❖The Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

My column in this issue is about money. I know, you would probably rather that I was writing about sex.

The Transverse Myelitis Association has grown so much since the Gilmurs first started our organization in 1994. We have grown in size, we have grown in both the quantity and quality of services we are able to provide to our members and we have certainly grown in stature. It has become absolutely obvious to me in the past couple of years that the TMA has grown most substantially in terms of potential. We are finally in a place to do so much more for our members. And what separates us from this reality is money.

First, let me assure you that we are seeking funds from the government, from foundations, and from pharmaceutical companies and from adaptive equipment manufacturers. These are institutions and organizations that we believe should have an interest in our Association and our membership. They should want to help us with our education, outreach and support efforts, and they should want to support TM research. We will continue to pursue funding from these sources.

This column is about the need for money and our TMA membership. I have said many times before, people give to the causes with which they have an emotional connection. In the case of health-related societies or associations, I give to those organizations based on whether a family member or a good friend had a particular disease or disorder. I believe that it works this way for most people. We want to make a difference in people's lives based on our personal experiences. In a sense, the process of giving to help others is a part of our own healing process for the losses we may have experienced that were caused by the disease or disorder.

Let's do the math. We have about 3300 people in our membership from all over the United States and from all over the world. Our membership is growing by around ten to twenty people per week. The back-of-the-envelope calculation is that there are about 34,000 people in the United States with TM, and that there are approximately 1200 to 1400 new cases each year. If we are going to help ourselves, 3300 people are going to have to do a great deal more than we are currently doing to make a difference – and the difference we are trying to make is in our own lives. The sad reality is that if you are waiting for someone else to do it for you, it isn't going to happen. They have their own diseases or disorders to worry about, and they are not going to be supporting our cause. Chances are, they don't have TM, they don't know anyone who has it, and they've never heard of it. They sure are not going to be sending any cash our way.

With just 3300 members emotionally connected to transverse myelitis, all 3300 of us need to be involved in giving money and/or raising money for our cause.

The Transverse Myelitis Association does not have a membership fee. It has been a fundamental principle of our Association that access to information and support should not come at a price. Unfortunately, however, information and support does create a cost. And someone is bearing the cost. Who is bearing the cost is published once a year with our annual financial report. And I need to be perfectly clear about this also, we are so grateful for all of the support we get from our membership. We appreciate your generosity and we are humbled by your trust in us. Now, count the numbers of people who are bearing the load for our group. It is instructive to go back a few years. As we grow, it remains a fairly small number and proportion of people who support what we do for 3300 people and growing.

If you are reading this column, TM has changed your life in some way. For most of you, it has changed your lives in the most fundamental ways. It has changed you, it has changed your family and it has changed your friends and neighbors. It is you, and your family and your friends and neighbors who have to make the difference. You are the people who are going to support our efforts. No one else is going to do it. And if you don't do it, it is not going to happen.

I left Baltimore in mid July with an incredible sense of hope – more

hope than I could have even imagined just a short year ago. Really, what incredible progress we heard about from these brilliant scientists and physicians. They are thinking about TM and they are talking about TM. And I left Baltimore filled with an enormous amount of frustration. Why frustration, because unless we are able to raise sufficient funds to encourage these research scientists to focus on TM, they won't. They will focus on MS, they will focus on Parkinsons, they will focus on ALS; all deserving of their focus. All worthy causes; people with MS, Parkinsons and ALS need their research and treatments and hopes for a cure. But so do we!

We will and we do benefit from the research in these areas, but it is tangential and it remains on the periphery. We want them looking straight at TM. We want them thinking about TM while they are eating their Cheerios in the morning; we want them obsessed with TM. That is the only way they are going to find better treatments for TM and that is the only way they are going to find a cure for it.

Let me put this out there in the most basic way. The doctors do not know what you have. They do not understand the cause or causes of TM, they are uncertain of the treatments, and there is definitely no cure. As we are all acutely aware, all of this uncertainty is not a good thing. The doctors at this Symposium want to initiate a process that would define "Transverse Myelitis." Pretty basic stuff. They want to define the diagnostic characteristics of TM. Then they want to begin research on possible treatments that could stop the demyelinating attacks before they do much damage to the myelin and nerve cells in the spinal cord. One might think that you could just invite thirty or forty of these people into your living room on a Sunday afternoon, feed them deli sandwiches and potato chips and have them discuss and resolve these issues. Well, it doesn't work that way. It is going to cost thousands and thousands of dollars to get these scientists and researchers and physicians together to agree upon a definition of TM, to define the diagnostic and treatment protocols. Thus far, the National Institute of Health has not been willing to fund this effort.

If we cannot get the most fundamental questions looked at – ***what is it*** – how are we going to get the most complicated questions looked at – ***how do you cure it***?

The Transverse Myelitis Association needs to be involved in the funding of TM research. We know that this needs to be done; we aren't going to count on anyone else to do it. We just need a lot of money. We need your help.

I have contributed a lot of money to The Transverse Myelitis Association. It is a lot for my income and my standard of living. Unfortunately, even with two jobs, I am not going to be able to come up with enough money to fund TM research. So, I decided that I had to do more. The TMA is planning a Children's and Family Workshop for next summer. I decided that I was going to send a fundraising letter to every single person I know. I am explaining how TM has changed Pauline's and my life, and I am asking that through their love and concern for us, that they allow TM to change their lives, as well. I am asking for them to make a contribution to The TMA to help us fund the workshop. If from this effort we collect more than what we need for the workshop, we will use these resources to fund TM research. This letter is going to every member of my family, to every friend I have from preschool to high school to college to graduate school, to members of my synagogue, to my insurance agent, to my doctors, and dentist and co-workers; everyone I know. If I had a barber, I would send the letter to my barber.

I am hoping that I can motivate our Association members to join me in this effort. People donate money to worthy causes all the time – why shouldn't they donate to our cause; to your cause. How long are we willing to wait for an answer to: what is TM? My goal is simple: we need to raise $150,000 for the Children's and Family Workshop by March 2002. The rest of my goal is to so seriously motivate the TMA membership to raise $150,000 that we end up with $150 million for TM research.

We have a group of incredible scientists who are at the threshold of some remarkable discoveries and some of these findings are going to impact how they think about and treat TM. They are interested in TM. ***How*** interested is going to depend almost entirely on whether there is money to fund their research. If the money comes from The Transverse Myelitis Association, the research questions are going to be framed entirely from the perspective of TM issues. If the money comes from somewhere else, the questions will not focus on TM, and the benefits will be far less direct – or the benefits will be minimal for TM patients.

