❖Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

I had every good intention of getting this newsletter completed and mailed by the middle of July. Like the rest of you, I am searching for the great cosmic balance in life -- the full-time job, the part-time job teaching two courses for the university, being a parent to my two sons (19 and 17) who think they live on Yasgur's farm.... Having 50 kindergarten students offers Pauline ample opportunities to develop good strategies and patience for dealing with me. I apologize for the late publication and hope that it proves to be worth the wait.

This issue of the newsletter contains a wonderful article written about transverse myelitis as a collaboration of Drs. Levy and Lynn from The Ohio State University. We believe that you will find the information extremely valuable and we are most grateful for their contribution. As we are a new organization, we have some very exciting information to report about our Association. There are articles about our not-for-profit status, our new logo, the Transverse Myelitis Internet Club and a new web site for the TMA. The TMA members contributing to the *In Their Own Words* column provide us with some insightful and sensitive perspectives on their experiences with TM. There is an article reporting the progress of the TMA survey with a brief description of some results. Our first Treasurer's Report appears in this newsletter. There is also a new column called *Member Q&A* which will provide a forum for our members to share information through the newsletter. Finally, we have some important announcements regarding our Board of Directors.

Most of my work for TMA is devoted to responding to people who contact us looking for help -- information and advice. There is so much that needs to be done -- the newsletters, the brochure, the membership directory, the survey research -- but these contacts are a constant reminder about our purpose. To understand the nature of these contacts, you only have to think about your own fear, anxiety and concern when you were told that you or your family member had TM.

Over the course of the past eight months, I have received beautiful letters and phone calls from many of you. I am always touched by the kindness and compassion of our members. I would also like to thank all of you who sent postage and made financial contributions. Your generosity is greatly appreciated by all of us.

My greatest frustration is that we have wonderful offers of help from many of our TMA members and have not been able to marshal our resources to put these offers to good purposes. Deanne and I struggle with this issue often. This is one area where we know we need to improve and we will work to provide opportunities to put your energy, creativity, skills and experience to good use for the Association and for each other. I ask that you do not become discouraged when there is not an immediate acceptance of the offer for help -- and I ask that you continue to make that offer known to us. We will respond positively to these offers. There is much work to be done and many worthwhile projects to tackle. We are getting there, and in the meantime, we ask for your patience.

Pauline and I wish all of you the best; please take good care of yourselves and each other.

Sandy

Can it be that since our last (and debut) newsletter was distributed our "ranks" have more than doubled? It is gratifying that so many with the transverse myelitis diagnosis are finding our developing organization; at the same time, I am concerned that there are

Letter from the President
Deanne Gilmur

so many who are diagnosed and have received little immediate information or support from their medical providers. The need for information is, to a large extent, why we exist. I have been working on improving and updating the packet of materials that I send when we are first contacted by a person with TM. The Transverse Myelitis Association brochure has been completed and is now in the early stages of becoming "photo ready" for printing. In addition, the bibliography is being updated with only the most recent research articles included. Sandy has been working on the membership directory, amongst many other Association projects. The directory will be sent to all of our members and will also be part of our initial contact packet.

We welcome Debbie Capen as our new Secretary. We are very pleased to have Debbie as an officer of the Association and know that she will bring energy and creativity to the position! To the people who have generously offered to take on officer's positions or other TMA responsibilities, I believe I can speak for the entire Association -- we thank you very much and look forward to your assistance. I also want to thank those who generously made contributions to the organization. We now have an organization account in which all contributions have been deposited. We have also accomplished the filing of our 501(c)(3) application and we have learned that any contributions made to our organization since our founding date (November 25, 1996) are tax deductible (*see related article on page 7*).

Sandy and I continue to be contacted by many who are newly diagnosed (or family members) with TM. Each person has many questions, many of which I cannot answer. I know that we would benefit from each others' experience and information. So, I am asking that you send your questions to Sandy or me for inclusion in the upcoming newsletters. When you read the questions in the newsletter, if you know a response, please send it to Sandy or me and the responses will be included in the next newsletter. In this way, we hope to use the newsletter as a mechanism to share coping strategies and treatments.

Many persons are struggling with employers who may not understand the fatigue and discomfort associated with even a "recovered" TM condition. Please make sure you understand your rights under the Americans with Disabilities Act (ADA) and request accommodations as needed. Every state has a disability office; contact this office to find out how you might be assisted. This is an issue we will address in more depth and detail in a later issue of the newsletter.

September 26th marked the 4th annual get together of families in the state of Washington with a member diagnosed with TM. This get together was held at Camp Prime Time, located

on the east side of beautiful White Pass in Washington's mountains. This weekend retreat is a regular event that we hope more will enjoy with us in years to come. We encourage you to find those in your community who have TM. This search will be made easier with the publication of the membership directory in the near future. You can help each other by sharing information -- or by just being there for each other.

My best to all of you!!!!
Deanne

The following are the first questions to be included in our Member Q&A column. If you know answers to these questions, please send them to either Sandy or Deanne. Members' answers will be published in the next newsletter.

Member Q&A

1. What are the benefits and risks of cyclosporine?

2. Which medications have you taken that have been effective in treating pain you have experienced from TM? If you are taking medications in combination, please identify the combinations and also provide dosages. What other treatments (besides medication) have you used to effectively manage pain?

Transverse Myelitis

Charles Levy, M.D.
Joanne Lynn, M.D.

It is our great honor to announce that Dr. Joanne Lynn and Dr. Charles Levy will serve on the Transverse Myelitis Association Board of Directors. We look forward to working with Drs. Lynn and Levy and know that their participation in the Association will both greatly enhance our organization and result in invaluable contributions to our members.

Joanne Lynn, M.D.

Dr. Lynn is an Assistant Professor of Neurology at The Ohio State University. She received her medical degree from The Ohio State College of Medicine and then served residencies in internal medicine and neurology at Stong Memorial Hospital, University of Rochester. She then returned to The Ohio State University for fellowship training in neuromuscular disease. She is currently on the staff of The Ohio State University Multiple Sclerosis Center and has special interests in clinical research on the treatment of MS.

Charles Levy, M.D.

Dr. Levy is an Assistant Professor, Department of Physical Medicine and Rehabilitation at The Ohio State University. Dr. Levy also serves as the Directors of Orthotics and Prosthetics Clinic, Seating and Positioning Clinic, and Stroke and Orthopedic Rehabilitation of the Department of Physical Medicine and Rehabilitation at The Ohio State University. He received his medical degree from The Ohio State College of Medicine. Dr. Levy served his residency in Physical Medicine and Rehabilitation at the Rehabilitation Institute of Chicago, Northwestern University Medical School, Chicago, IL.

Transverse Myelitis: Symptoms, Causes and Diagnosis

Joanne Lynn, M.D.

Transverse myelitis (TM) is a neurologic syndrome caused by inflammation of the spinal cord. TM is uncommon but not rare. Conservative estimates of incidence per year vary from 1 to 5 per million population (Jeffery, et.al., 1993). The term myelitis is a nonspecific term for inflammation of the spinal cord; transverse refers to involvement across one level of the spinal cord. It occurs in both adults and children. You may also hear the term myelopathy, which is a more general term for any disorder of the spinal cord.

Clinical Symptoms

TM symptoms develop rapidly over several hours to several weeks. Approximately 45% of patients worsen maximally within 24 hours (Ibid.). The spinal cord carries motor nerve fibers to the limbs and trunk and sensory fibers from the body back to the brain. Inflammation within the spinal cord interrupts these pathways and causes the common presenting symptoms of TM which include limb weakness, sensory disturbance, bowel and bladder dysfunction, back pain and radicular pain (pain in the distribution of a single spinal nerve).

Almost all patients will develop leg weakness of varying degrees of severity. The arms are involved in a minority of cases and this is dependent upon the level of spinal cord involvement. Sensation is diminished below the level of spinal cord involvement in the majority of patients. Some experience tingling or numbness in the legs. Pain (ascertained as appreciation of pinprick by the neurologist) and temperature sensation are diminished in the majority of patients. Appreciation of vibration (as caused by a tuning fork) and joint position sense may also be decreased or spared. Bladder and bowel sphincter control are disturbed in the majority of patients. Many patients with TM report a tight banding or girdle-like sensation around the trunk and that area may be very sensitive to touch.

Recovery may be absent, partial or complete and generally begins within 1 to 3 months. Significant recovery is unlikely, if no improvement occurs by 3 months

(Feldman, et. al., 1981). Most patients with TM show good to fair recovery. TM is generally a monophasic illness (one-time occurrence); however, a small percentage of patients may suffer a recurrence, especially if there is a predisposing underlying illness.

Causes of Transverse Myelopathy and Myelitis

Transverse myelitis may occur in isolation or in the setting of another illness. When it occurs without apparent underlying cause, it is referred to as idiopathic. Idiopathic transverse myelitis is assumed to be a result of abnormal activation of the immune system against the spinal cord. A list of illnesses associated with TM includes:

Table: Diseases Associated with Transverse Myelitis

Parainfectious (occurring at the time of and in association with an acute infection or an episode of infection).

