashville, Tennessee which is about an hour from camp. The Center for Courageous Kids does not provide transportation to and from the airport. The TMA will be researching the possibility of renting accessible transportation for the travel days before and after camp to assist families who will require this transportation.

In making your travel arrangements, please consider that families will be scheduled to arrive at camp beginning at about 3:00 Wednesday afternoon and camp will be concluded at 1:00 Sunday afternoon (central time). Please do not purchase airline tickets before you have been formally notified by camp that your family has been accepted.

We are asking our families and the TMA community to get involved in fundraising for our family camp. The TMA is going to have an obligation to provide financial support to the camp for our families and there will be some significant transportation and related expenses. If you make a donation to support our family camp, please be sure to write ***TMA Family Camp*** on your check. We are always grateful for your support!

The 168 acre camp is located in Scottsville, Kentucky; 24 miles southeast of Bowling Green, KY, and just 65 miles northeast of Nashville, TN. The camp has a state of the art medical center and helipad, an equestrian center, bowling alley, indoor swimming complex, gymnasium and climbing wall, beautiful lodges, a dining hall and theater, an arts and crafts and music center and so much more. The camp is an entirely accessible facility and the camp offers an exceptional accessible recreation program for the children. Thus far, the camp has served over 8,000 children and family members from 30 states and Canada. We know that our camp will significantly increase the numbers of international families that the Center for Courageous Kids is able to serve.

The Center for Courageous Kids was founded by Elizabeth Turner Campbell. She was also a founder of Camp Boggy Creek in Florida, a Paul Newman Hole in the Wall Camp. After her involvement in Boggy Creek, she wanted to establish a camp in her hometown. She is the daughter of Cal Turner, Sr., the founder of The Dollar General Corporation which originated in Scottsville.

We are really thrilled about establishing a relationship with a world-class camp for the children and families in our community. If you have not already done so, please contact Linda Malecky (if you are located in the US or Canada) or Suzie Wedlake (if you live in Europe, Asia, Africa, and Australia). Please ask to be added to the children's and family database. Being added to the camp mailing list is just one of the reasons you should be participating in this database.

Please feel free to join me, Pauline and Kazu in our excitement about this new and wonderful camp experience.

Thank you, Center for Courageous Kids!

TMA Program for Older Teens and Young Adults

The first retreat weekend for older teens and young adults was held in 2006 at Victory Junction in North Carolina. This retreat was a powerful experience where for the first time many young people met others with TM, NMO and ADEM. The physicians and researchers from our community attended camp and provided a wonderful educational program. These retreats have been going on every other year and we are interested in continuing this important program for our young people.

We are requesting your opinions and ideas in order to design a program that most effectively meets your interests and needs. We are asking people who are between the ages of 16 and 35 to fill out our survey so that we can make informed decisions about what program we should be offering to the young people in our community. Even if you have no interest in the program or would not plan to attend, we would be interested in receiving your perspectives. The survey will only take you ten minutes to complete.

We will not disclose anyone's personal information when we do the analysis or present the results of the survey. Your anonymity will be protected and your name will not be associated with the responses you provide us. You can access the survey from the following web page:
www.surveymonkey.com/s/TMAYoungAdults

Thank you for your time and your thoughtful responses.

Benefits.gov and Disability.gov

Benefits.gov was launched in an effort to provide citizens with easy, online access to government benefit and assistance programs. The program's mission is to reduce the expense and difficulty of interacting with the government while increasing citizen access to government benefit information. The site's core function is the eligibility prescreening questionnaire or "Benefit Finder." Answers to the questionnaire are used to evaluate a visitor's situation and compare it with the eligibility criteria for more than 1,000 Federally-funded benefit and assistance programs. Each program description provides citizens with the next steps to apply for any benefit program of interest.

Benefits.gov does not allow you to apply for benefits and cannot guarantee your eligibility for any program. In addition, Benefits.gov is not designed to be a comprehensive listing of all programs for which you may be eligible. Its purpose is to provide you with a list of benefits you may be eligible to receive, as well as information on how to apply for those programs.

Benefits.gov is a partnership of many Federal agencies and organizations with a shared vision – to provide improved, personalized access to government assistance programs.

The mission of Disability.gov is to connect people with disabilities, their family members, Veterans, caregivers, employers, service providers and others with the resources they need to ensure that people of all abilities can fully participate in the workplace and in their communities. This federal government website provides an interactive, community-driven information network of disability-related programs, services, laws and benefits. Through the site, Americans with disabilities, their families, Veterans, educators, employers and many others are connected to thousands of resources from federal, state and local government agencies, educational institutions and non-profit organizations. New resources are added daily across 10 main subject areas – benefits, civil rights, community life, education, emergency preparedness, employment, health, housing, technology and transportation.