I often hear people say, well, I'm interested in getting involved, but I just don't know what to do. The Blandfords have a pre-schooler with TM. The pre-school had a hop-a-thon to raise money for The Transverse Myelitis Association. They raised more than $4000 from these children hopping in place. The Dorocaks raise thousands of dollars from the Reading for Rachel Program. It is easy to do and all of

the instructions and materials you need can be found on our web site. The Hamiltons raised almost $50,000 this year from raffles and a neighborhood picnic bar-b-que. The Callahans raise thousands of dollars every year from a golf outing and other activities. Paula's brother, Buddy, also has a golf outing for the TMA every year. Heather O'dell has been raising money from car washes. Gunny is out raising money for the TM cause in many different ways; he wrote a book about his experience with TM, got it published and is donating the proceeds for TM research. Lori Biehler and Beth Lekander have been finding all sorts of unique items to sell to raise money for the TMA. Lori is about to begin a raffle for a Harley Davidson Motorcycle. Deana Green and her friend generously donated their brother's wonderful paintings to be sold to support the TMA. Ann Moran solicited quilting squares from TM members from all over the world. She lovingly created a quilt from these donated squares and is selling this international quilt to raise funds for the TMA. We have people involved in all sorts of fundraising efforts; we had a group of junior high school students participate in a marathon volleyball game to raise money. I don't think it is really about how – it is really about the motivation to just go do it.

Jim has posted a link on our web site, which was designed to help children initiate and organize a fundraising project. It is called ***The YouthNOISE Raise and Donate Toolkit***. The link for this site can be found on our web site at: http://www.myelitis.org/fundraising. While the site was designed for children, adults would also find this information useful in getting a fundraising project started.

People willingly support the causes and the institutions that they believe in and trust. We should encourage people to support our cause. And I am imploring you to support our cause. I used to support a number of important causes – from social organizations to religious organizations to healthcare associations. Today, I support far fewer organizations and even with the few that I do support, I provide them with much less than I have in the past. I devote what resources I have to The Transverse Myelitis Association. Most of the charitable organizations I made contributions to in the past had fairly large bases of support. The prevalence of cancer and heart disease is very high; the numbers of people who have emotional connections to those causes are likewise very high. I have focused my financial resources on The Transverse Myelitis Association based on the very simple fact that if I do not take care of my own issues, who is going to do it.

Please ask yourselves the same question – if you do not take care of yourselves and each other, who is going to take care of us? I implore each of you to take care of us.

Please contribute what you are able to afford to contribute. We know that for some of you, many of you, you are unable to make a contribution; and that is why there is no membership fee. But even if you are unable to make a contribution, you can get involved in fundraising efforts. Please do so. Send a letter to everyone you know. Have a bake sale. Participate in Reading for Rachel. Have a hop-a-thon.

If you have experience with raising funds for organizations such as ours, we need your help. Please help us make a difference in your life and the lives of the people you have come to know and care about through the TMA.

The Transverse Myelitis Association requires sufficient funding to continue to provide our current services and to expand our services as great opportunities arise. We need funding to continue to operate. At our last board meeting, Paula reported that to date, this year, we had spent $4000 more than we had received in contributions. We were not running a deficit, only because we had a balance in our operating account from the previous year. I was shocked. Our expenses to that point were almost exclusively printing and postage costs. I'm not sure, exactly, what "overhead" means, but I don't think we have any. We use our operating funds to pay for the services we offer to our members. We do not have offices, so we do not pay any rent, we pay our own phone bills, we pay for our own Internet access, and we purchase most of our own supplies. And no one is paid for anything they do. Even many of the support services we receive, for instance from the graphic artist, are contributed at no cost to the Association. How could it be that we were not receiving enough contributions to cover printing and postage? We need to do more to support this Association if we are to continue to grow and offer our current services.

Our membership needs to do more … in California, New York, Ohio, Michigan, Texas, Washington, Germany, England, Brazil, Australia, France, India, Mexico, Italy, Spain, Scotland, Portugal, Ireland, New Zealand, Canada, Denmark, Argentina…. We can all do more.

I got involved in this endeavor, because I love Pauline, and I care about her so much, and I want her life to be without pain. I want for her to

have her full life back. I know she is grateful for what recovery she has had, but I also know what she lost. That is where it starts for me and that is where it ends for me … Pauline. In between, there are the hundreds of people I have spoken to on the phone, emailed, and met and hugged, who have totally changed my life. I have been changed in the most profound ways by all of you. And I believe that is where it is for all of us. We have come to care about each other … but we care most about ourselves. So, what I am asking you to do; what I am pleading for you to do, is help yourself. I believe we can make a difference in your lives. Help us do that for you. Focus your resources on the cause that has most impacted your life. Get yourself motivated to focus the attention and resources of your friends and loved ones on our cause. Use your influence and skills and creativity to raise money for our cause; for your cause.

Please take good care of yourselves, and each other.

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Whether you are a person with TM or a health care professional involved in treatment or research in the area of

Transverse Myelitis and the Multiple Sclerosis Connection

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TM, there are several reasons why it is appropriate to discuss the relationship between Transverse Myelitis and Multiple Sclerosis.

One reason is that people with TM tend to end up seeing MS specialists as neurologists. MS is a common inflammatory disease of the central nervous system (variable incidence 1-100 per 100,000 population depending on location) where as the incidence of TM is much less in the range of 1 to 5 per million. Most departments of neurology at academic medical centers have one or more specialists in MS and these physicians also see people with other inflammatory or immunologic disorders of the spinal cord. I am aware of only one clinic with its primary focus on TM and this is the relatively newly formed TM clinic headed by Dr. Kerr. MS specialists have experience with treatment of the problems associated with spinal cord disease. Therefore, the clinicians who see and treat people with TM cannot help but view TM through a looking glass that is colored by what knowledge we have about the causes and pathology of MS.

The second reason is the fact that many people view ATM as one manifestation of a larger group of demyelinating illnesses. Dr. Lael Stone (1997) has written:

> *There is very little information about the immunologic aspects of ATM. Although this neglect may reflect the rarity of the disease, it more likely reflects a common belief, rightly or wrongly, that ATM is part of a spectrum of CNS demyelination, the cause of which can be unraveled through study of other more common diseases, such as MS.*

Dr. Weinshenker (1998) has written that "MS is almost certainly not a single disease but a series of IIDD [idiopathic inflammatory demyelinating diseases]." Syndromes such as TM may be viewed as a monosymptomatic idiopathic inflammatory demyelinating disease and have a poorly defined relationship to MS.

The third reason is that a small number of people with ATM are actually experiencing their first attack of MS.

For these three reasons, I want to review some of what the medical literature says about the relationship between ATM and MS.

MS is a chronic inflammatory demyelinating disease of the central nervous system that affects over 200,000 persons in the United States. The etiology remains unknown, but evidence suggests that MS is an autoimmune disease likely directed against the protein components of myelin. Pathology of the MS lesion shows many features of a delayed type hypersensitivity reaction. Despite investigation of 16 bacterial and viral agents, none yet have been convincingly linked to MS. (The latest contenders are the Human Herpes 6 virus and Chlamydia pneumoniae).

It has been estimated that 40 to 50% of first attacks of MS are monosymptomatic or consist of neurologic symptoms, which can be caused by a single lesion in the central nervous system. Spinal cord attacks are characteristic of MS but the syndrome of complete acute TM is

unusual as an initial symptom of MS. Only 0.7% of a Canadian population of 3500 people with MS had acute TM as their first attack (Paty and Ebers, 1998). Because of the low frequency of TM as the initial onset of MS, the literature is limited. Optic neuritis (ON) is one of the best studied of the monosymptomatic syndromes in MS and it is worth looking at what is known about optic neuritis and its relationship with MS to determine what might be relevant to the topic of TM and MS.