Viral: herpes simplex, herpes zoster, cytomegalovirus, Epstein-Barr virus, enteroviruses (poliomyelitis, Coxsackie virus, echovirus), human T-cell, leukemia virus, human immunodeficiency virus, influenza, rabies

Bacterial: Mycoplasma pneumoniae, Lyme borreliosis, syphilis, tuberculosis

Postvaccinal (rabies, cowpox)

Systemic autoimmune disease

Systemic lupus erythematosis
Sjogren's syndrome
Sarcoidosis

Multiple Sclerosis

Paraneoplastic syndrome

Vascular

Thrombosis of spinal arteries
Vasculitis secondary to heroin abuse
Spinal arterio-venous malformation

The cause of idiopathic transverse myelitis is unknown, but most evidence supports an autoimmune process. This means that the patient's own immune system is abnormally stimulated to attack the spinal cord and cause inflammation and tissue damage. Examples of autoimmune diseases which are more common include rheumatoid arthritis, in which the immune system attacks the joints, and multiple sclerosis, in which myelin, the insulating material for nerve cells in the brain, is the target of autoimmune attack.

TM often develops in the setting of viral and bacterial infections, especially those which may be associated with a rash (e.g., rubeola, varicella, variola, rubella, influenza, and mumps). Approximately one third of patients with TM report a febrile illness (flu-like illness with fever) in close temporal relationship to the onset of neurologic symptoms. In some cases, there is evidence that there is a direct invasion and injury to the cord by the infectious agent itself (especially poliomyelitis, herpes zoster, and AIDS). A bacterial abscess can also develop around the spinal cord and injure the cord through compression, bacterial invasion and inflammation.

However, experts believe that in many cases infection causes a derangement of the immune system which leads to an indirect autoimmune attack on the spinal cord, rather than a direct attack by the organism. One theory to explain this abnormal activation of the immune system toward human tissue is termed "molecular mimicry." This theory postulates that an infectious agent may share a molecule which resembles or "mimics" a molecule in the spinal cord. When the body mounts an immune response to the invading virus or bacterium, it also responds to the spinal cord molecule with which it shares structural characteristics. This leads to inflammation and injury within the spinal cord.

Vaccination is well known to carry a risk of the development of acute disseminated encephalomyelitis (ADEM) which is an acute inflammation of the brain and spinal cord. This was particularly common with the older antirabies vaccine which was grown in animal spinal cord cultures; the use of the newer antirabies vaccine grown in human tissue culture has almost eradicated this complication. This is also thought to occur as an immune system response.

Transverse myelitis may be a relatively uncommon manifestation of several autoimmune diseases including systemic lupus erythematosis (SLE), Sjogren's syndrome, and sarcoidosis. SLE is an autoimmune disease of unknown cause which affects multiple organs and tissues in the body. Features of this illness include arthralgias (joint pain) and arthritis (joint inflammation), rashes, kidney inflammation, low blood counts (including white and red blood cells, platelets), oral ulcers and the presence of abnormal autoantibodies (antibodies which are directed against the person's own tissues) in the blood. The fully developed syndrome of SLE is easy to recognize; however, this illness may begin with just one or two signs and is then more difficult to diagnose.

Sjogren's disease is another autoimmune disease characterized by invasion and infiltration of the tear and salivary glands by (lymphocytes) white blood cells with resultant decreased production of these fluids. Patients complain of dry mouth and dry eyes. Several tests can support this diagnosis: the presence of a SS-A antibody in the blood, ophthalmologic tests that confirm decreased tear production and the demonstration of lymphocytic infiltration in biopsy specimens of the small salivary glands (a minimally invasive procedure). Neurologic manifestations are unusual in Sjogren's syndrome, but TM can occur.

Sarcoidosis is a multisystem inflammatory disorder of unknown cause manifested by enlarged lymph nodes, lung inflammation, various skin lesions, liver and other organ involvement. In the nervous system, various nerves, as well as the spinal cord, may be involved. Diagnosis is generally confirmed by biopsy demonstrating features of inflammation typical of sarcoidosis.

Multiple sclerosis is an inflammatory autoimmune disease of the central nervous system (brain and spinal cord) which results in demyelination or loss of myelin (the insulating material on nerve fibers) with resultant neurologic dysfunction. A definite diagnosis of MS is not given until a patient has had at least two attacks of demyelination (hence, multiple) at two different sites in the central nervous system. The spinal cord is frequently affected in multiple sclerosis and may be the site of involvement of the first attack of MS. This presents the possibility that patients with acute transverse myelitis could later go on to have a second episode of demyelination and receive a diagnosis of MS.

Just what percentage of patients with a first attack of acute transverse myelitis will go on to develop MS is unclear in the medical literature, ranging from 15 to 80%; however, the majority of studies show a low risk. We do know that patients who have abnormal MRI scans of the brain with lesions like those seen in MS are much more likely to go on to develop MS than those who have normal brain MRIs at the time of their myelitis (between 60 and 90% for those with abnormal brain scans, less than 20% for those with normal scans in one study). It is also suggested in the medical literature that patients with "complete" transverse myelitis (which means severe leg paralysis and sensory loss) are less likely to develop MS than those who had a partial or less severe case. The literature also suggests that patients who have abnormal antibodies in their spinal fluid, called oligoclonal bands, are

at higher risk to develop MS subsequently.

Myelitis related to cancer (called a paraneoplastic syndrome) is uncommon. There are several reports in the medical literature of a severe myelitis occurring in association with a malignancy. In addition, there are a growing number of reports of cases of myelopathy associated with cancer in which the immune system produces an antibody to fight off the cancer and this cross-reacts with the molecules in the spinal cord neurons. It should be emphasized that this is an unusual cause of myelitis.

Vascular causes are listed because they present with the same problems as transverse myelitis; however this is really a distinct problem primarily due to inadequate blood flow to the spinal cord instead of actual inflammation. The blood vessels to the spinal cord can close up with blood clots or atherosclerosis or burst and bleed; this is essentially a "stroke" of the spinal cord.

Diagnosis

The general history and physical examination are first performed, but often do not give clues about the cause of spinal cord injury. The first concern of the physician who evaluates a patient with complaints and examination suggestive of a spinal cord disorder is to rule out a mass-occupying lesion which might be compressing the spinal cord. Potential lesions which might compress the cord include tumor, herniated disc, stenosis (a narrowed canal for the cord), and abscess. This is important because early surgery to remove the compression may sometimes reverse neurologic injury to the spinal cord. The easiest test to rule out such a compressive lesion is magnetic resonance imaging of the appropriate levels of the cord. However, if MRI is not available or the images are equivocal, myelography must be performed. A myelogram is a set of X-rays taken after a lumbar puncture has been performed either in the neck or in the low back and a contrast agent (dye) is injected into the sac that surrounds the spinal cord. The patient is then tilted up and down to let the dye flow and outline the spinal cord while the X-rays are taken.

If the MRI or myelogram shows no mass lesion outside or within the spinal cord, then the patient with spinal cord dysfunction is thought to have transverse myelitis or vascular problems. The MRI can sometimes show an inflammatory lesion within the cord. It is difficult to get to the cause of the inflammation, because biopsy is rarely done on the spinal cord because of the damage this would cause. The physician would next send blood for general bloodwork and studies for SLE and Sjogren's syndrome, HIV infection, vitamin B12 level to rule out deficiency and a test for syphilis. The next test which is commonly performed is a lumbar puncture to obtain fluid for studies, including white cell count and protein to look for inflammation, cultures to look for infections of various types, and tests to examine for abnormal activation of the immune system (immunoglobulin level and protein electrophoresis). A MRI of the brain is often performed to screen for lesions suggestive of MS. If none of these tests are suggestive of a specific cause, the patient is presumed to have idiopathic transverse myelitis or parainfectious transverse myelitis, if there are other symptoms to suggest an infection.

References

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Transverse Myelitis: Medical Specialists Medical and Rehabilitation Treatment

Charles Levy, M.D.

Medical Specialists

Anyone that has been diagnosed with transverse myelitis has probably dealt with a number of medical specialists. Below is a brief description of each specialist's orientation and sphere of expertise. Please note, this summary is intended to be full of generalizations. Any individual physician can take it upon her or himself to acquire a greater knowledge base and expertise. These "definitions" are my own, and I apologize in advance if I offend any of my professional colleagues. I, myself, am a physiatrist (*see below*).

Family practitioners are physicians who are trained to treat virtually anyone who might walk in the door of a doctor's office. Their training includes rotations in pediatrics, obstetrics and gynecology, emergency medicine, and internal medicine. The strength of this training is an ability to formulate a treatment plan for patients with a multitude of complaints. Often, family practitioners act as a kind of triage. Patients with routine complaints are treated and followed, but for patients with relatively uncommon diseases such as TM, a referral to a neurologist is often in order.

Internists are specialists in internal medicine. The scope of an internist's practice typically includes diseases of the heart, lung, liver, kidney, blood, digestive system, joints, and endocrine systems. Internists are trained to treat adults, and many will seek subspecialty training in a particular organ system. Like family practitioners, internists tend not to have advanced training in the neuromuscular system, and would typically refer a patient with TM to a neurologist.

Neurologists are specialists in the neurologic system. They study and treat diseases of the central nervous system (the brain and the spinal cord) and the peripheral nervous system (the nerves from the spinal cord to the muscles and the sensory nerves). Neurologists also treat some diseases of the muscle. The neurologist will often be the one called on to make the diagnosis of TM and determine if a cause can be found. If a specific cause can be found (i.e., a bacterial infection), then efforts are focused on fighting the root cause, if

possible (i.e., antibiotics).