Disability.gov has implemented both social media and personalization tools to enhance the effectiveness of the web site. You can register for a ***My Disability.gov profile***, which allows users to vote and comment on resources, participate in group forums and view additional resources that are recommended based on their actions on the site. Visitors can also follow daily tweets on Disability.gov's Twitter account, connect with other fans on Facebook and LinkedIn or read weekly guest blogs from experts on disability issues on ***Disability Blog***.

UK TM Conference a Great Success

Two hundred TMers, family, friends, doctors and physiotherapists attended the UK TM Conference in April 2011 near London. Drs. Doug Kerr and Daniel Becker flew in from USA for the Conference. After our first one-day UK Conference in 2007 (Doug Kerr's first visit to London!) we decided that our next Conference needed to be more leisurely, outside London, residential and over a weekend.
Most members seemed to agree this Conference ticked all those boxes, and feedback used the words 'inspiring' and 'fantastic' several times. Using a residential conference centre allowed everyone a lot more time for socialising and meeting new friends, and to visit workshops on physiotherapy, FES, WII-habilitation, continence equipment, knitting for pain management, life coaching, etc. Not a lot of time was spent sleeping, although the rooms were very comfortable!

The Conference presentations are now available for viewing on YouTube as

one of the 'playlists' on the TM 'channel.' Dr. Kerr's keynote presentation 'Living with TM' is no. 2 on the playlist. There are other excellent presentations on bladder management, neuropathic pain, FES and activity-based restorative therapy, physiotherapy, gait and balance and stem cell research.

The TM Society Committee of 10 worked hard for 8 months to put the Conference together, and we were aided by several family and friends who worked as volunteers. Farshideh Bondarenko spent the entire two days in an ongoing Physiotherapy Workshop, demonstrating how TM ought to be treated with the aid of a couple of assistants. I asked one young member, how has the Conference been for you. She responded, "It has changed my life. Farshideh got me to stand up -- for the first time in 6 years!"

Lew Gray
lewgray@blueyonder.co.uk

The James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders

In 2008, The Transverse Myelitis Association established the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders. We urge you to make a tax deductible donation to this critically important program by using the link: http://www.myelitis.org/fellowship-donation

There is no greater need in our community than the provision of medical care by neurologists who have experience and expertise in these rare disorders. There is also a critical need to foster the development of scientists who are interested in these disorders. What better way to recognize and honor Jim than to establish a fellowship that will ultimately provide the best clinical care to the people Jim has devoted his life to helping and find the causes and cures for TM, NMO, ON and ADEM.

The purpose of the James Timothy Lubin Fellowship in Rare Neuroimmunologic Disorders is to encourage the development of medical specializations in TM, ADEM and NMO through a year of study under a leading TM, ADEM or NMO specialist. The fellowship is focused on the provision of exceptional clinical care and/or research into these rare neuroimmunologic disorders. Award of the Fellowship will be based on the expectation that the recipient will continue to specialize in ADEM, NMO and/or TM. If the fellowship includes a clinical and basic science research project, the fellowship term may be up to two full academic years.

The fellow will be required to work with a mentor (a TM, NMO and/or ADEM specialist). The mentor must be a faculty member with demonstrated clinical specialization and practice in at least one of the disorders. Preference will be given to medical centers of excellence in the disorders. If the fellowship includes a research program, the mentor must also be a scientist with research experience and publications in these rare disorders.

In order to award one fellowship each year, the TMA will need to raise $100,000. The number of fellowships we can offer will only be limited by the resources we are able to devote to this important program. Most of the people that I speak with for the first time are seeking a TM or a NMO or an ADEM specialist. If you have one of these disorders or if you are a family member or friend of a person with one of these disorders, an investment in this fellowship program will bring you very direct and profound benefits.

We urge you to get involved in this fundraising effort. I know that over the years many people have been inspired by Jim. Please join us in honoring Jim by supporting this important program. I can think of no greater legacy for Jim than to have highly motivated, brilliant and skilled physicians enter the discipline of neuroimmunology. Please make a donation to the TMA for the purpose of funding the James Timothy Lubin Fellowship and then please make your contributions a regular part of your generous giving. If you have been considering starting a fundraising program with your friends and family, this fellowship would be an excellent focus of your efforts. What more pressing or critical issue do you have in your own life or in your child's life than to assure that you or they have the best medical care available and that there are researchers who are interested in understanding TM, NMO, ADEM and ON.

In Their Own Words

In each issue of the Journal we include a column called ***In Their Own Words*** that presents the experiences of our members. Most of these articles recount the experiences that people have from their onset of ADEM, NMO or TM. The articles also include excellent descriptions and explanations of medical procedures or treatments that people have received. The column represents an excellent opportunity for people to share their important experiences surrounding having one of these very challenging disorders. Over the years, we've heard from many people that they find these articles inspiring and informative.