ON is an acute inflammation of one or both of the optic nerves (usually unilateral). Its manifestation varies from mild visual blurring or subtle alterations in color perception to total blindness. The prognosis is very good with significant recovery of vision over weeks to months. This recovery is hastened by administration of high dose intravenous corticosteroids. The reported risk of development of MS after ON varies widely from report to report – from 13% to 88%. The risk seems to be greatest in the first two years after ON (about 20%) and rises by an additional 20% by 5 years. Studies have reported life table estimates of risk within 15 years to be in the range of 45 to 80%.

Brain MRI has been demonstrated to predict those patients with optic neuritis who are at higher risk to develop MS. Six studies of optic neuritis demonstrate that patients with "clinically silent" cerebral white matter lesions on brain MRI have a risk of subsequent development of MS that is 4 to 5 times higher than that of patients with a normal brain MRI at the time of presentation with ON (38% vs. 8% on average). Various suggestions have been made about the type of MRI lesions that are strongly suggestive of MS. The University of British Columbia criteria for such lesions are: 1) 4 white matter lesions; 2) 3 white matter lesions , one periventricular in location; or 3) all lesions > 3mm in diameter and predominantly in the white matter.

Results from six studies of patients with ON and cerebral MRI: percentage developing MS:

Study	Abnormal Brain MRI:		Normal Brain MRI:	
Jacobs	6/23	(26%)	3/25	(12%)
Martinelli	7/21	(33%)	0/16	(0%)
Frederiksen	7/30	(23%)	0/20	(0%)
Miller	12/34	(35%)	0/19	(0%)
Morrisey	23/28	(82%)	1/16	(6%)
Beck	55/150	(37%)	19/202	(9%)

These rates of conversion vary with criteria used for MRI abnormalities and length of follow-up. The Morrisey study is the longest follow-up with 5.5 years average and allows a longer time for conversion. The higher rate obtained of 82% in that study does suggest that most patients with ON accompanied by MRI brain abnormalities suggestive of MS on presentation will eventually develop clinically definite MS.

The syndrome of acute TM can be caused by many different illnesses: infectious, autoimmune, etc. The neurologist searches for clues that the TM is due to any of the known causes. If none of those clues are present, then a diagnosis of idiopathic TM is made. Various clinicians have reported on long term follow-up of their own personal patients with TM, trying to see how many develop MS and if there are characteristics or laboratory studies at the time of the acute attack that might predict whether a particular patient with TM will develop MS.

The risk of developing TM is quite low in most studies ranging from 0 to 36% with one outlying study that cited a rate of 80%. These studies show the following:

1) One of the strongest variables predictive of whether TM will convert to CDMS is whether the lesion was *complete* vs *incomplete or partial* TM. The syndrome of complete TM is very unlikely to develop into MS. Complete means that there is total loss of movement and sensation below the level of the spinal cord affected by inflammation. In the study by Lipton and Teasdale in 1973, the risk of conversion to CDMS following an episode of complete transverse myelitis was very low – 2.9% after a variable follow-up period of 5 to 42 years. Most long-term follow-up studies yield rates of conversion of less than 25%. However, a more recent study by Ford et al in 1992 showed that 12 of 15 (80%) of patients with the more common partial myelopathy converted to CDMS within a mean follow-up time of 3.2 years.

2) Symmetry vs Asymmetry of motor or sensory loss -- It is a general observation that patients with MS frequently present with asymmetry of level or severity of weakness or sensory loss from one side to the other. People with acute TM are more likely to present with symmetric weakness. Scott et al (1998) reported that the degree of symmetry of motor and sensory neurology dysfunction in patients presenting with acute transverse myelopathy was a reliable discriminator of which patients would eventually develop MS and which appeared to have idiopathic TM. They reported that 15/16 patients with acute myelopathic MS had asymmetric motor or sensory findings and all ATM patients exhibited symmetric

weakness and all but one (19/20) exhibited symmetric sensory loss. They concluded that symmetry is a much better distinguishing factor than severity of the motor or sensory loss in their study.

3) Cerebrospinal fluid studies -- Various abnormal findings in the spinal fluid have prognostic value for predicting the development of MS in people presenting with monosymptomatic demyelination. In one prospective study of 183 people with monosymptomatic suspected MS, the presence of oligoclonal bands in the CSF was associated with a 24% conversion rate to MS within the follow-up period of 34 months, while only 9% of patients without oligoclonal bands in the CSF developed MS during the same period (Moulin et al, 1983).

4) MRI findings of cord and brain:

Cord: There is a tendency for spinal cord lesions to be smaller or multifocal in MS compared with ATM, but the MRI appearance often does not help distinguish between these entities. Swelling of the cord is more common in ATM than in MS but can be seen in MS.

Brain: The most important laboratory finding which will predict the chance that a patient with ATM will develop CDMS is the presence of asymptomatic lesions on the brain MRI.

Patients with Transverse Myelitis converting to Multiple Sclerosis:

Study	Abnormal brain MRI	Normal brain MRI
Ford	12/15 (80%)	1/3 (33%)
Morrisey	10/17 (59%)	1/11 (9%)

CHAMPS Study – Controlled Trial of High-Risk Subjects in A Multiple Sclerosis Prevention Study

Clearly brain MRI can help to identify a subset of patients with monosymptomatic demyelination who are at high risk to go on and develop MS. Treatment with interferon beta or glatiramer acetate has been the standard of care for patients with clinically definite relapsing MS for several years as each of these agents has been shown to reduce exacerbations by approximately one-third. Certain observations suggest that the currently available interventions may be more efficacious if given early in the disease course. However, prior to the CHAMPs trial, there was no data available about treatment of patients with a monosymptomatic presentation. These observations formed the impetus for the organization of the CHAMPS trial to determine if treatment of patients with monosymptomatic demyelination would have beneficial effects on the rate of conversion to clinically definite MS and on the clinical course that follows.

The study enrolled 383 subjects with monosymptomatic presentations of MS: optic neuritis, brainstem, and spinal cord and abnormal cerebral MRIs, putting them into a high risk category for the subsequent development of MS. Each subject was treated with 3 days of high dose intravenous steroids followed by an oral taper of prednisone. Subjects were then randomized into two groups: one to receive interferon beta 1a IM q week (193) and the other to receive placebo (190). Each subject was followed with serial examinations until the study was completed or they reached the primary endpoint which is the development of a second clinical attack of demyelination which would warrant the diagnosis of clinically definite MS. The planned period of followup was to be 3 years.

The results of this study were published in the NEJM in September of 2000. The breakdown of enrollees by site of their monosymptomatic presentation was:

Optic neuritis	50%	192 patients
Brainstem/ Cerebellar	28%	108 patients
Spinal cord	22%	83 patients

The published article only reports on the pooled group as a whole. During the period of the study, a statistically significant difference was seen in the number of subjects treated with interferon who went on to have a second attack of demyelination compared with those treated with placebo. (p=0.002, Kaplan- Meier Estimates of cumulative probability of the development of clinically definite MS). For the group as a whole, the cumulative probability of developing CDMS was 35% in the IFN beta-treated group and 50% in the placebo group.