Someone who is a specialist in physical medicine and rehabilitation is called a physiatrist. While other medical specialists aim at preserving and maintaining life, physiatrists are trained to preserve quality of life. When a neurologist examines the patient, he or she is trying to determine the cause of the disease with the hopes of prescribing a medical or surgical treatment. When a physiatrist examines the patient, he or she is trying to determine what the patient's ambitions, abilities, and limitations are. The physiatrist then tries to map a strategy to improve the patient's ability to function. Both neurologists and physiatrists typically prescribe medicines to alleviate symptoms, such as pain or spasticity; neurologists are trained to be experts regarding diagnosis and providing specific treatment. Physiatrists typically concern themselves with treating the problems brought on by loss of function, regardless of the diagnosis. They are expert at determining what kind of devices can make life and work easier (which brace, crutch, walker, reacher, wheelchair, etc. is needed). Physiatrists often consult and coordinate care delivered by physical, occupational and speech therapists, orthotists and prosthetists, psychologists, social workers and others. Physiatry is one of the smallest medical specialties with less than 6000 practitioners nationwide. Perhaps for this reason, physiatrists are a resource that is often overlooked in the treatment of people with debilitating diseases.

Medical and Rehabilitation Treatment

Medical treatment for people with TM can be divided into three phases. The first is the acute phase which might last from days to weeks. This phase begins when a person first falls ill. Typically, that person would go to a physician for help, and the medical community would try to discover what is wrong and try to fix it. If the problem was a broken bone in the leg, this process would usually be relatively simple. X-rays would be taken, and the bone would be set or casted, if needed. In the case of transverse myelitis, a person would probably be hospitalized and have lots of tests taken, including blood tests, magnetic resonance imaging (MRI's), or computed tomography (CT or CAT) scans. A "spinal tap" might be performed to analyze the cerebrospinal fluid. Depending on the seriousness of the illness, a catheter might be inserted into the bladder to help drain urine, and a breathing tube might be inserted to help with respiration. During this time, a cause might be found and specific treatment tried, or no cause might be found. In this case, sometimes intravenous (IV) steroids may be given. Some people will recover completely. Many others will be left with lasting deficits and will need help learning how to live their lives.

After the acute phase, people with TM enter a rehabilitation phase. During this time, the focus of care shifts from trying to find a cause and treatment to learning to live with a terrible disease. Two types of accommodations must take place. First, there is coming to terms psychologically. Here a person might feel the stages of grieving as if someone had died. The loss that a person with TM feels is real. Abilities that all healthy people take for granted vanish. Even the simplest tasks become effortful. Feelings of sadness, rage, grief, remorse, and guilt are not unusual. The task confronting the person with the disease is to rebuild his or her life. Most people base their self-worth, value, and satisfaction in living, at least partially, on what they are able to accomplish every day. When a person's self-sufficiency and independence are damaged, that person must rebuild an identity that allows the person to feel proud and whole from a new set of standards. Likewise, the family and loved ones are challenged to rebuild their relationship to the injured person. This can be excruciatingly difficult, yet many

people accomplish this successfully. Despite the multitude of sorrows, there are often unexpected joys, such as finding support from those who were thought unsympathetic or unavailable, and finding talents that were hidden. Although I am not disabled myself, it is my impression that this accommodation is a lifelong task. Resources that might make this adjustment easier are psychological assistance from a counselor, discussions and meetings with religious leaders and congregations, and making contact with other people who have experienced the same or similar disease or injury.

The second set of adaptations is physical. I am not aware of medical literature specifically dealing with rehabilitation after transverse myelitis. However, much has been written regarding recovery from spinal cord injury (SCI), in general, and I think that this literature applies. The physical issues include bowel and bladder management, sexuality, maintenance of skin integrity, spasticity, activities of daily living (i.e., dressing), mobility, and pain.
Of primary importance is the level at which the spinal cord has been injured. The spinal cord is typically divided into four sections: the highest is the cervical (neck) region; then in descending order are the thoracic (chest), lumbar (low back), and sacral (lowest back) regions. Nerve roots exiting the cervical cord carry messages from the brain to the arms, thoracic to the chest and abdomen (i.e., the belly), lumbar to the legs, and sacral to the leg below the knee and bowel, bladder, and sexual organs. Because the nerves must travel through the spinal cord to connect with the brain, an injury to the spinal cord at a particular level usually effects function at that level and below. Therefore, a person affected at a specific thoracic level would typically have function disrupted in trunk balance (the thoracic nerves), as well as problems with leg movement and bowel and bladder control which are supplied by the lumbar and sacral regions of the spinal cord.

The bladder is controlled by nerves exiting the low thoracic, high lumbar, and mid sacral spinal cord. Bladder function may thus be impaired in SCI. Two general problems can affect the bladder. The bladder can become overly sensitive, and empty after only a small amount of urine has collected, or relatively insensitive, causing the bladder to become over extended and overflow. An overly distended bladder increases the likelihood of urinary tract infections and, in time, may threaten the health of the kidneys. Depending on the dysfunction, treatment options include timed voiding, medicines, external catheters for males (a catheter connected to a condom), padding for women, intermittent internal catheterization, or an indwelling catheter. Surgical options may be appropriate for some people.

A common problem in spinal cord injury is difficulty with evacuation of stool, although fecal incontinence can also occur. The neurologic pathways for defecation are similar to those of the bladder. Many lacking voluntary control of the bowel may still be able to achieve continence by diet, strategic use of stool softeners and fiber, and the technique of rectal stimulation. In rectal stimulation, a finger is inserted into the rectum to cause the internal and external anal sphincters to relax allowing the stool to pass. Other aids include suppositories and oral medications. There are some surgical options, although this is rarely necessary.

Sexuality is a complex issue. The bad news may be that sexual experience is impacted by spinal cord injury. Genital function is often altered (i.e., difficulties with erection and ejaculation for men and difficulties with lubrication for women). The good news is that sensual experience and even orgasm are still possible. Lubricants and aids to erection and ejaculation (for fertility) are available. Many individuals with SCI find unexpected erogenous zones. Ultimately, sexual experience happens in the brain, not in any specific organ. Adjustment to altered sexuality is aided by an attitude of permissive experimentation, as the previous methods and habits may no longer serve.

At The Ohio State University Medical Center, a

nursing clinic is dedicated to provide practical help in matters of bowel, bladder, and sexuality for people with disabilities.

Skin breakdown occurs if the skin is exposed to undo pressure for a sufficient amount of time. Skin integrity is maintained in people without disabilities by two related mechanisms. First, the able-bodied have sensation, so that if they sit in one position for too long, they get uncomfortable. Secondly, they have the strength to shift position as necessary. Either or both of these mechanisms can be impaired in SCI. Sitting position should be changed at least every 15 minutes. This can be accomplished by standing, by lifting the body up while pushing down on armrests, or by just leaning and weight shifting. Wheelchairs can be supplied with either power mechanisms of recline or tilt-in-space to redistribute weight bearing. A variety of wheelchair cushions are available to minimize sitting pressure. Redness that does not blanch when finger pressure is applied may signal the beginning of a pressure ulcer. Good nutrition, vitamin C, and avoidance of moisture all contribute to healthy skin. Pressure ulcers are much more easy to prevent than to heal.

When the spinal cord is injured, muscle groups below the level of injury may become spastic. This manifests as stiffness and resistance to movement. They may also become hyper-reflexic and jerk when touched or hit. The cause of this is not fully understood. The management of spasticity must always be based on the person's function. For example, some people with TM will use the spasticity in their legs to help them walk. If this is treated, they may lose this ability. In contrast, someone whose spasticity prevents them from sitting in a wheelchair must be treated. If there has been a recent increase in spasticity, it is important to search for a cause. Noxious stimuli such as ingrown toenails, urinary tract infections, bowel impaction, kidney or gallbladder stones must be suspected.

Medical treatment of spasticity centers around four medications. Baclofen (Lioresal) is thought to inhibit reflex activity. It is considered the drug of choice for spasticity due to spinal cord injury. It is generally well-tolerated although it can be sedating. Abrupt discontinuation of baclofen can cause seizures and hallucinations. Diazepam (Valium) works by a similar mechanism, but is more likely to be sedative, and has been implicated in slowing recovery from brain injury. Dantrolene sodium (Dantrium) affects the muscles directly. While it is considered to be the drug of choice to treat spasticity due to brain injury, it may also play a role as an adjunct in the treatment of SCI spasticity. Tizanidine (Zanaflex) is a new drug to the US, but has been available in Europe for a long period of time. It reduces spasticity by a different mechanism than baclofen or dantrium and is generally well tolerated. Because it is more expensive than baclofen, and because most US physicians have less experience with it, it usually would not be the first choice.

Individuals with TM may find ordinary tasks such as dressing, bathing, grooming, and eating very difficult. Many of these obstacles can be mastered with training and specialized equipment. For example, long handled sponges can make bathing easier as can grab bars, portable bath seats and hand-held shower heads. For dressing, elastic shoe laces can eliminate the need to tie shoes while other devices can aid in donning socks. Occupational therapists are specialists in assessing equipment needs and helping people with limited function perform activities of daily living. A home assessment by an experienced professional is often helpful.