We are most appreciative of people's willingness to share their very personal stories. It is our hope that through the sharing of these experiences, we will all learn something about each other

and about ourselves. It is our hope that the stories will help us all realize that we are not alone. It is important to bear in mind that all newsletters and journals are archived on our web site. Should someone do an internet search of your name, your article is likely to be identified in their search results. You may submit your stories by sending them either by e-mail or through the postal service to Sandy Siegel. Please be sure to clearly state that The Transverse Myelitis Association has your permission to publish your article.

We've made our website talk! ReadSpeaker Added to www.myelitis.org

ReadSpeaker is an innovative program that transforms text into speech. We added ReadSpeaker to our website to facilitate access to information for people who have visual impairment from Optic Neuritis, Neuromyelitis Optica or Multiple Sclerosis. Also, for thousands of people who visit our web site seeking information and support, English is not their first language. Listening to the text could make it easier for people to understand this critically important information.

It is very easy to use; no plug-ins or downloads are required. To activate speech on a web page, all you have to do is look for the "SayIt" icon on the page and click it.

All of the text from the article will be read to you and the speech quality is excellent.

Children's Database

The Transverse Myelitis Association is collecting information for a pediatric/young adult TM (recurrent TM)/NMO/ADEM/ON data base. The information we are collecting will be used: 1. to develop a contact list that will be used by the TMA to notify and recruit families and older teens and young adults for the family camps and the older teen/young adult retreat opportunities; 2. to develop a contact list to recruit for pediatric studies and clinical trials related to TM/NMO/ADEM/ON; and 3. to develop a directory that can be used by TM/NMO/ADEM/ON families to share information and support between families in similar situations.

This project is being directed by Linda Malecky. Linda's daughter contracted TM at the age of two in 1999. To further the progress of the directory and to provide additional support, Suzie Wedlake, whose daughter contracted NMO in 2005 aged four, has graciously offered to head up the directory project in Europe, Asia, Africa, and Australia.

The TMA believes that it is extremely important for families (including the children with TM/NMO/ADEM/ON) to be able to find other families and children for information and peer support. If you have a child (25 years old or younger) with one of the rare neuroimmunologic disorders, and you live in North or South America, please send your information to Linda Malecky via email: ***lamalecky@verizon.net***. If you do not have internet access, you can send Linda the information via the postal service: 107 Tweed Way, Harleysville, PA, 19438. If you live in Europe, Asia, Africa, or Australia, please contact Suzie Wedlake by email at ***wsuziewms@aol.com*** or by postal service at 17 Vicarage Road, Penygraig RCT, South Wales CF40 1HR. The information from the different geographic areas will be combined before mailings are sent.

If you have any questions or concerns about the project, feel free to call Linda (215-855-3488) or myself (614-766-1806). We believe that this project will help us better serve the families in our community by making you aware of important opportunities and by facilitating a support network for our families. We are grateful to Linda and Suzie for their willingness to make this critically important project possible.

Learning about ADEM, NMO, ON and TM videos on www.myelitis.org

A tremendous resource about TM and the other neuroimmunologic disorders is the streaming video that Jim has posted on the web site. The presentations from the 2010 (Dallas), 2008 (Seattle), 2006, 2004 and 2001 (Baltimore) Symposia, from the Southwest Symposium (sponsored by the Cody Unser First Step Foundation), and from the 2002 children's workshop are available under the link 'Symposia Information' or by typing http://www.myelitis.org/events.htm into your web browser. Jim has the presentations organized as they appeared in each of these symposia program agendas. You can also find PDF files of most of the handouts and PowerPoint presentations. The video presentations are also available by going through the Streaming Video Presentations link from our main web page or by typing http://www.myelitis.org/multimedia.htm into your web browser.

Support Groups

Alabama

I am honored and happy to be a new contact person for the TMA Alabama Support Group. It has been my mission for the past 11 months to help others find the TMA website, TM Facebook Groups and offer the support that is needed when first diagnosed. I found those first few weeks, after my son was diagnosed, to be so terrifying and lonely.

Darlene Robertson
(205)542-7458
TransverseMyelitisAlabama@hotmail.com
Facebook: search for: Transverse Myelitis Awareness Day

Indonesia

I am Tatiyana from Jakarta, Indonesia. You can call me Yana. I am a graduate of the University of Indonesia in Economics. My entire career has been in Human Resources working with people in recruitment and selection, learning and development, performance management, competency, and information systems.

I was diagnosed with Transverse Myelitis in January 2009 at Penang-Malaysia. I returned to Jakarta where I was given high dose steroid therapy. I had no positive reaction to the steroids. I believe that my illness began in 2008. I was in a wheelchair after two months and required care 24 hours a day. I was examined by many different doctors in my country, but no one ever mentioned TM as a diagnosis. Finally, in December 2010, I went to Singapore where it was determined that I had TM. I was also told that there is no cure for TM and my symptoms.