In addition, accumulation of new lesions on brain T2-weighted MRI scans differed significantly between the IFN and placebo groups. At 18 months follow-up, the IFN group had a 1% median increase in T2 lesion volume compared to the 16% increase in the placebo group. At all measurement times (6, 12 and 18 months), there were fewer new or gadolinium-enhancing lesions in the IFN treatment group.

This is an exciting clinical study which sheds new light on the value of intervention with immunomodulatory agents at the earliest point for patients with transverse myelitis and other

monosymptomatic presentations of demyelination whose MRI studies give evidence of a high risk to develop MS. This study also supports the importance of obtaining a cranial MRI for patients who present with TM to determine if there is a high risk of the development of MS and whether there is benefit to be obtained from early initiation of interferon therapy.

This is a brief review into some areas of overlap between TM and MS. As Dr. Stone mused, there is a belief and a hope by many that the study of MS may contribute some understanding into the pathology and eventual treatment of transverse myelitis. Certainly, it is a fertile ground from which more focused research and understanding specific to transverse myelitis may grow.

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There are several pieces of evidence suggesting that infectious agents may be important in the cause of TM. In general, it is believed that 40% of TM cases are preceded by an upper respiratory infection, though some special groups may have as many as 81% preceded by a febrile illness.

Acute Viral Infections of the Spinal Cord

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There is clear evidence that inflammation is present in TM, including elevation of CSF lymphocytes and neutrophils, and often the presence of elevated IgG levels or oligoclonal bands. The fact that the immune system is activated during TM suggests that TM is caused by either an infection or an autoimmune process. However, TM involves a rather limited area of the nervous system. Only the spinal cord is involved, so there must be some local factors provoking the inflammation at that site. One local factor that may be responsible is an infectious agent. Though the evidence described thus far is indirect, there are many cases where direct evidence of an infectious agent is available and infectious agents have been identified. These are described in more detail below.

Diagnosing infectious causes of TM can be very difficult. There are a large number of infectious agents that can cause TM, and they generally do not have differentiating characteristics. This means that when a person develops TM, it is usually not possible to determine from the history or examination whether an infection is

responsible or which infectious agent should be searched for. It is often necessary to look for many different infectious agents in each patient. This is difficult because there are few tests that can screen for several agents at once, e.g. cultures for herpes viruses. In particular, serology tests and PCR testing search for only a single agent. Each patient must have many different laboratory tests as a result. Many of the suspect viruses are common, with most people being infected with them. In these cases, it is not enough to show that a person has been infected with a particular virus at some time; rather it must be proven that the virus is infecting the patient at the time the TM strikes. This is not always possible.

When patients present with an acute spinal cord syndrome, the initial diagnostic emphasis is on anatomical/ surgical lesions. This leads to extensive clinical evaluations and imaging before blood work and lumbar punctures are performed. The search for infections can be delayed as a result. By the time an infection is sought, the infectious agent may be eliminated by the patient's immune system. Complicating the search further, when the patient presents it may already be too late to identify an infection. In some cases, it is likely that the symptoms of TM result from collateral damage from the immune attack rather than from the infection itself. Thus, when the patient develops symptoms, the infectious agent is already being removed by the host's inflammatory response. Finally, many viruses remain latent in our bodies. This means that once we acquire them, we never totally eliminate them. They can then reactivate from time to time. An example of this is chicken pox, which most people get in childhood, yet continues to live in a latent state in our sensory nerves, and then episodically reactivates in the form of shingles. The reactivation may be due to changes in the immune system, such as inflammation. Thus, it is often impossible to tell whether a virus is causing the TM or whether the inflammation of the TM is causing the virus to reactivate.

Infectious causes of TM can result from viral, bacterial, fungal, parasitic, or postvaccinal inflammation. A number of viruses can cause TM. The herpes family includes: Epstein-Barr virus (EBV, which causes mononucleosis), Varicella zoster virus (VZV, which causes chicken pox), Cytomegalovirus (CMV), Herpes Simplex Virus (HSV, which causes fever blisters and genital herpes), Human Herpes Virus 6 (HHV6, which causes a childhood rash), and Herpes B (which infects monkeys, but can be transmitted to humans who work closely with monkeys). The enterovirus family commonly causes gastrointestinal illnesses including diarrhea. Several members of this family may cause TM, including Coxsackieviruses, Echoviruses, hepatitis (A,B and C), rubella, measles, mumps, and Poliomyelitis. Retroviruses tend to cause TM that develops over months or years. Retroviruses include HTLV-I and II, and HIV (AIDS). Rarely, other viruses are reported to cause TM, including Influenza (flu), Lymphocytic Choriomeningitis (LCM, a childhood disease), rabies, and West Nile Virus.

There are several bacterial infections that can cause TM. Lyme Disease (neuroborreliosis) is the most commonly recognized. It occurs in the spring and summer when ticks are most active, and typically has a myelopathy accompanied by pain radiating down the limbs, cranial nerve abnormalities, or encephalitis. It is often preceded by a rash. Mycoplasma pneumoniae usually occurs in children where it causes upper respiratory infections and ear infections. Cases have been reported of TM due to Yersinia enterocolitica (which causes abdominal pain), Chlamydia psittaci (Psittacosis, which is caught from certain birds), Rochalimaea henselae (cat scratch fever), syphilis, and tuberculosis.

The only fungal organism that causes TM with much frequency is cryptocossus. Aspergillus may also cause TM. Both are usually seen in patients with suppressed immune systems.

A number of parasitic diseases can cause TM. In general, these may be identified in patients that have appropriate exposure histories. Eosinophils may be seen in the CSF. These include schistosomiasis, toxoplasmosis, cysticercosis, toxocaraisis, gnathostoma, and angiostrongyllus.

The bacteria, funguses and many of the viruses can be cultured from either the blood or spinal fluid during the acute phases of the TM. However, some of the viruses, bacteria and parasitic diseases require serology to make the diagnosis. Serology tests measure the antibodies that a person makes against a particular infection. For the most part, each organism is tested separately. Serology tests are usually optimal when a blood sample at the time of the acute TM is compared to a second sample 6 weeks later. Finally, several of the infections can now be diagnosed using PCR. Several PCR tests can be obtained on a single spinal fluid sample. The PCR test looks for DNA from a particular virus, with each virus requiring a separate test. It can measure extremely small quantities of a virus with results available in a few hours.

With continued advances in our understanding of and ability to diagnose infectious diseases, we

should continue to expand the list of infections that can cause TM. As we learn more about what organisms are found in TM patients, we should be able to explain more of the idiopathic cases. It is also hoped that we will be able to better understand the causes of TM and perhaps minimize the disability or prevent cases due to infectious causes.

Levy: I'm speaking with Andrea Behrman today. Dr. Behrman is an Associate Professor and researcher in the Department of Physical Therapy, University of Florida, and is involved in work that I have known as body weight suspended treadmill training.