Physical therapists assist with mobility. Besides teaching people to walk and transfer more easily, they can recommend mobility aids. This includes everything from canes (single point vs. small quad cane vs. large quad cane) to walkers (static vs. rolling vs. rollator) and braces. For a custom-fabricated orthotic (brace), an orthotist is necessary. Careful thought should go into deciding whether the brace should be an ankle-foot orthosis, whether it should be flexible or stiff, and what angle the foot portion should be in relationship to the calf portion. Some will benefit by a knee-ankle foot orthosis.

Each person should be evaluated individually. I believe that the best results occur when the team is coordinated by a physician so that the therapists and orthotists are united with the patient on what is to be achieved. The physician best trained to take this role is the physiatrist.

Pain is common following SCI. The first step in treating pain effectively is obtaining an accurate diagnosis. Unfortunately, this can be very difficult. Causes of pain include muscle strain from using the body in an unaccustomed manner, nerve compression (i.e., compression of the ulnar nerve at the elbow due to excessive pressure from resting the elbow on an armrest continuously) or dysfunction of the spinal cord from TM. Muscle pain might be treated with analgesics, such as acetaminophen (Tylenol), non-steroidal, anti-inflammatory drugs such as naproxen or ibuprofen (Naprosyn, Alleve, Motrin), or modalities such as heat or cold. Nerve compression might be treated with repositioning and padding (i.e., an elbow pad for an ulnar nerve compression).

Nerve pain from the spinal cord is sometimes called "dysasthetic pain". Because of the SCI due to TM, nerve messages traveling through the spinal cord may become scrambled and misinterpreted by the brain as pain. Besides the treatments listed above, certain antidepressants such as amitriptyline (Elavil), or anticonvulsants, such as carbamazepine, phenytoin, or gabapentin (Tegretol, Dilantin, Neurontin) may be helpful. Stress and depression should also be addressed since these conditions make pain harder to tolerate.

This brief overview is not meant to include all possible areas of concern. I am grateful for the editing provided by Cindy Gatens.

Dr. Lynn and I would both be happy to entertain specific questions in the future. Please send your questions to Sandy Siegel either by postal service or e-mail, and he will pass the questions on to Dr. Lynn and I. We will attempt to provide you with answers to your questions in the next TMA Newsletter.

During the process of preparing to file Form 1023 for "Recognition of Exemption Under Section 501(c)(3) of the Internal Revenue Code" for the Transverse Myelitis Association, it was brought to my attention that the association is already considered an exempt organization. According to IRS information, an organization like ours that has incorporated, has an Employer Identification Number (EIN), and has gross receipts in each taxable year of normally not more than $5,000 is considered tax-exempt under Section 501(C)(3) even if the organization has not filed Form 1023. Since our organization has gross receipts less than $5,000, it is not required to file Form 1023 to be tax-exempt. However, an organization that has not filed Form 1023 and received a "determination letter of IRS recognition of its 501(c)(3) status", can not promote public recognition of the fact that it is a tax-exempt organization.

So, what does this mean, you might ask. Well, it appears that it means that any contributions that have been made to the association are, in fact, deductible. But, we can not promote the association as a tax-exempt organization.

Tax-Exempt Status Update

Dick Gilmur

By filing Form 1023, an organization like ours can receive a "determination letter of IRS recognition of its 501(c)(3) status" which then enables an organization to obtain certain incidental benefits, such as public recognition that it is a tax-exempt organization, providing advance assurance to donors of deductibility of contributions, non-profit mailing and other privileges. This past summer the necessary forms were filed with the IRS. To date, we have not received the "determination letter of IRS recognition". Therefore, we can not promote the association or seek benefit from public recognition of the fact that we are a tax-exempt organization.

An interesting bit of information from the IRS states that "Generally, if an organization files its application within 15 months after the end of the month in which it was formed, and if the IRS approves the application, the effective date of the organization's Section 501(c)(3) status will be the date it was organized". This is to let you know that these steps have been met in that the organization was incorporated or formed on November 25, 1996, and the necessary forms were filed on June 25, 1997. Therefore, the expectation is that we will receive the "determination letter of IRS recognition" and that will make us a tax-exempt organization with bona fide 501(c)(3) status since our founding date. Stay tuned.

AN UPDATE TO TMA STATUS...

On September 11, 1997, the IRS issued its determination letter. The Transverse Myelitis Association is now formally considered exempt from federal income tax under section 501(a) of the Internal Revenue Code as an organization described in section 501(c)(3). Due to the generosity of our members, the Transverse Myelitis Association has an account balance of $727.22. There have been no Association expenses that have been drawn against this account; Deanne and Sandy have been paying for all of the printing, postage and telephone costs of the Association.

As you are aware from Dick Gilmur's article about the 501(c)(3) process, the TMA is now a not-for-profit organization and your contributions are tax deductible. There are no membership dues required of TMA members, and we would like to maintain this policy for the Association. It is our goal to have sufficient funds to perform the work of the Association through voluntary contributions and some form of institutional funding.

If you are interested in making a contribution to the Transverse Myelitis Association, please make your check to the Transverse Myelitis Association and mail it to Paula Lazzari, Treasurer, Transverse Myelitis Association, 10105 167th Place NE, Redmond, WA, 98052. We greatly appreciate your generosity!

Treasurer's Report

Paula Lazzari

The Transverse Myelitis Association Logo

Sandy Siegel

A logo is a symbol; the meaning embodied in that symbol concerns how the organization would like to be perceived by those who view it. How organizations are identified by these symbols is an important matter. All one has to do is consider "the golden arches" or "Elsie the cow" to be convinced of the power of these symbols. So, when we thought about how we wanted to be perceived, we gave careful consideration to the symbol we wanted to use as a representation of the Transverse Myelitis Association. The image in the corner of our logo is a compass. We could have used a question mark. All of us have been through the process of asking questions about TM. The vast majority of our members heard the words "transverse myelitis" for the first time when they were being told that this was their diagnosis. What is it? Is there a chance that anyone can catch this from me? Can my children inherit it? Am I going to recover? Is there a chance that I could have another episode? How many other people have TM? Where are they? What causes TM? Is there a cure for it? Are there any treatments for it? We have all been through these questions -- and many more. And many of these questions remain unanswered or we have ambiguous answers. So, a question mark would have been a reasonable choice. But not a very positive choice.

A compass is an instrument that provides direction. The word "compass" also has several meanings, one of which is "to grasp mentally, understand, comprehend." Another is "to reach successfully, achieve, accomplish." A compass is a wonderful symbol for the Transverse Myelitis Association. It is our fervent hope, our commitment to our members and our fundamental goal to assist you on your search for answers -- so that we can all more fully understand TM. The Association will work to provide information to our members about TM and will be advocates for people with TM on many issues. We will assist you in finding each other so that you can offer each other both information and emotional support and encouragement. And we will work to encourage medical research on transverse myelitis. You are not alone. It is the goal of TMA to provide you with direction and guidance through this journey.

My name is Kerry DeFilippo. I am a 30 year old married male with two children. Amanda is five and Timothy is three. I am employed as a fleet service clerk (ramp work) with American Airlines at O'Hare Airport in Chicago. My wife, Joan, is also 30, stays at home with our children full time and cares for other children, as well.

I was diagnosed with Transverse Myelitis on Christmas Day, 1995. My symptoms began on December 17, 1995. I had a tight band feeling around my waist. Upon visiting my primary care physician the following day, he referred me to a neurologist. The neurologist asked several questions and gave me a thorough physical exam. He scheduled a MRI to be done the following week. Within three days, the tightness traveled down to my feet, and the only sensation that I was able to feel was extreme cold in my feet. I was sent to the ER and had a MRI done that showed a lesion at the T-2/T-3 level. I was given the option to stay in for a five day treatment of IV steroids, or go home for the holiday and return the following Tuesday for the five days. Given the prognosis of the sensation probably staying where it was, I opted to go home. Unfortunately, the prognosis was wrong; the sensation had moved up to my chest. I had no feeling from midchest down to my feet. I was admitted on December 24, and a spinal tap was done on December 25. This confirmed the doctors' suspicion of Transverse Myelitis.

I cannot say that I was ever in "pain", however, I was very uncomfortable throughout the

In Their Own Words

In each issue of the newsletter, we will bring you a column which presents the experiences of our members. Their stories are presented ***In Their Own Words*** by way of letters they have sent us. We are most appreciative of their 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. You may submit your stories by sending them either by e-mail or through the postal service to Sandy Siegel.

Kerry DeFilippo
Chicago, Illinois
January 13, 1997

hospital stay and for a few weeks beyond. I was in the hospital for five days, during which I received IV steroids once a day. I did not need any other treatments, such as physical therapy or antibiotics. The doctors felt that my onset of the illness was about six weeks prior to the loss of feeling. I thought I had a sinus infection, however, looking back, I realize it was a viral infection. I had been extremely tired and run down for about a week. I did not go to the doctor, because I figured he'd tell me it was viral and to wait it out. This is the only thing that they can trace my onset to. I have been told that if the loss of feeling ever does return, it won't necessarily follow a "virus"; it may just occur at any time, if it does at all.

I have been diagnosed with Acute Transverse Myelitis, and in March I was diagnosed with Carpal Tunnel Syndrome. This was a "good" diagnosis; the neurologist felt that if I didn't have CTS, it could be early signs of Multiple Sclerosis. I have been told by my neurologist and a neurologist that I visited for a second opinion, that Transverse Myelitis may lead to Multiple Sclerosis in some patients.