During this time I kept looking for information on TM. It is very rare in Indonesia and there is no support group in my country. Then I found The Transverse Myelitis Association led by Sandy Siegel. I was grateful to find information and support.

I decided that I wanted to help people in my country who have TM. I would like to help them find information about their condition and to also offer support. People are so confused when they receive this diagnosis.

It has been difficult for me to adjust to my condition. I believe that my plan for daily survival has helped me. 1. I manage my emotions and find happiness in the small things around me. 2. I know how to make myself comfortable. 3. I don't fix myself to a plan – I remain flexible and adaptable to change. 4. I focus on helping others; especially healthy people. There is something powerful about being able to help a healthy person. 5. I keep moving forward. I have started a cookery business and do Human Resources Consulting. 6. I have learned to live with and accept pain. 7. I value what I have. 8. I pray.

I hope that other people in Indonesia with ADEM, NMO, ON and TM will contact me.

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North Carolina

I was diagnosed with TM in 2004. I was in the hospital for a week before TM was discussed. By the second week, it was considered as a possible diagnosis. I spent three months in a rehab hospital with another year of outpatient therapy. There was very little understanding of TM by my neurologists and my primary care doctor. I visited the John Hopkins TM Center with the encouragement of my primary doctor. My visit to Johns Hopkins was when we started to understand something about TM and what the attack did to my body.

My husband has been wonderful throughout my experience with TM. He has an abundant supply of tolerance and compassion. But he cannot understand in the same way another person with TM can understand my experiences. I would like to be able to be there for other people and to be there to listen.

If you live in North Carolina, I would love to hear from you.
Vickie Trull

6132 Hazelwood Lane
Archdale, NC 27263
(336)689-4745
bvtrull@yahoo.com

Alabama Passes Statewide TM Awareness Day!

Alabama has joined a small, but growing number of states that have passed a statewide Transverse Myelitis (TM) Awareness Day. This solidifies another significant cog in the machine that is being constructed to raise the awareness of, and to ultimately direct financial resources toward research into the pathophysiology of TM, as well as the management of the quality of life of the victims and families of TM.

The strategy is for individual organizations, in individual states, to obtain support at the state level in the form of TM Awareness Days. When TM awareness has been established in enough states, we may have created enough political clout to push for a National TM Awareness Day.

I became motivated to establish (with help from Kevin Weilacher of the International Disability Coalition) a TM

Awareness Day in Alabama, when my son, Daniel, was stricken by TM in late 2010. Within 24 hours, a backache morphed into paralysis from the chest down. Daniel was fortunate in that he lived near a major medical center where a diagnosis was made, and treatment was promptly initiated. As a result, Daniel has regained the ability to walk, though he still suffers periodic weakness in his legs as well as other symptoms associated with TM.

There are many stories of victims of TM who were not diagnosed in a timely manner because TM is somewhat under the radar. We have interviewed a number of health care professionals who are largely unaware of TM. By raising the awareness of TM, we hope to increase the likelihood of a timely diagnosis and the subsequent initiation of the appropriate therapy, improving the prognosis of the patients affected.

We must remember that the ultimate goal of this effort is not to merely obtain proclamations of sympathy for those afflicted by this disorder, but to create political and moral pressure to direct funding toward research in the area of autoimmune neurological diseases such as TM, MS, and others. I believe these conditions are closely related and that advances in one of these areas will likely benefit the others. It is also important to assist the families of those who are afflicted by TM as they are often blindsided by an acute onset disease which will likely result in some level of permanent disability for a family member.

The first step in establishing a TM awareness day is to submit a packet of materials to your state representative. My success in Alabama was likely the result of a number of factors which I would like to share:

- A personal story detailing the onset, diagnosis, and effects of the onset of TM.
- An informative letter describing TM, its frequency of occurrence, and the prognosis of the average patient.
- Here's the tough one – some connection to a state representative that will read the material and will have enough clout to push the proclamation through. This is not as hard as it might seem, as everyone knows somebody who knows a state representative. The key is to have some sort of direct communication with the congressman so that he is aware of what you will be submit-

Proclamation

By the Governor of Alabama

WHEREAS, Transverse Myelitis, a disease with approximately 1,400 new cases diagnosed in the United States each year, is not widely recognized by the general public as being a significant, serious spinal cord condition; and

WHEREAS, Transverse Myelitis is a devastating condition, affecting the neurological system, causing the spinal cord to become inflamed, and can occur in a single condition or in the presence of an existing illness; and

WHEREAS, symptoms include back pain, numbness of the lower extremities and headache, and as the condition progresses, paralysis, sensory loss and bowel and bladder dysfunction may occur; and

WHEREAS, current research indicates that Transverse Myelitis affects three to four of every one million people; and

WHEREAS, although spinal cord injuries have been well publicized by the media, Transverse Myelitis is often overlooked; and

WHEREAS, recovery from Transverse Myelitis can be difficult, with only one third of persons diagnosed with the disease making a full recovery; and

WHEREAS, increased awareness of Transverse Myelitis will help accomplish improvements in diagnosis and further scientific research:

NOW, THEREFORE, I, Robert Bentley, Governor of Alabama, do hereby proclaim June, 9, 2011, as

Transverse Myelitis Awareness Day

in the State of Alabama and encourage all citizens to be aware of the needs and issues facing Transverse Myelitis patients.