Body Weight Suspended Treadmill Training Or Locomotor Training

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Interviewed by
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Is body weight suspended treadmill training an accurate title?

Behrman: If you read in the scientific literature, you will find that this intervention is referred to as treadmill training, body weight support treadmill training, or maybe even suspended treadmill training. I prefer "locomotive training." Body weight support refers to the device, whether it be an air-compression system, or a crank, or something else to help support the person's body weight. Treadmill -- we understand what that is. The equipment merely affords the environment in which we train. A treadmill with a harness is the best equipment available today with which to apply the training principles. However, the equipment may change as technology advances. So, I'm going to suggest we call this intervention "locomotor training."

Levy: So it is really not the equipment that makes the difference.

Behrman: Right, the equipment is a means. The process is more important. The process here is a transmission of sensory information that resembles walking to the spinal cord and brain. This includes joint angles, joint positions, the speed of the limb as it moves through space, timing and weight bearing. We used to believe the brain would issue the executive command or signal to walk to the muscles via the spinal cord. The spinal cord acted like a telephone cable and simply carried commands to the muscles. It turns out the spinal cord is not just a telephone cable but actually is, to some degree, "smart." If the sensory information that is provided to the spinal cord looks like walking, the spinal cord can recognize this information and responds by generating a stepping pattern of muscle activity.

Levy: So if the spinal cord is intact below the level of injury, it doesn't necessarily need the brain to generate muscle activity. Your work has focused on applications to actual human patients with spinal cord injury, but my understanding is that this work originated with animal studies. In particular, a cat can have complete severance of the spinal cord and still have a walk in certain circumstances.

Behrman: Basic scientists performing animal experiments have determined the spinal cord does make a contribution to the control of locomotion, so that it does have its own circuitry that can generate a stepping pattern. When the cat with the severed cord is placed on a moving treadmill with the body weight support, it can walk. However, the cat cannot walk off the treadmill and go climb a fence or chase mice. The cat still needs an intact connection from the brain to the spinal cord to walk at will. A cat with a completely severed spinal cord walks faster as the treadmill speeds up. But this is due to the sensory drive of the treadmill and not from a willful decision to speed up.

Levy: Locomotor training involves suspending a person from a harness while over a moving treadmill. Why is the suspension of weight needed? Why not bear full weight? What does a treadmill do that something else might not do?

Behrman: Many people with spinal cord injuries are too weak to hold themselves upright against gravity. The way we have compensated for this in the past might have been to place a brace around a person's knee or ankle to prevent buckling or to use assistive devices such as walkers or canes. The walkers and canes improved stability by providing a larger base of support. They also reduced the amount of weight born in the legs by transferring some of that weight through the arms. However, leaning forward, and loading the arms while gripping the walker produces very different sensory messages to the spinal cord than normal walking with the trunk upright, arms swinging fully. It may be that changing the typical arm task from swinging to weight bearing or changing the hip position diminishes the spinal cord's capability of producing a stepping response.

There are four potential advantages to gait training with a body suspended treadmill system. First, the person can be aligned into an upright posture similar to that of normal walking. Over time the amount of body weight support will be reduced; in other words, more and more load is being returned to the individual to control. We may begin training at 40-50% of an individual's body weight and reduce it over time. Second, some people gain a feeling of security knowing that they can't fall. Third, the treadmill assists in driving the person's legs and is helpful in providing an adequate speed of walking for training. This speed is often unattainable by the individual's control of walking over ground. Finally, there are the trainers who are going to help move the legs through a pattern very similar to walking which are critical to perform the training. Trainers may help to place a foot, assist with knee extension, or aid in timing between legs. All of these elements in combination make up the training.

Levy: How old is this therapy? Where did it come from?

Behrman: The therapy itself is still experimental and is being developed as we speak and thus is not available in most clinics today. It developed out of the basic sciences by researchers that were interested in understanding the nervous system and how it controls movement and, in particular, walking or locomotion. With animal models, neuroscientists examined how the spinal cord itself functions. They found an inherent rhythm generator within the spinal cord which goes, goes, goes, goes. It will even persist without sensory drive to it. With the sensory drive, it generates motor output. Some people call this activity "central pattern generation." Researchers from the mid-70s or earlier have pursued this work, such as Grillner, Edgerton, Rossignol, and Barbeau. Some of the more clinical work has been only in the last ten years or so starting with Wernig in Germany and Barbeau in Canada. Basic science work in animals has been translated somewhat to the human model by Harkema and Edgerton in California.

Levy: How many clinical trials are you aware of now?

Behrman: Barbeau in Canada conducted a clinic study using similar training to this in stroke populations. In the United States, a clinical trial is underway right now; it is sponsored by the National Center for Medical Rehabilitation Research and will continue for about four more years. It is a randomized clinical trial for acute spinal cord injury, comparing traditional therapy to this new locomotive training. The website for this clinical trial is: http:// www.rctinsci.medsch.ucla.edu/.

Levy: Tell me more about a clinical trial and what we can expect?

Behrman: A clinical trial does not necessarily answer all the questions definitively. Different research questions are asked during the trial and may generate other questions. Outcomes may vary according to the population, medications, or other elements that are necessary or pertinent.

Levy: So, what we are talking about now is a new therapy that is still not standard therapy. There is some reason in initial studies to be encouraged that some form of body suspension that allows an upright posture can be helpful, that some type system to move the lower limbs or what we think is to mimic normal gait can be helpful in restoring gait. You have worked with some patients with this. Tell me about your biggest successes and the limitations of those patients. What can they do and what do they have trouble with? Do they look totally normal? Do they look somewhat normal? Are they still using devices? And tell me about some of the patients who haven't benefited very much.

Behrman: Successful locomotor training and outcomes do not mean that after training the individual walks exactly as they walked before a SCI. But I think people see gains in their mobility and the amount of time they walk. They may still require some assistive device because of the community they live in, for example, with uneven terrain. They may not have developed adequate balance. This training primarily addresses the need to reciprocally move one's limbs necessary for walking. Two other components to walking are the need to balance while walking and the need to adjust to one's environment.

Levy: Walking is a complex activity. It depends on strength and coordination. It depends on an ability to change the program depending on challenges in the environment. It depends on having, basically, a reciprocal gait activity or gait pattern. The body suspended treadmill training seems to be able to restore some elements that might not be accessed in traditional physical therapy. It doesn't necessarily replace all of the elements. How much any given individual will benefit is hard to predict before that patient is evaluated. Some important factors include the level and completeness of injury, how weak or strong a person is, whether there are contractures, and whether the bones are strong enough to accept weight. It is uncertain now how much influence the time from the injury is but there may be a suspicion that sooner might be better than later. The presence of

contractures, perhaps certain medications, may have a negative effect on walking. We are not sure, but there are some animal models that say some of the medications that help reduce spasticity may also have the effect of retarding the neural response to certain training. Is that a fair estimation?

Behrman: All are correct. Let me comment on the last, though. Again, that is something that we don't know. We don't know the interactions of some of these spasticity-reducing medications on the training or a lot of the other activities.