After my visit to the neurologist in March, 1995, I regained much of my feeling, all except in my left foot. I have limited feeling there. I am experiencing many of the initial symptoms on a "here and there" basis. These include a burning sensation in my back, shocking sensations down my back and periodically down my thighs. I am still extremely tired on most days, seemingly for no reason. I have trouble doing certain things like video taping. Any consistent movement or holding my hands still bothers me. I am able to work, and I recently gutted my kitchen and remodeled it completely. The neurologist and I both feel that getting back to a "normal" life is very important. He stated that doing my carpentry work that I enjoy doing is probably not the "best" thing in the world to do, however, I cannot sit by and watch my illness stay in remission or progress. Therefore, I take things very slowly. This was a hard adjustment to make, but it is worth it in the long run. Things such as cutting the grass are done by my wife, whereas, I used to do that. She feels that there is no need to do things that she can do instead.

As far as treatment goes, I would not take the steroids again. I do not feel that they were effective in any way with this occurrence. I do take pain medication when necessary. I have used Aleve and Naproxyn. I sleep when I need to, take it easy when my body tells me to, and basically let my body tell me what's happening.

I have since had another MRI in December, 1996. My lesion has shrunk a bit. I have been tested for Sleep Apnea, possibly related to TM.

I am very lucky that I was not affected as badly as others have been. I was always able to walk, which many others are not able to do. I realize that I may be affected again, at any time without warning. I also realize that I may never be affected again. I am hoping for the latter. I was concerned about my children developing this and their pediatrician and my neurologist have both assured me that it is not inherited, however, immune systems are. There is no way to know if they will or not, so it is not something that I can let occupy my mind. One thing I have learned from this is definitely live for today.
This illness began in a small town in S. W. New Hampshire where we spend our summer at our daughter's house. She was having her first child and I was there to help. On April 12, 1996, three days after the birth in the later afternoon after shoveling some very light snow during which my back was hurting a little, I entered the house. Up to then I was in very good health and had never broken a bone.

> *I was diagnosed with Transverse Myelitis on Christmas Day, 1995.*

As I walked across the room, my legs started bending in different directions, and I thought it might be leg cramps. Later, there was some numbness around the navel, but mostly a crazy walk. I went to bed as usual, got up about one o'clock to go to the bathroom, and I stepped on my left leg. It was as hard and stiff as a board, and I fell, breaking my left femur.

After four days in a small hospital for repair of the fracture, my lower body was numb, with weakness in my legs. Following a consultation with a neurologist, I was sent to Dartmouth-Hitchcock Hospital where an MRI and lumbar puncture were performed. The spinal fluid showed no disease, but the MRI showed a lesion at T8-10 level of the cord. There was no evidence of a tumor, and transverse myelitis was suggested. Another MRI a week later showed no change. The diagnosis was "lower thoracic myelopathy: spastic paraparesis" or transverse myelitis. Seventeen days later an MRI showed a normal thoracic cord.

After eight days in acute care I was transferred to a rehab hospital where I had comprehensive treatment for five weeks at a wheelchair level, learning to use a walker the last week. My right leg was quite strong except for some buckling. That soon stopped. The left was paralyzed. Spasms in the left were very painful probably because of the tender hip - leg incision. Spasms continued nightly in the right foot. After about five months, spasms decreased. Cold weather made them worse. Now, ten and a half months have passed, and I seldom have any.

Marie U. Walker
Garner, North Carolina
February 26, 1997

I also had pain in my left foot, instep and heel, especially at night. An X-ray showed no fracture, and pain disappeared in about three months. My lower body is numb from the level of my navel to my toes, more so on the right side. Also, on the right I do not feel pain or temperature, such as hot water in a shower. On the left leg there are unpleasant sensations: when touched or rubbed it reminds me of sandpaper or sunburn; when touching metal it feels like a cut in the skin. The toes on my left foot do not spread out; however, swelling in both legs and feet have disappeared. Proprioception (activity of special receptors in joints telling where limbs are by touch and

pressure) is diminished in the left leg and foot. I have tenderness in my left back between the lower thoracic and upper lumbar area.

I continued therapy as an outpatient twice a week, once land, once pool, and my husband continued the mat therapy and standing exercises, which therapists have added; now I do most of these on my own. In the 10th and now 11th month I have had therapy only once a week, strengthening the left leg using various apparatus, improving my gait and balance, and walking with a cane. However, I continue with pool exercises two or three times a week which I highly recommend. It's a joy to be able to walk in the water! Great exercise! My left leg has recovered miraculously. I can stand on it and move it in all directions almost at full range.

Bladder and bowel sphincter control is lost. For bladder control I "go" at timely intervals; if I can feel a "stretching" or fullness, I must hurry. At night when I first got home, I had a commode next to the bed, but because of the weak leg I often couldn't get to it in time. The bladder is so full that upon sitting or standing gravity takes over. Finally, I thought of diapers; no one mentioned these in rehab, and they had not occurred to me. Now that I am so much stronger, I use a female urinal at night. I have two, one for late night and one for early morning. No one mentioned these either in rehab. They work very well.

As for bowel hygiene, when I feel fullness, I must hurry. Sometimes it's necessary to help digitally, but that's not necessary when I have enough fiber in my diet.

I have been deeply inspired by Chris Reeve, especially the article, "New Hopes, New Dreams," in Time Magazine, August 26, 1996, pp. 40-52 by Roger Rosenblatt. Chris energetically supports research for spinal cord injuries and related diseases and works to raise money as well as public awareness. He has the courage to carry on with hope for the future. People with transverse myelitis can have hope, too.

Richard Boyle
Ohio
February 19, 1997

My name is Richard Boyle. I am 52 years old with Transverse Myelitis. On July 3rd I had the symptoms of a very bad cold. Sneezing, runny nose and whatnot. On July 7th, I began to limp. On July 10th, I began to drag my right leg, and on the 14th I was in the hospital. They had me on a Solumedrol drip for five days. At that time I developed a problem with my bowels, but no problem with my urinary tract. They tested me for MS. That was negative. They did a lumbar puncture. That was negative also. I was released after seven days and sent to another hospital for therapy. I was still able to use my left leg pretty good, but was still dragging my right. After seven days in the other hospital, I began to limp on my left leg. I was getting worse. I figured if I was going to die, let me die at home. So, there I went.

Eventually, I lost all control of my bowels. My wife couldn't take it any more, so I was admitted to the Cleveland Clinic where I was diagnosed with TM by Dr. Richard Ransohoff. I spent eight days there, and was sent home to a rehab center where I spent 41 days. I plateaued there and was sent home. While I was at the rehab center, my wife decided to leave me, and I have been alone since. That was five months ago. I have been going to Easter Seals for the last three months, and have improved some. Of course, it's not fast enough for me. I wear an AFO on my left leg, and have pretty good mobility. I have regained about 25% of my right leg. I don't drag it anymore; I can lift it, but not too well. I wear a KFO on that leg, but only sometimes. I don't wear it all the time as I used to. I have a friend who is into natural foods, and I have been taking Echinacea, black currant oil, Chlorophyll, Coenzyme Q10 10 mgs., Psyllium husks for fiber, Aloe Vera juice 2 ounces, Pancreatic Enzyme for digestion, along with the Docusate stool softener. The first four I mentioned are for nerve regeneration and muscle regeneration, and I personally believe they are helping. A good solid determined mind is also a great asset. I continue to improve slowly, but I refuse to quit. Seven months ago, I couldn't walk; now, I can with certain aids. So, to me, it's worth the effort.

Water therapy helps immensely. What I can't do too well outside the water, I can inside the water. I walk in five feet with no help, and in three feet I have taken eight steps without holding on to anything. It's getting progressively better. I hope what I have shared with you can be of some assistance to someone somewhere. It can't hurt. What I take is all natural stuff.

Mae Louise Clayton
Colorado Springs, Colorado
January 19, 1997

Hello, Transverse Myelitis Victims. My name is Mae Louise Clayton, age 71. I've lived in Colorado Springs for 33 years. My medical history is nothing to be desired during this period of time. I had cancer in 1962 removing all my female organs except one ovary. In 1972 I had a bleeding ulcer and they had to remove 3/4 of my stomach. I started having back problems in 1976 with deteriorating disks. After six back operations, things began to look up. In the late '80s, I did a series of 12 acupuncture treatments to keep the pain down. I was getting much better and back to a normal life. But in October '95 I started dragging my right foot as I walked. I was sent to the hospital. I took an MRI and it showed it was a mild stroke. On January 7, '96 I tried to get up and pull myself out of bed and my legs buckled and I tried to grab the bed spread and couldn't with my hands. At this time, the doctors here thought it was a certain drug causing this condition. That was not the case after further investigation. Now I've been diagnosed with the disease called Transverse Myelitis. This is my story about it and how it has effected my life and others.

This is nothing I ever dreamed about. I did learn there are others in every part of the country who have it, too, in some form or another. At least I know I'm not alone with this dreadful disease. I have it in my arms, hands, legs and feet and also my hips. My legs feel sometimes like they have tight bands around them and that I am trying to get out of them because they're so tight. My hands feel like sand all the time and ache constantly. If I was to rub your back, I would be thinking I was rubbing sand on your back. The way the doctor explained it to me is that it's just like someone severed all the nerves in my spine. They go every-which-way and sometimes they feel like they're going to tear right out of my back. My legs below my knees feel so heavy sometimes. I can hardly lift them at all. It's the nerves in there that's damaged and making it feel that way. I'm taking PT as an out patient. I go two times a week. They put my hands in a whirlpool and it makes them feel so good. I can stretch my finger out afterwards, but then in an hour or so, my hands get tight and start feeling like sand and hurting again.