Given Under My Hand and the Great Seal of the Office of the Governor at the State Capitol in the City of Montgomery on the 30th day of March 2011.

Robert Bentley

Governor Robert Bentley

ting to him rather than just mailing it and depending on the staff to favorably prioritize your packet.
- A dogged persistence doesn't hurt a bit.

If you are considering leading the charge to establish an awareness day in your state, we ask that you choose a date in early June. The five states that have founded TM Awareness Days have chosen early June dates (June 9 in Alabama) and we feel that consistency among the states will facilitate the transition to a national TM awareness day.

Darlene Robertson
Member, Board of Directors
International Disability Coalition
http://disabilitycoalition.org/
TransverseMyelitisAlabama@hotmail.com

You can find The Transverse Myelitis Association on Facebook. It is a great way to support the TMA and it a wonderful way to network with people in our community. Please take the time to become a fan of the TMA and tell your friends and family about your community's page. Our page is a great way for us to raise awareness about these disorders and about your experiences.

Our link is:

http://www.facebook.com/myelitis

WebMD Health Exchange

http://exchanges.webmd.com/transverse-myelitis-association

The WebMD Health Exchange is a place where you can get support and information for health issues from experts and other members who are dealing with ADEM, NMO, ON and TM via discussions, tips and resources sharing.

The TMA Member Exchange connects to WebMD's resources and is also linked to information from our web site. The Exchange is searchable not only on WebMD, but on the Web, making it easier for users to find the TMA.

Another great feature of the Exchange is that we can include our support groups; each support group can create their own local or regional Exchange and each of these groups will be indexed in the WebMD searchable Exchange directory. By creating local Exchanges, it would make it easier for our members to find local resources. If you are interested in creating a local Exchange for your state or country support group, please get in touch with Jim and he can help you get started.

Important Reminder About The Transverse Myelitis Association Membership Directory

In order to receive a TMA membership directory, you must be willing to have your name and contact information listed. Those who have designated that they do not want to be listed in the directory will no longer receive one. The purpose of the directory is to assist our members in finding each other in their local communities, states and countries. As our membership is small and widely scattered around the globe, the directory serves as a way to facilitate the local or regional sharing of information and support. The value of this directory is commensurate with the numbers of our members who are willing to participate in our support network.
It is the expressed policy of the TMA not to share this information for any commercial purposes. The vast majority of our members are listed in the directory. This designation was made when you first completed the membership form on www.myelitis.org or when the original email or telephone contact with the Association was made. If you are not currently listed in the directory, and would like to change your designation so that you can receive the directory, please send an email to ssiegel@myelitis.org requesting that your contact information be listed.

This would also be a good time to check the directory to be sure that your current information is accurate. If your phone number or email address has changed, please notify us. Your membership information will be updated. When you send us any changes, please include all of your information so your membership listing can be easily found and the changes identified.

In addition to receiving the directory, another important benefit of being listed in the directory is having access to local support groups. Over the past several years, our local support groups have been developing around the country and around the world. If you are not listed in the membership directory, we assume that you do not want to be contacted. We do not provide your information to anyone, including the support group leaders who are currently operating in and around your area, or to those who will establish groups in your area in the future.

Due to the increasing size and cost of the TMA Membership Directory, we will be printing and mailing new directories no more frequently than every two years. If you are not currently listed, please consider doing so. We appreciate the willingness of so many of you to make yourselves available to assist others in your communities, states and countries.

We Don't Want to Lose You

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes to me via email at ssiegel@myelitis.org; you can send changes to me by mail, or you can fill out a change of information form on the web site: http://www.myelitis.org/memberform.htm – just click on the box indicating that you are changing existing information.

The Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates. We save a considerable amount of money by doing our mailings in this fashion. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you, after your grace period, and this class of mail is not returned to the sender. The cost to the Association is substantial. These are wasted printing and postage costs. Please keep your information current. Your diligence is greatly appreciated.

Contacting the TMA by Email

When writing email messages to the officers of the TMA or to support group leaders, please use TMA, Transverse Myelitis, TM, ADEM, NMO or ON in the subject header of the message. Please be sure to include a title in the subject header. The volume of emails that we receive and the way spam filters work makes it increasingly difficult to sort through emails to find legitimate messages. Also, if you would like to send an attachment, it is always a prudent approach to send an email notifying the person that you are going to follow up your message with a second email that includes the attachment; and explain the nature of the attachment. If you want to be sure that we see it, save it and open it, please include a subject header in your message and use words that will identify you as a person interested in contacting the TMA. We appreciate your help!