Levy: What lessons has this therapy taught us that allows us to be more hopeful than we might have been. Is there any reason to be more optimistic about the potential for functional restoration than we were ten years ago?

Behrman: Yes. I think we talked a little bit about this, but one view that we have had is that the spinal cord is simply a telephone cable that carries messages. But, evidence from scientists indicates that there is circuitry within the spinal cord itself that can contribute to the control of walking. If we can tap this ability in physical rehabilitation, it may further enhance the ability to walk after SCI. Another view has been that the damage after SCI is permanent. This is beyond our current discussion, but there are certainly researchers who are examining regeneration or growth strategies after injury. Growth stimulants or growth factors or transplants may help resolve, somewhat, some of these disconnections or make more appropriate connections in the spinal cord. It turns out that the spinal cord really can learn very similarly to the way that the brain can learn. In the past we assumed that the recovery of walking, as you and I know it, was not possible based on the anatomy and physiology of the spinal cord. Now there is an abundance of opportunity to facilitate this recovery of walking. Think about other individuals with other pathologies or neurological problems. If I have had a stroke, my spinal cord is still intact. Now, some of the input from the brain is altered but I still have an intact cord itself. Maybe we can use information from the spinal cord to teach the brain something. So, we are kind of working in reverse here. I think that is the opportunity. Perhaps it is not a permanent loss. It may be repairable and if it is repairable, then specific training may stimulate and drive the repair in the right direction.

Levy: So, we are presenting a new hopeful therapy. It is not standard therapy and it is not something that someone is likely to be able to go to their local PT gym now and enroll in. What advice would you give to somebody who has got a disability from a spinal cord injury or a stroke or some other process?

Behrman: Stay in the best shape you can and the best level of fitness that you can. For each person that may be a little bit different. If you have the opportunity to stand, for example, then stand. Standing is a great way to maintain the joint flexibility of your knees and ankles. For some people standing is not available. If not, then a person should make sure to try to lie on his or her stomach to maintain hips flexibility. You never know what advance is coming down the road. Lung capacity is important. Smoking is not beneficial for walking or other activities. Persons who have joint and muscle flexibility and are more fit will be in a better position to accept the opportunity to pursue walking or whatever therapy may be available in the future. Another important element is to stay informed. There are many other sites or opportunities to communicate with others or learn about research all the way from scientific literature to the science section of the New York Times to websites. There are popular magazines, such as New Mobility or Paraplegia News that will have articles to websites on National Institute of Health and the Veterans Affairs research. So, I would recommend that persons read, stay in touch, and keep fit.

Attempting To Recognize Transverse Myelitis Subtypes

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Transverse myelitis is a syndrome of spinal cord dysfunction in which most of the functions, namely motor, sensory and sphincterial are compromised to some degree below a definable sensory level. In more than 80 % of cases, the peak of dysfunction is seen within l0 days. Before the onset of neurological symptoms, non-specific symptoms, such as fever, nausea and muscle pain occur. Initial neurological signs are paresthesias, backache and paresis of legs. Sphincter dysfunction often occurs when weakness and sensory disturbances are present. Thoracic level occurs in 80 %, while cervical and lumbar levels occur in 10% each. In the clinical setting, it is often difficult to distinguish among the various possible causes of TM. MS is often considered a strong possibility, which might not always be the case. Retrospective analyses have provided

useful information regarding the acuity of presentation and its relationship with prognosis, but have not often sorted the various etiologies.

Ropper and Poskanzer studied 52 patients and suggested that patients with acute onset of symptoms tended to have poor prognosis. They reported 4 types of presentation according to symptoms, including paresthesias, pain, weakness and urinary retention. 37 % of patients gave history of previous infection, and 13 % were later diagnosed with MS, but presentation, severity of disease and prognosis were not compared.

Berman studied 62 patients in Israel, reported incidence of 1.34/mill/year and no seasonal preponderance. 37% had a history of previous infections and only one patient developed MS. No attempt was made to characterize clinical differences among groups. Prior to our study, a clinical and laboratory comparison of TM based on presumed cause had not been performed.

We attempted to determine whether clinical differences related to various etiological subgroups. We also presented an estimate of the incidence of TM in a US population.

In our study we found that various types of TM may be distinguishable on the basis of clinical presentation, imaging and CSF studies. In contrast with previous studies, which isolated homogeneous patient populations by studying only the most severe cases, we attempted to classify cases according to cause by means of objective criteria.

Patients with parainfectious-TM (PI-TM) were weaker on initial exam and suffered spinal shock more frequently. They were likely to have more severe and persistent back pain. They have ascending cord dysfunction more frequently and over a great number of segments.

Patients with MS-TM more often had numbness and paresthesias and tended to show spastic paraparesis on initial exam.

PI-TM had a tendency to show spinal cord swelling, while patients with MS-TM tended to show small plaque-like lesions with gadolinium enhancement. The PI-TM CSF did not contain Oligoclonal bands, while the MS-TM CSF did. The incidence of TM was 4.6/million/year. In the PI-TM 73% of infections were from the upper respiratory tract.

Recurrences were seen also in the PI TM. The second episode followed periods of neurologic stability up to years and were not preceded by URI.

Prognosis for recovery of ambulation and bladder control was variable. Patients with PI-TM were less likely to recover bladder function or independent ambulation at discharge. However, in the long term, patients with MS more likely required catheterizations. Recovery varied. If ambulation was not recovered within 2 months, patients with PI-TM tended to remain wheelchair bound.

While the number of cases in each category was small and the retrospective nature of the study limits the strength of the conclusions, there do appear to be differences between PI-TM and MS-TM. A larger prospective study should provide more conclusive information.

Abstract

This article summarizes the clinical presentation and the available information on the neuropathophysiology of neuropathic pain. A review of the somatosensory nervous system anatomy involved in neuropathic pain is also included. The focus is on the peripheral nervous system (PNS) because its mechanisms of pain are better defined than in the central nervous system (CNS). Also, the vast majority of neural damage occurs in the PNS, most likely due to its increased exposure to traumatic injury compared with the CNS. Clinicians who recognize some of the cardinal signs of the most common neuropathies can diagnose and treat their patients earlier, reducing the burden of neuropathic pain. Advances in our understanding of the neural mechanisms of chronic pain will hopefully help to define therapeutic strategies in the future.

The Pathology Of Neuropathic Pain

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There are 2 types of chronic pain: inflammatory nociceptive pain, which is pain associated with tissue damage, and neuropathic pain, which arises from damage to the nerves that carry pain signals from tissue, not damage

to the tissue itself. Neuropathic pain is a classic, localizing, neurological sign. It signals damage to the nociceptive neurons that transmit pain signals, just as weakness signals damage to the motor pathways. However, for reasons as yet unknown, neuropathic pain will develop in only a subgroup of patients who have a neurologic lesion. It is important to note that any type of a lesion (e.g., infectious, neoplastic, or vascular) can produce pain if it affects the pain pathways.