If I'm not looking at my feet when I move them, I don't know where they are. They play tricks on me. As long as I'm looking at them, I can set them there where I want them to set. Also, in my fingers, when I pick up anything, I can't tell what is in my hands unless I see it. If I'm looking at it, I can pick it up and if I'm not looking, no use in my trying to pick it up. Having this myelitis in my hips makes me feel like when sitting on a stool or chair without a ball or something. I can't sit steady on it. I've fallen twice. My husband or someone still has to help put me over into the shower and help me get into the tub. I have one of those shower stools (I wobble on it, too). I sit on it after I get in there. I have to have help in order to get out. Even with all the grab bars my son-in-law and son put in, I still have to have help.

Test after test was made this past year at three different hospitals trying to find out what was wrong with me and why I was feeling this way. About a month ago, they found out what it was. At the first hospital, they thought it was the polio syndrome coming back on me (I had polio when I was a young girl). That was ruled out. But then they came up with perinthal neropathy. I was treated for this for 37 days in Penrose Hospital with PT and medication. Things were working out pretty good with the occupational therapy and PT. They helped some, but not enough. After 37 days of treatment and PT, they let me come home. I was not satisfied with the results I was getting so I wanted to get a second opinion. I went to the University hospital in Denver and saw a Dr. Wright. After being treated up there for a while, they decided they did not know what was wrong with me. I had them all puzzled. I took test after test, different kinds of tests trying to find out what was wrong. But they could not find out what was causing this condition and that is when they suggested the Mayo Clinic. Dr. Wright set up an appointment for me at the Mayo Clinic at the neurological center in Rochester, Minnesota. Finally, on November 7, I had my first appointment at the Mayo Clinic. I consulted with Dr. Sorenson, one of the nicest doctors you could ever want to have. Cliff, my husband, and I stayed in a motel and we would go up to the Clinic every morning about 7:30 and they would put me through many kinds of tests each day. It was for a week and on Friday that's when I had a consultation with Dr. Sorenson. That's when he told me that there's nothing they could do for me. He did tell me he knew what I had, but there was not a treatment for it. That's when he told me I had Transverse Myelitis. I never heard of it. He went on to explain where all the nerves in my spinal cord were damaged or inflamed.

It has taken me quite a while to get over the shock of hearing that I will never be well again or never walk again and never use my hands unless a miracle happened. He also said trying to surgically correct the problem may cause more damage than I have. Our whole lives have changed. I've talked to people who have it (myelitis) in just their feet and legs, but never in both hands, feet and legs. I have what you might call a "triple dose." We just live it one day at a time and see what happens. Some days I hurt so much I want to just throw up my hands and quit, but I can't give up. I've got to go on. There's so much to learn about this rare disease. I can't stop now. Now I'm confined to a wheelchair 100% of the time. I can transfer from my wheelchair to a seat or my bed, but it is very difficult for me. My family made some adjustments to our home to assist me to exist in my home. We installed grab bars, ramps on the front porch and in our den and built a platform to make a chair higher for me to transfer easier. Cliff is now shopping for a special van that will accept wheelchairs. My condition is so different from all the ones I've read in Transverse Myelitis magazines, newspaper clippings or on the internet. This condition has nearly covered my whole body. From my elbows to my finger tips. Then from my waist down to my toes. My bowels and kidneys function on their own (so far). I didn't know there was such a disease as Transverse Myelitis until they said I had it and requested information from NORD. I hope this letter will be helpful to someone who has Transverse Myelitis. I also would welcome any comments from anyone who has Transverse Myelitis. Please call or write me anytime. I would like to discuss how you got it, to what extent you have it and how you are coping with Transverse Myelitis.

Mae Louise Clayton
1707 Bates Drive
Colorado Springs, Colorado 80909
(719) 596-3261

I was sitting at my desk one day while operating my computer. Tennis was on my mind as I had a hot game scheduled that night. My left arm began to feel numb and my right leg felt like it was going to sleep. My right foot began to feel warm. I sat back from the computer and began to self diagnose all of this. I must admit that the thoughts that ran through my head began to make me sweat with anxiety.

I called a friend of mine that is a doctor in the local hospital emergency department and asked him if he thought that I was having a heart attack. He said, "no", but that in his opinion, I should drive over to my regular doctor and get him to check me out. I called my doctor's office and inquired about seeing the doctor and was told that the earliest that I could see him was the next day. I explained to this doctor's nurse that I might be having a heart attack and really needed to be seen sooner. The nurse told me to come on down and that she would work me in. I shut down the computer, and headed to the doctor's office in my car. On arrival, I had difficulty walking straight and I was concerned that I might even look like I had been drinking. Since it was only 11:00 AM, I was not entirely comfortable with the fact that I might be seen staggering into the doctor's office. I walked as straight as I could and spoke to several people that I knew on the way in.

The doctor saw me in short order and gave me a few simple coordination tests, i.e., finger to nose, knee reflex, etc. He was baffled but interested. Further observation and tests were needed. He wrote up an order for me to be admitted to a local hospital and told me to drive over to the hospital and check myself in. My control was getting worse, but I could still walk and drive.

I tried to contact my wife to let her know what I was doing, but her voice mail was full and I was unable to make contact or leave her a message.

Once I got to the hospital and went through the admitting process, they began right away to put me through many tests to include cat scan, MRI, Doppler studies, blood work and several other tests. My condition was definitely getting worse as I was having difficulty moving my arms and legs at all. I was definitely worried about losing the ability to breathe on my own as I became paralyzed totally from my neck down (except my lungs).

I asked the nurse to call my brother who worked nearby as I really thought that I might be on the way out of this world. My brother showed up shortly and his presence had a great calming influence on me. We were actually able to joke and laugh to relieve tension. My brother remained with me until well into the night and until my wife could be located and informed that something was amiss.

Sometime during the testing in the afternoon, a small spot was located on my spinal cord at C-3 in one of the MRI scans. A neurologist was consulted and I was put on high doses of steroids to hold down swelling and inflammation of what appeared only as a dark spot about the size of a BB on my spinal cord.

I was put in intensive care and constant check was made to insure that I could continue to

Anonymous Male 50s
February 20, 1997

breathe on my own. I could move nothing except my neck and head. I could talk, smile, blink my eyes, and even wiggle my ears, but I could not raise my finger, wiggle my toes, or move anything from the neck down.

I remained in intensive care and on steroids for a week although I did get stepped down to less intensive degrees of intensive care during the week.

During my first week I felt like I was floating in space, as I could not feel the bed under me. My mind was very alert as I could not feel my body and did not have any of the usual aches and pains to think about. This allowed me some time of intense concentration and thinking. I actually had a religious vision, which was my

first and last so far. Looking back on the religious vision, one has to wonder if the steroids didn't help it along. The "vision" provided me with a great deal of comfort.

This was obviously a very emotional time for me. How can you "lose it all" and not be emotional? In fact, now at 23 months since it happened, I still get emotional about it.

After my first week I was moved to another hospital noted as "rehab." It was great just to see the sunlight as they hustled me into the ambulance and strapped me down. I was on an adventure although I was totally helpless. Once in my new environment, I was checked in and given a corner room. The people at the hospital were great. They literally took care of my every need. They smiled and laughed and offered all sorts of encouragement.

My family would come in and ask me to move my toe or my finger, but I could move nothing. My 13 year old son came to visit me and was delighted to be able to tell me that he had just gotten a 54 on his English test and didn't have to worry about me strangling him in retribution.

After a couple of days in rehab., I noticed that I could just barely move one of my right toes. I could not ring for the nurse. This concerned me and I did panic occasionally when I wanted someone to help me, but had no way to call for help. This was noticed and the call button was placed under my head so that I could move and use my head to push the call button. I also rang the call unintentionally several times.

As days passed, I began to move other fingers and toes. I actually could raise my knee about an inch off of the mattress after a week in rehab. After two weeks in rehab (three weeks from ground zero) two young women came in to see me about getting started on physical therapy. This was all new to me. My attention thus far had consisted of being fed and changed by the nurses.

The women from physical therapy cranked up my bed making me sit up. I immediately felt faint and they cranked me back down. Apparently, when you are paralyzed, the muscles that hold up your blood pressure do not work, so upon testing it was discovered that by raising or lowering the head of my bed, my blood pressure would change thirty points. This, I was assured, was going to improve as the nurses cranked me up and down from time to time just to exercise my circulatory system. The feeling of faintness caused by this was not pleasant and I would break out in a sweat like I was going into shock.

Day by day, I began to move something new. I had almost no strength, but I could move parts of my body. I remember my physical therapist bringing in a hand grip measuring device and reading a grip strength of one half of a pound with my left hand and two pounds with my right hand. I believe normal grip strength (based on my brother trying out the device) would have been about 130 pounds for me.

After a month, I could sit up in bed. The therapists were working with me and trying to get me to use a board to slide from the edge of the bed over to a wheel chair. I had a finger splint that I could put on my wrist and activate the call button and dial the phone if it had been placed in just the right spot on the bed. I could also work the TV. Without the splint, my finger was like a wet noodle. Having delusions of grandeur, I asked my wife to bring my laptop computer up to the room. It was a while before I could do much with it, but just having it close by gave me a challenge to strive for.