Privacy on the Internet

The information we provide on our web site and in our publications to our membership is one of the most important functions of The Transverse Myelitis Association. When you share your information in an In Their Own Words Column, you change lives. I have no doubt about this, because I hear from people every day who are inspired and informed by these writings. The access our support group leaders provide to people in their communities is invaluable. To know that you are not going through this experience alone or to find support and information in your community is truly a blessing for people.

Sharing information in our publications and on our web site is a selfless, kind and generous act, and we are all grateful for your participation. It is also very important to understand and accept that once this information is posted on our web site, it is available to anyone who has a computer and internet access across the globe. This ubiquitous access is the incredible value and also the bane of the information technology age.

So, we want and need for you to be generous about sharing this information, but we also want for you to be informed and judicious about making these decisions to share information. If you do not want to be found in a web search or you do not want for your information to be identified in a web search, please do not write an article for the newsletter or journal and please do not volunteer to be a support group leader. In addition to the information in our publications, it is important to bear in mind that any postings you put on a message board or in a list-serve group can also be accessed through a web search. It is almost always the case that if you are wanting anonymity in your life, the less you put out there electronically, the better, and that includes email messages, because once you hit that send button, you have no control over what the person does with that information on the receiving end.

It is also critically important to bear in mind that The Transverse Myelitis Association does not put membership information on our web site or post it electronically anywhere. We publish the directory in paper copies and we mail these directories only to our members who are listed. We send electronic copies of our member information to the people who do our mailings around the world, but they only receive the information for the people for whom they do the mailings. They do not receive the entire membership database. We expend a great deal of effort in protecting your information and limit to the extent possible, the electronic versions of this database.

If you want privacy, we do what we can to help you achieve that end. Please help us by making informed decisions in regards to what you submit for publication and what you post on the web site on our message boards and in the list serve groups. The TMA functions so effectively as a support network, because so many of you are willing to share and to help others. We urge you to continue to do so; we depend on your willingness to do so. But we don't want for you to participate in this sharing, if this activity is going to compromise any concerns you might have about privacy. Be smart and be realistic about how the internet works and what is private and what is public about the internet.

Awareness and Fundraising

Helping to Fund the Work of Your TMA

The officers and board members of the TMA are volunteers; they receive no compensation of any kind for their work. There are no employees in the TMA. There are no offices; the officers work out of their homes. In order to facilitate access to support and information, the TMA does not charge membership fees. As TM, NMO, ADEM and ON are rare conditions and our membership is small, it is extremely difficult to raise funds for our cause. We work most diligently to focus our resources on the direct services to our members. We operate exclusively on the basis of the voluntary support of our members. There are numerous ways for everyone to help support the TMA, even if you are not in a position to make a financial contribution. Please consider getting involved in one of our fundraising efforts.

Search the Internet and Raise Money for the TMA
You can raise money every time you search the web, at iSearchiGive.com. Make it your homepage and use it to find everything from news on the economy, to mood-lifting jokes (we recommend the latter). The Transverse Myelitis Association gets a penny (or more!) every time you search. Believe it or not, it adds up quickly and best of all, it costs you NOTHING!
> Start iGiving at:
www.iSearchiGive.com/TMA

Donate your cell phones
You can donate your cell phones to help raise funds for The Transverse Myelitis Association. Go to http://cellphones.myelitis.org

Online Shopping
There are numerous online shopping opportunities, as well as sales on eBay which can be made through the following link: http://www.myelitis.org/store.htm A percentage of the sales are donated to the TMA.

Save Gas. Save Time. Raise Money!
With over 700 stores in the iGive Mall and access to hundreds of exclusive coupons, free shipping deals, and sales, iGive is the smart way to shop. You'll find everything from daily necessities to special occasion and holiday gifts, at stores you know and love. So save a trip to the mall, and avoid the long lines. You'll never pay more when you reach a store through iGive, and up to 26% of each purchase benefits The Transverse Myelitis Association!
> Start iGiving at:
www.iGive.com/TMA

Café Press Shop for items with The Transverse Myelitis Association logo to raise awareness and show your support!
http://www.cafepress.com/myelitis

Amazon.com You can shop at Amazon.com for Books, Music, DVDs, Videos, Toys and more.
http://www.myelitis.org/amazon

Music Downloads for any device!
Shop for your favorite song or album from our mp3 store powered by Amazon and download music that works with an ipod or any mp3 player.
http://www.myelitis.org/shopmp3

eBay
Now you can sell an item on eBay and donate from 10% to 100% of the final sale price to help support the TMA.
http://www.myelitis.org/ebay

If you are a teacher, a student or a parent of a student and would like to establish the Reading for Rachel Program in your school, everything you will need to get the program started can be found on the Reading for Rachel web site: http://www.readingforrachel.org. All funds received by The Transverse Myelitis Association for the Reading for Rachel Program are used exclusively for research to better understand TM, to find treatments for the symptoms of TM, and to ultimately find a cure. If you are interested in starting the Reading for Rachel Program in your school, you can also contact Cathy Dorocak, Rachel's Mom and International Chair of the Reading for Rachel Program: cathy@readingforrachel.org; (440)572-5574.