Lesions residing anywhere within the central nervous system (CNS) or the peripheral nervous system (PNS) can produce neuropathic pain, and they are highly subject to several modifiers: genetic, environmental, and behavioral.[1,2] Genetic differences have been observed in inbred strains of rats, showing that after surgery on peripheral nerves, some strains of rats exhibit striking pain-related behavior, whereas others are seemingly unperturbed by the same procedure.[3] Genetic modifiers may help to explain the incomplete expression of neuropathic pain in patients with lesions.

The most common type of neuropathic pain syndromes are the sensory polyneuropathies, the mono-neuropathies, and the central pain syndromes.

Clinical Characteristics of Neuro-pathic Pain

The most striking sign of neuropathic pain (as opposed to nociceptive pain) is the relative lack of tissue pathology. Most patients do not have obvious tissue injury (although they may have had previous injury) yet complain of pain, and their complaints often seem to be out of proportion to the pain that would be expected to accompany the original injury.

The cardinal features of neuropathic pain include constant pain, which can be superficial or deep, sharp or aching, lancinating pain (i.e., sudden and sharp, severe bursts of pain), and allodynia (i.e., pain experienced after normally nonpainful stimuli, such as light touch). Patients with allodynia can have difficulty wearing clothing. Neurologists often look for motor deficits in neurological disorders, yet many neuropathic pain patients do not have motor damage. If motor deficits are present, they can be helpful in localizing the area of nerve damage, because the technologies available for localizing motor deficits (e.g., electromyography) are better developed than current methods for localizing sensory deficits.

PNS Lesions

Polyneuropathies

Many polyneuropathies are mixed (i.e., sensory and motor nerves are affected), although some patients can have pure sensory neuropathy and some can have mixed autonomic neuropathy. If the patient complains of pain, it indicates that the neuropathy is affecting their small nociceptive fibers. Some sensory neuropathies affect predominantly the large sensory fibers, producing a pattern of sensory ataxia and loss of proprioception, whereas neuropathies that affect the small fibers produce pain.

Diagnosing Peripheral Neuropa-thies

Traditional tools such as electromyography and nerve conduction studies are useful primarily if the neuropathy affects the motor fibers or the large sensory fibers. Nerve conduction studies reflect conduction in the large myelinated axons; they do not reflect activity in the small myelinated fibers and unmyelinated C and A-d fibers. Thus, normal nerve conduction study results do not preclude a diagnosis of neuropathy.

Quantitative sensory testing is a helpful adjunct but is not universally available. It involves the application of controlled mechanical, thermal, or chemical stimuli. Patients report their perception of the stimulus and indicate the point at which it becomes painful, which allows an evaluation of the patient's sensory threshold for various types of stimuli.

Sural nerve biopsy is a technique that is used less frequently because of the resulting scarring, as well as risk for infection, sensory deficits, and, ironically, neuropathic pain syndromes in some patients.[4] Skin biopsies are beginning to replace sural nerve biopsies for the diagnosis of peripheral sensory disease in many patients. Skin biopsies require a small sample of the epidermis be taken, using local anesthetic, from anywhere on the body. Skin biopsies can be repeated, which is useful for monitoring response to therapy or disease progression. The biopsy sample is immunolabeled with an antibody against PGP9.5, a panaxonal marker so the small sensory nerve endings in the skin can be seen and counted using a light microscope. Skin biopsies allow quantitative measurement of the sensory nerve endings in the epidermis because they exist as individual nerve endings that can be counted. Measurement of the sensory nerves that end in the dermis (i.e., the large, myelinated Ab fibers that encode touch) cannot be as precise because dermal axons tend to cluster in bundles.[5]
Normative data are available to show the normal density of cutaneous nerve endings and provide a point of comparison for the test patient.[6] However, like sural nerve biopsies, clinical diagnostic skin biopsies are only offered at specialized center such as Johns Hopkins University and the

Massachusetts General Hospital.

These epidermal neurites are almost all nociceptors. Many other types of sensory receptors are located in the dermis, so they are not included in epidermal nerve density counts. Skin biopsies therefore are especially useful for patients with disorders of pain neurons. For example, a recent study by Oaklander et. al. showed that there are fewer remaining nerve endings in the skin of patients with posttherpetic neuralgia PHN than in patients without PHN after shingles (dermal innervation is also reduced in PHN after shingles.)[7] In fact, all skin biopsy studies of neuropathic pain patients show that epidermal innervation is reduced in neuropathic pain syndromes.[8-10] Oaklander recently showed that a minimum innervation level of approximately 650 neurites/mm2 may be necessary to avoid the presence of pain after shingles. Below this threshold, the minimum number of primary nociceptive neurons is not preserved and the result is PHN.[11]

Pathophysiology of Mononeuropathies

Nerve roots are vulnerable to compression (e.g., compressive radiculopathy, infections, and tumors). If the lesion is proximal to the dorsal root ganglion, there may be abnormality of the central axons but not necessarily of the peripheral axons. Therefore, tests aimed at the peripheral axons will not detect the injury in those situations. Likewise, complete degeneration of the axon is not necessary to produce clinical symptoms: lesions may be in the form of perinodal retraction of myelin or frank demyelination. Demyelination with ephaptic spread of action potentials between adjacent axons is believed to underlie bursts of lancinating pain because the action potentials transmitted along a few fibers can inappropriately spread to many other axons.

Neuropathic pain can also result from the post-injury remodeling of cell membranes of sensory neurons. The remodeled membrane develops new properties that generate action potentials in places where action potentials are not normally generated. Transmission may also be abnormal. When mechanical transducers are present in axonal sprouts located along damaged nerve, a simple tap can produce pain.

Surgery is another cause of painful mononeuropathies. A recent review of surgery- and trauma-induced chronic pain suggests that trauma and surgery should not be considered together as a single categorical cause of chronic pain. Accidental trauma pain patients are more likely to be younger and male than patients with iatrogenic nerve injury. In one study of chronic pain patients, surgery was a cause of pain in up to one fourth of the study population.[12]

Complex Regional Pain Syndrome

Complex regional pain syndrome (CRPS) is one of the most severe and mysterious neuropathic pain syndromes. CRPS patients are typically in their 30s or 40s, but can be younger. A common cause of nerve injury in CRPS is trauma incurred on the job, or in sports and recreation, which explains the relatively young ages of patients. Interestingly, about 5% to 10% of CRPS patients report no history of trauma. It is important to recognize that there may have been some sort of internal trauma that was not recognized.

The clinical symptoms of CRPS always include pain, hyperalgesia, and allodynia. If there is also motor axon damage, then there may be dystonia, weakness, or atrophy. One common presentation is the patient wearing a single glove over the painful hand to protect it from painful contact, and perhaps to receive some relief from the ongoing soft, mechanical stimulation provided by the glove.

The International Association for the Study of Pain (IASP) classifies CRPS as either CRPS I (pain with no known nerve injury) or CRPS II (pain with known nerve injury).[13,14] They are otherwise clinically identical. It is likely that in CRPS II, at least in most cases, patients actually do have an injury that has not yet been detected.