Each morning I was changed, bathed and transferred over to the wheelchair. Eventually I was wheeled down to the end of the hall to a large "play room." The room was full of people doing all sorts of things ranging from memory games to ping pong. My therapists selected a few toys and we began therapy. I enjoyed it, but even the simplest things were almost impossible for me. I was exhausted after 30 minutes. Just having my legs manipulated to improve my range of motion was tiring.

I was hooked up to a catheter that stored urine in a leg pouch, but this didn't prevent me from having the other kind of accident. Often I had to ask for a time out from therapy and a nurse would have to be found to change my diaper. I got over the embarrassment in a hurry. You just had to do the best that you could and get on with the program. The nurses and therapists were nothing short of fantastic. They were truly angels.

I got to know everybody. I discussed things with the janitors, the nurses, the therapists, and the doctors. I knew a great deal about the lives of many of them before I left the hospital.

As time passed, I was hauled to a standing position. Unfortunately, I could not stand up for one second, even if I held on to wooden rails on either side of me. Later I was able to stand for three seconds before crashing back into my wheelchair.

After eight weeks in rehab., I could walk a complete circuit around the halls on my floor with a walker. I can tell you though, that I took many a spill to the hard vinyl floor on the way to that feat. The nurses were afraid of the liability of my taking off on my own and they scolded me several times for taking off without them.

I told the floor nurses that I looked forward to the day that I could streak naked except for my support stockings (used to hold up my blood pressure) down the halls. Soon after that comment, they figured it was about time for me to go home.

I went home in the rehab van as I sat in my wheelchair. The physical and the occupational therapist had already checked out the house for hazards and the need for ramps, etc. My shower needed a chair and a flexible hose with shower head. My toilet needed an elevated seat so that I could transfer from the wheelchair back and forth.

My bladder was operating at about 30% and I wet the bed often. I had learned all about bowel programs, digital stimulation, and rubber gloves in the hospital. Naturally, I was not ready for any long excursions away from my bed or my bathroom.

My friends were all great and offered all sorts of encouragement. Many of my problems were so personal that I hardly wanted to discuss them with my doctor, much less my family and friends.

As I improved my strength and my ability to get around, I still had some sort of "malaise" that was physical more than mental. I believe it related to my sporadic blood pressure. I just didn't feel like doing much. I wanted to do things, but when I actually got into the process of getting up and doing something, I would lose interest or it was just too much effort. I still have some of that at 23 months from ground zero.

After being home for about two months and going to rehab twice a week, I began to feel a burning sensation in certain parts of my body. It was like a severe sunburn or like sitting for hours on a block of ice. As time has progressed, I still have the burning that is mild on my back and shoulders including my arms and fingers. It is more severe on my left side running down the inside of my thigh to my feet. It covers my mid-section across my stomach. Nothing gets rid of the pain. I've been to several pain clinics and tried most drugs. I am fortunate that I can sleep. When I do sleep, I do not feel the pain. When I wake up, it is like something turned the pain switch back on. I continue to look for relief from this "bear." I do not take any medication, however.

A spinal cord stimulator that puts electric current into your spinal cord overriding the pain signals has been suggested. The theory of this is to put so many messages through the spinal cord that the pain gets blocked out to some degree in the traffic jam.

Well, here I am today 23 months from ground zero. I drive to work each day although I don't work as long and hard as I used to. I passed my flight physical at 12 months and I am flying my twin engine airplane alone and on instruments. I have been fully checked out. I go to the local YMCA where I am on the board and work out two hours twice a week. My strength continues to build. I estimate that my legs are 60% of original and my upper body is 80% of original.

I have to be careful about getting into the shower as my feeling of hot and cold from the neck down is very spotty. Many places below my neck cannot tell if you are touching me with a pin or your finger, but I can feel the touch. I still can't run so I can't play tennis. I fall down occasionally. I still use a catheter and the rubber gloves are in the bathroom. I am out of the diaper. It has been slow and painful, but it has been the most interesting journey I have ever been on. I think I have grown a great deal as a result of it. I am much more conscious of the pains and problems of others. I am much closer to my family. I have sure spent lots of time at home with them. My 16 year old son wrote a school paper about how much he admired me. So, some good has come out of this as well as some bad. I feel very fortunate to have survived this ordeal as well as I have. I have talked to people that have had much worse and much better experiences than I have.

My wife is a real champ. How she has put up with me through all of this I will never know. I would have thrown myself out with the garbage long ago except for the fact that I didn't have the strength to pick myself up.

I have always tried to look at the good in any situation. I believe that much of life is about learning how to overcome adversity. One of my nurses told me that the Lord won't give you more than you can take. He sure can put you to the test though.
Since the production of the last newsletter, Jim Lubin was formally assigned the position of Director, Internet and Web Site for the TMA and will serve on the TMA Board of Directors. Jim has been a tremendous source of support for people with TM. The TMA recognizes his many skills and his energy and efforts in creating a forum for so many people with TM to find each other and to exchange information and encouragement. We congratulate Jim on his new positions and look forward to the many contributions Jim will be making to the TMA and its members.

TMA Internet Activity

Jim Lubin and Sandy Siegel

The Transverse Myelitis Internet Club (tmic) was established in August, 1996. The purpose of the tmic is to provide a forum for people to communicate with others about transverse myelitis. In order to participate in the tmic, you need access to the Internet. When a person "posts" a message to the forum, all of the participants in the tmic automatically receive that e-mail message. An Internet list group, such as the tmic, is a very effective way to communicate with a large number of people about a particular topic. For instance, I may be experiencing sensations in my feet that I have not before experienced and I am not certain what they mean. I could post a message on the tmic that described my circumstances and the new sensations, and would ask if anyone else had experienced anything like that themselves. Everyone in the group would receive that message, and more often than not, I would receive more than one response from people who have experienced similar sensations and they might also discuss what their doctors told them was the cause and consequence of those sensations.

At present, the membership of the tmic is approximately 140 people. It is likely that there is no larger group of people with TM who are in regular contact with each other. The membership of the tmic, as the membership of TMA, is international in scope. The tmic has become a wonderful way to exchange information, receive support and find answers to questions. Recently, there was a posting from a parent with a child who had been diagnosed with TM. The parent was seeking ideas and approaches regarding how their child was going to be integrated into the school environment in a positive and healthy way. The responses to this person have been both very informative and heartwarming. There has also been a request for other children who might be interested in talking to and corresponding with this child. Again, there have been positive responses to this request. This is but one of the many many issues that are regularly communicated about on the tmic.

An archives has been established for the messages that have been posted from the beginnings of the forum. The archives may be searched by the author, the date of the posting, or by the string of ideas or content of the postings. There is also a search engine that has been established for the tmic. This is one of the most important and valuable features of the tmic. You can search all of the archives by typing in a word or a string of words. The search engine will locate all of the messages that include the words you have entered. The instructions that appear on the site to perform this type of search are as follows:

*Search List Archive: You can use the booleans **and**, **or**, or **not** in searching. Without these booleans, we'll assume you're **anding** the words together. Evaluation takes place from left to right only, although you can use parentheses to force the order of evaluation. You can also use wildcards (asterisks) to search for matches to the beginnings of words only.*

For those of you who have not spent time searching for information on the Internet, these instructions may sound as daunting as the instructions for programming your VCR. In both cases, we recommend that you get your children to do it -- they likely know what it all means. Actually, it is not difficult and you will quickly discover how a search operates. Perhaps an example will demonstrate the power and value of this search engine. Let's say that my neurologist has just prescribed baclofen as a medication for me. I would like to know how it has worked for other people with TM and if they have experienced any side-effects from the medication. I search the archives by entering the word "baclofen" in the space and either press return or use my mouse to hit the search button. The search engine will list each of the messages that have been posted that include the word baclofen. I can read each of these messages to find if the information I want is included. I may read a message from a person who's experiences sound very much like mine. I can use their e-mail address to contact that person directly and begin a dialogue with that person through e-mail to explore their experiences with baclofen, and, likely, many other experiences with TM.

In order to perform a search of the archives, you may follow the links to the archives from the tmic site. You may also go directly to the archives search by using the following address: **http://www.eskimo.com/~jlubin/search.html**.

If you would like to subscribe to the tmic, you can get to the site using the following address: **http://www.eskimo.com/~jlubin/disabled/tmic**. You may subscribe to the forum in one of two ways. There is an electronic TMIC-List subscription form at the site. To subscribe to the tmic mailing list, you just enter your real name and full internet e-mail address in the boxes provided and click the subscribe button. You should receive a message confirming you have been added to the list. If you do not

receive a confirmation, you will have to repeat this process. You will receive every message that is sent to the tmic. The second method for subscribing to the tmic is to send a message to **tmic-list-request@eskimo.com** with the subject "subscribe" (without quotes). You will receive a message confirming you have been added to the list. At various times, the number of messages at the tmic becomes fairly large, and there are some people who would rather not receive all of those messages at the same time. It is possible to subscribe to a list digest of the tmic. To do so, send a message to **tmic-digest-request@eskimo.com** with the subject "subscribe" (without quotes). You will receive a message confirming you have been added to the digest. Those subscribing to the digest receive one message sent every two days; the digest is one message containing all the messages from the past two days, or as soon as it reaches 40K.