Donations by Check
We always welcome and are grateful for a donation to the TMA. You can download a donation form to include with your check from the link: www.myelitis.org/donation-form.htm Please make a check or money order payable to The Transverse Myelitis Association and mail it to:

The Transverse Myelitis Association
Sandy Siegel, President
1787 Sutter Parkway
Powell OH 43065-8806

Thank you!

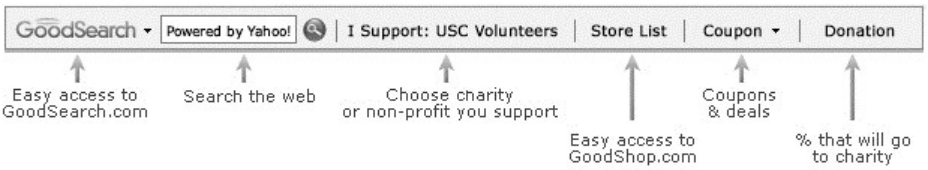
The Transverse Myelitis Association Credit Card Program

Share your passion and donate to our cause with your everyday purchases. We've partnered with Capital One® Card Lab Connect to bring you our newest fundraising program, which helps us earn money effortlessly every day! Just carry one of our custom credit cards (it comes with a competitive rate), and 1% of purchases made with the card will be donated to The TMA. We'll also receive a $25 bonus donation when you make your first purchase. And not only will you be donating to our cause with each purchase you make, you'll be helping to spread the word when people see your unique card, which includes our name and logo, as well as Margaret Smith's artwork as backgrounds.

Apply online via a secure web page at **http://www.myelitis.org/creditcard**

We urge you to only make purchases with this credit card that you are able to pay off each month. We would love to receive the benefits from this program without your paying any interest on your purchases.

The Transverse Myelitis Association is an all-volunteer, non-profit organization. We greatly appreciate your support!



The Goodsearch Toolbar for the TMA

Please add the Transverse Myelitis Association Goodsearch Toolbar. Once added to IE or Firefox, each time you shop at more than 1,300 stores (from Amazon to Zazzle!) a percentage of your purchase will automatically be donated to The Transverse Myelitis Association - at no cost to you (and you may even save money as the toolbar provides coupons and deals as well!). The toolbar also has a search box and each time you search the Internet, about a penny is donated to The Transverse Myelitis Association.

And please pass this along to all of your friends. The two minutes it takes to add this toolbar to your browser can make a lifetime of difference!

Get the toolbar NOW!

http://www.goodsearch.com/toolbar/transverse-myelitis-association

The TMA Greeting Card Program

http://www.myelitis.org/cards/

We are thrilled to introduce The TMA Greeting Card Program. The cover of each of the cards is a beautiful water color painting of landscapes or flowers. The back of the cards include the TMA logo, our web address and a description of our Association. The inside of each card is blank and perfect for offering your own sentiments. We urge you to use these wonderful paintings as your regular cards for the holiday season, for thank you and everyday notes or for any purpose.

The proceeds from the sale of these items will be used to fund the many important programs of The Transverse Myelitis Association. As the neuroimmunologic disorders are rare and our membership is small, it is extremely difficult to raise funds for our cause. We work most diligently to focus our resources on the direct services to our members. By using these beautiful greeting cards, you will be supporting the important work of the TMA and also raising awareness about acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis.

About the Card Artwork

Sandy and Margaret Smith are members of The Transverse Myelitis Association from Pittenweem, Fife, Scotland. They are active members of the Scotland Support Group led by Margaret Shearer. Sandy has TM. Margaret is an artist. Margaret has created beautiful paintings of landscapes and flowers. She has donated this artwork to the TMA and we are very pleased to be able to offer you these beautiful greeting cards.

Honor the Children in Our Community and Support the TMA

The Transverse Myelitis Association held a Children's and Family Workshop in Columbus, Ohio in July, 2002. The TMA Workshop focused on children from infancy to their early twenties and included their brothers and sisters and their parents. For most of the parents and children, the workshop represented the first time they had met another child with TM. One of the many activities they participated in during this special weekend involved working with an art therapist from Chicago, Lori Stralow Harris. With the help of Ms. Harris, the children created beautiful paintings which were constructed into a quilt of courage and hope. The original artwork currently hangs in the Johns Hopkins Transverse Myelitis Center where it is appreciated by the hundreds of patients every year who are cared for at the Center. We are very pleased and proud to be able to offer you the children's artwork through Café Press. The proceeds from the sale of these items will be used to fund the many important programs of The Transverse Myelitis Association. We hope you will take the opportunity to enjoy the children's work and to support the TMA.

http://www.cafepress.com/tmagifts

Help Raise Awareness with a TMA Wristband

For the past 3 years, thousands of our members have been helping to raise awareness of the TMA by wearing bright blue wristbands. They have been available on the TMA website and at our symposia for purchase. The wristbands are available in a marbled blue/grey in the adult size and solid blue in the youth size. The youth size also fits women with small wrists. These wrist bands are made with 100% synthetic silicone rubber and debossed with the abbreviations ***TM-ADEM-NMO-ON*** and ***www.myelitis.org***.

Many families have purchased these wristbands as party favors for birthday celebrations, fundraisers for raising research dollars, and to just proudly wear every day. Several people have sent us photos of themselves displaying their wristbands at known landmarks around the world. All of the money raised through the sale of the wristbands goes towards the cost of printing and mailing out the information that you receive in newsletters like this one, and for mailing out new member packets for those newly diagnosed with TM, ON, ADEM, and NMO.

The wristbands are inexpensive – only $2.00 each – and you can either order them online at our website, making your purchase with a credit card transaction, or you can mail a check to The Transverse Myelitis Association and when we receive your payment, we mail them to you.

To order online, please go to our website at: www.myelitis.org/wristbands.htm.

For check payments, please mail your payment along with your order request to:
The Transverse Myelitis Association
Sandy Siegel
1787 Sutter Parkway
Powell OH 43065-8806

Specify "for TMA wrist bands"

Shipping charges:
1-5 - $1.00
6-10 - $1.50
11-25 - $5.00

For quantities more than the above, please send an email. If you would like us to calculate your shipping for you, you can send an email to wristbands@myelitis.org and we will tell you how much to send. You can also call Debbie Capen at (951)658-2689 to get your total cost and more information.

Don't miss out on getting your own one-of-a-kind TMA wristband!

Donate your birthday to charity!

Use your birthday to change the world! We all get things we don't need for our birthdays; why not use this special occasion to raise money for a cause you really care about? Facebook has a feature that allows users to create a Birthday Wish and ask their friends to donate to the cause of their choice as a birthday present. Facebook also provides promotional tools, such as emails to friends, status messages, and more. To create your own Birthday Wish, go to ***http://apps.facebook.com/causes/birthdays/new***

In the step "Pick the cause you're raising money for" enter "myelitis" in the search box and select The Transverse Myelitis Association.

Thank you … and HAPPY BIRTHDAY!

Inkjet and Toner Recycling Program

The Transverse Myelitis Association has partnered with the Funding Factory Recycling Program to collect empty inkjet and toner cartridges. This is an important fund raising effort for the Association.

Please go to our web site at www.myelitis.org/recycle. Once you register, you can order pre-paid UPS return labels that you put on any box you have. When you fill in the information, use your own name as the "Organization" name, but also, **please use id number 63960 as the beneficiary. This ensures that the TMA**

will be receiving the benefits of the collected cartridges. When filling out the contact information, the form asks for a "title". You can list "other" and put "supporter" for your title. Once the company has your information and you request shipping labels, they will ship them to you to place on the boxes. Once the boxes are filled, you can take them to any place that picks up UPS packages (such as "Mailboxes, ETC.").

We appreciate your participation in this important program!

Donating by credit, debit, or gift card

The Transverse Myelitis Association is set up with several companies to securely process donations online using any credit, debit, or gift card with the following logos: Visa, MasterCard, American Express, Discover.

PayPal and Google Checkout are available to process donations from the United States and worldwide. Network for Good is only available to donors residing in the United States.

You can make secure donations online by going to ***http://myelitis.org/donations.htm.*** We greatly appreciate your support!

Medical Advisory Board

SUPPORT GROUP LEADERS

SUPPORT FOR WOMEN DURING PREGNANCY AND PRECONCEPTION
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AN ONLINE MAGAZINE FOR WOMEN IN WHEELCHAIRS
WENDY CRAWFORD
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The Transverse Myelitis Association is proud to be a source of information about Transverse Myelitis and the other neuroimmunologic disorders. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information and advice, consult a qualified physician. The Transverse Myelitis Association does not endorse medications, treatments, products, services or manufacturers. Such names appear in this publication solely because they are considered valuable information. The Transverse Myelitis Association assumes no liability whatsoever for the contents or use of any medications, treatments, products or services mentioned.

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Family Camp Victory Junction
October 6 - 9, 2011

Family Summer Camp August 1 - 5, 2012
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