Regardless of whether you are a regular subscriber or a digest subscriber, you post messages to the list or forum by sending mail to **tmic-list@eskimo.com**. Everyone subscribed to the list, or digest, will receive your message and will be able to respond. Once you subscribe to the list, it is a good idea to send a message to the group introducing yourself and letting everyone know you are new to the forum. Many new members introduce themselves and offer a brief description of their history with TM.

As with most Internet activities, the rules governing conduct are ambiguous. There are a few rules of the tmic that are designed to create a positive environment for those participating in the tmic forum. When responding to a particular message, it is a good idea to quote only the parts of the message that are relevant to your response. Often times people will include an entire previous posting in their response. Everyone then has to scroll through what, in some cases, is a very long message of which only one or two lines are really necessary. It is good nettiquette not to use bold type. On the Internet, it is read as someone "**SCREAMING**." If you send an attachment to everyone, use your virus scan software to check the file before you send it. Please keep the messages to the tmic focused on the subject of transverse myelitis. There are rare occasions when the discussions have wandered beyond TM, and this is inevitable. But we hope to maintain the focus of the forum on TM. It is an interesting phenomenon that as a group of people we represent the diversity that exists in American society -- and since we have an international membership -- the diversity around the world. What we all have in common is that we have been diagnosed with TM or have a family member or close friend with TM. Some of us are anthropologists -- the science of finding all people entertaining as opposed to annoying. Not everyone shares that world view. The forum is open for discussions of TM -- all aspects of TM from the physical, the emotional and psychological, the social to the spiritual. Diversity can be a strength for all of us who have to deal with these issues. The most important rule -- ***be nice to each other***.

In the event that you should ever wish to end your subscription to the tmic, send a message to **tmic-list-request@eskimo.com** with the subject "unsubscribe" (without quotes) and you will be removed from the list.

You do not need to own a computer and modem or have an Internet service provider or on-line service to benefit from the tmic. Most public libraries around the country provide Internet access to their patrons. In many cases, the libraries offer courses that will provide you with basic skills for using the Internet. There are also libraries that will allow you to set up an account to receive e-mail at the library. If this is the case, you can subscribe to the tmic by using this account. Ask your library what services they offer, and if you need assistance, show them this article and ask them for help getting to the tmic site. If your public library does not yet have Internet access, there may also be a college or university in your area that might allow you Internet access through their computers.

TMA on the Internet http:// members.aol.com/tmassocwa

A TMA web site was established in 1997. Our web site provides some basic information describing the mission of the TMA. You may also read the TMA newsletter and download a copy of the questionnaire from this site. The potential for using our web site as a means of quickly disseminating information is tremendous. At present, the web site has become one of the most effective methods we have for reaching out to people with tm. Our site has been registered with Yahoo.com; if you perform a yahoo search using "transverse myelitis", the TMA web site will appear close to the top of the list. The tmic is also near the top of the list of sites. Thus far we have received over 2000 hits (visitors) at our site. Many of these visitors have identified themselves as people with TM and have asked to become members of the Association.

As is evident from the article discussing some of the survey material, most of our members have recently been diagnosed with TM. It is our fervent goal to find more people with TM, both who have been recently diagnosed and also those who have had the diagnosis for a longer period of time. The Internet has become an invaluable asset in providing a mechanism for providing and exchanging information. It has also become one of our most effective methods for finding people with TM -- or assisting them with finding us!

A survey of our members was conducted in January, 1997. The questionnaire was included in the first newsletter of the Association. I requested that the surveys be returned by March. The purpose of the date was to motivate people to complete the survey in a reasonable amount of time -- **it was not a deadline**. We are encouraging our members to complete the survey, if you have not already done so. If you have the questionnaire, please fill it out and return it. If you do not have a copy of the questionnaire, you may download it from our web site. You may send it to me either as an electronic version by e-mail or you can mail it to me through the postal service. I have reproduced copies of the questionnaire; if you do not have a copy, please contact me, and I will send you one.

All of us want to know more about transverse myelitis; and all of us want for our doctors to understand more about transverse myelitis. We are in a very unique and valuable position to assist them in learning more about TM. If we are going to help doctors better understand tm, this information is going to have to come from you. And we cannot afford to miss one experience; each will teach the doctors something important about this condition. I would like to thank all of you who have taken the time to fill out the survey and return it. I would like to urge each of you who have not filled out their survey to please do so. Our intention is to continue to provide this survey to new members of TMA and to build the base of information regarding TM. We will find methods for disseminating this information to our members and to doctors who diagnose and treat TM patients. For those of you who have sent names and addresses of your doctors, I will maintain a file and be sure that each of them receives whatever results we produce from our analysis.

There is a great deal of work involved in entering the information into a format that can be used for analysis. I have only just begun that process. Because most of the information is open-ended and in text form, the analysis will require a considerable amount of time.

Jessie Danninger will be a participant in the research project. Jessie graduated in 1995 with a B.S. degree in statistics from North Carolina State University and is currently employed as a statistician at the Research Triangle Institute in North Carolina. Jessie was diagnosed with TM in 1993. We will have other assistance during the course of the research process. It is imperative that we produce results that will provide meaningful information for physicians.

We will seek guidance from the physicians on our Board of Directors, as well as other medical specialists. We hope to get most of the data entry completed during the winter months. We will keep you informed throughout this process. As we collect information, we will publish it in the newsletter. When a final research product is produced, you will receive a copy. And as we update the data from new members, we will continue to publish the new information in the newsletters.

At present, we have received 103 completed surveys. From the number of returned surveys there are 70 females with tm and 33 males with tm. The following tables present a few important characteristics about the people who returned their surveys.

The majority of people (64 of 103) were diagnosed with TM in their thirties, forties and fifties. The highest number of respondents (28) contracted TM in their forties. There were 7 children who contracted TM under the age of 10. Seventeen of the respondents were diagnosed with TM over the age of sixty.

Regarding the current age of our respondents, the largest number (30) is in their forties. The next highest number of people are in their fifties. The vast majority of our respondents (78 of 103) are between the ages of thirty and sixty-nine. There are four children who are currently under the age of 10.

The Transverse Myelitis Survey

Sandy Siegel

The majority of the respondents (49) had TM for one year or less when they filled out the survey. There are 26 respondents who had TM for 5 years and longer when they filled out the survey, and only 10 persons who had TM for 10 years and longer when they completed the survey. It is quite evident from this result that most of the people who have contacted the Association have had TM for a short period of time. It is possible that persons who have had TM for longer periods of time are not concentrating their efforts at looking for information about TM as those who have had the diagnosis for a shorter period. If we are going to reach out to these people, we will need to find creative ways to find them. We might be able to contact people who have had TM for longer than 5 and 10 years through an outreach program with neurologists.

The last table illustrates the responses to the survey question which asked respondents to identify the location of their lesions. There were 36 people who responded that there were no lesions found. The remaining responses are remarkable in their diversity. The only unique response representing five people was T10. There are others affected at the T10 level, but their lesions covered a larger area. Most of the locations identified were reported by either 1 or 2 people. The second highest response after T10, was 4 people who identified T6. More than half of the respondents (47) reporting lesions have identified their location as affecting some area of the thoracic region. There are 20 people who identified lesions in the cervical region. Only 6 respondents reported lesions in the lumbar region of the spinal cord.

These are just a few simple examples of the types of analyses we will be able to perform from the questionnaires. What we learn from this research should help doctors and should ultimately help our members. We look forward to hearing from all of you who have not yet returned a questionnaire.

Age Diagnosed	Number of
<1	1
1-5	4
6-9	2
10-19	6
20-29	9
30-39	18
40-49	28
50-59	18
60-69	9
70-79	6
80-89	2

Current Age	Number of
<1	0
1-5	3
6-9	1
10-19	5
20-29	7
30-39	12
40-49	30
50-59	24
60-69	12
70-79	6
80-89	3

Time with TM	Number of
<1	19
1	30
2	12
3	7
4	10
5	6
6	4
7	2
8	2
9	2
10	1
11	1
12	1
15	1
21	1
23	2
24	1
29	1
34	1

Location of Lesions	Number of Respondents
Brain Stem	1
Bottom of Brain Stem	1
C1-C2	1
C2	2
C3	1
C2-C3	2
C4	1
C4-C6	1
C4-T2	1
C5	1
C5-C6	1
C6	2
C6,T2	1
C7	1
C7-T3	1
C2-C4,C7-T1	1
C8-T1	1
C4,T9	1
L1	1
L2	2
T1-T4	1
T2	2
T2-T3	1
T3-T4	1
T4	1
T5	3
T5-T6	3
T6	4
T7	2
T6-T7	1
T7-T8	1
T8	2
T8-T10	3
T8-T12	1
T9	2
T9-T10	2
T10	5
T9-T12	1
T10-T12	1
T3-T4, T10-T11, Conus	1
Lower Thoracic	1
Thoughout Entire	1
Below Base of Spine	1
Entire Spine from C2 to	1
None/No Lesions	36

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You can reach TMA on the Internet

You can send us information, submit stories and articles for the newsletter, contribute your articles for the ***In Their Own Words*** column, send us your questions and answers for the ***Members Q&A*** column, and refer new members to TMA by using our Internet address. Please send your e-mail to:

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Dr. Charles Levy and Dr. Joanne Lynn to serve on the Transverse Myelitis Association Board of Directors