Extraterritorial pain is often seen in CRPS expanding either outside of the area of injury (often proximally), or to the whole limb. Mirror pain, or pain in the other limb or the area immediately opposite the original injury, is also common. It is prudent to refer patients with CRPS to a center experienced in the diagnosis of nerve injury for advanced evaluation.

Lesions Affecting the Neurosensory Ganglion

The sensory ganglia are damaged less frequently than the peripheral nerves because they are fairly well protected by the vertebrae. However, they are vulnerable to bony compression. Several paraneoplastic syndromes and other autoimmune problems (e.g., Sjogren's syndrome) can attack these ganglia.[15]

By far, the most common sensory ganglia problem is herpes zoster or shingles, which currently affects 15% of Americans.[16] These lesions affect the sensory ganglia themselves: the trigeminal ganglion innervating the face or the dorsal root ganglia innervating the body. Acute shingles can appear on the body or the face. The most important concern with

herpes zoster infection is PHN, which occurs in roughly 10% of shingles cases.[17] PHN can last long after the shingles has resolved, and in some patients is a lifelong disorder. The risk for PHN is directly proportional to age.[18]

Shingles causes sensory ganglion cell bodies and their to axons die.[19,20] In some patients, these reductions in nerve endings are bilateral and segmental.[7,21]

CNS Lesions

CNS-induced neuropathic pain is less common than PNS-induced neuropathic pain. Clinical conditions that affect the lateral spinothalamic tracts are far more likely to produce pain than conditions affecting the dorsal column and medial lemnisci. Not uncommon in clinical practice are syrinxes (abnormal cavities in the spinal cord), which affect sensory fibers as they decussate. When syrinxes enlarge, patients can present with a severe segmental pain syndrome in the absence of motor findings because the motor axons remain laterally located in the spinal cord.

In the CNS, there is no one disease that causes neuropathic pain; it can occur with stroke or multiple sclerosis, or any disease state in which a lesion affects the ascending pain pathways.[22-24] Spinal cord injury can combine injuries to both the PNS and CNS.

Functional magnetic resonance imaging (fMRI) has recently shown the presence of widespread cortical plasticity, some of which may account for extraterritorial pain or the spread of pain. Vacant synapses from dying neurons are often filled by neurons in adjacent areas. This plasticity may explain why a patient with phantom pain in an amputated hand can trigger that pain by touching lightly near the corner of his or her mouth. In the cortex homunculus, the mouth region is located adjacent to the hand, so fibers may have sprouted from the mouth area into the hand area.

Conclusion

Neuropathic pain signals damage to nociceptive neurons just as weakness indicates damage to motor nerves. Unfortunately, localization of lesions in nociceptive pathways is not always straightforward. However, understanding the neurophysiology of neuropathic pain can help the physician diagnose and determine the best treatment. In the future, we hope to have better markers or laboratory tests to confirm sensory neural injury.

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Abstract

Neurologists have the option of choosing from among numerous drugs and drug classes when treating neuropathic pain. The challenge, therefore, lies not in having limited options for treatment, but in the art of practicing medicine, i.e., of identifying neuropathic pain and empathizing with the patient without the benefit of either an objective test or a complete understanding of pain pathophysiology, and providing the best evidence-based options for therapy. The International Association for the Study of Pain definition of pain - a sensory and emotional experience, signaling actual or potential tissue damage - illustrates the dual nature, both objective and subjective, of this condition. The neurologist's unique understanding of the complex interactions that occur in the nervous system can provide a significant contribution to the care of patients with pain.

Additionally, we must remember that many patients, unable to quantitatively describe their pain and witnessing the medical community's lack of codified remedies, leave the physician's office thinking that the practitioner views their pain, even when incapacitating, as psychosomatic. An equally important role of the practicing neurologist, therefore, is to acknowledge the patient's experience of pain without attempting to validate its source. This article includes strategies for approaching a neuropathic pain patient, useful methods to treat the whole patient, and a discussion of why a holistic approach is important. An overview of the pharmacotherapies available for the treatment of neuropathic pain and their role in treating the whole patient is also provided.

Treating Neuropathic Pain And The Neuropathic Pain Patient

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Treating neuropathic pain means treating the neuropathic pain patient by first understanding what the patient is experiencing. This can be difficult, as there are no empirical tests for pain. Yet, the pain is completely real to the patient, and may even be incapacitating. The primary role of the physician is to make the appropriate diagnosis and focus treatment on the most important features of the patient's pain as reported by the patient. This should always include the presumed underlying pathophysiologic mechanism but must also focus on other contributing factors, some of which may be more amenable to treatment than the primary process.

What Is Pain?

The International Association for the Study of Pain (IASP) defines pain as: "The unpleasant sensory and emotional experience of actual or potential tissue damage or an experience expressed in such terms."[1] Since pain is both a sensory and an emotional experience (i.e., it affects the whole person), the whole person must be treated. The degree of pain intensity can be affected by the patient's attitude and perceptions of

his surroundings. A broken toe will seem less painful if injured on the way to the airport to start one's vacation than if this takes place on the way to an Internal Revenue Service audit. Similarly, a cancer patient with back pain will experience a lessening of pain when assured by the physician that the pain is not indicative of metastasis or recurrence of the cancer. In fact, the use of environmental factors for managing pain intensity, known as distraction therapy, is widely used by practitioners and patients to help patients perform daily activities in spite of pain and other discomforts. The popularity of distraction therapies is the result of its demonstrated effectiveness in both the laboratory and the clinical setting.[2]

Despite the exponential growth of our knowledge about the brain in recent years, we do not yet understand the intricate pathophysiological mechanisms of neuropathic pain. We do, however, know that the brain, through the production of hormones and direct nerve connections from the brain to the pain fibers, is capable of far more control over the pain system than was previously thought. Yet since we have not identified a means to specifically harness this descending control system, a physician's best hope for providing effective treatment is to present patients with the various pain-management strategies and to support them in their search for the one or ones that work, remembering that efficacy is subjective and patient specific, much like in the treatment of psychiatric illness. Similarly, the success of treatment can be assessed only by individual patients reporting on changes in their symptoms.

The IASP definition of pain also includes the phrase "actual or potential tissue damage or an experience expressed in such terms." Acute pain is experienced immediately upon injury and notifies the individual of tissue damage. Neuropathic pain is caused by nerve damage proximal to the sensory nerve endings in the skin. Neuropathic pain has no protective or predictive value, because it persists long after tissue (i.e., nerve) damage has occurred. In essence, the lack of a specific measure of tissue damage does not preclude the sensation of pain.

Patients with neuropathic pain may also report fatigue, difficulty in concentrating, depression, and insomnia, and the severity of these symptoms may seem disproportionately high relative to the initial injury. Again, the most effective approach is to acknowledge the patient's discomfort and make a commitment to treat the pain. The hope gained from knowing that the physician will attempt to treat one's pain provides an effective distraction.

Types of Pain

The 3 types of pain (somatic, neuropathic, and visceral) are often co-occurring or comorbid as a mixed syndrome, so treating the neuropathic component may only treat part of the patient's symptoms. Most pain patients, especially those with chronic pain, have a mixed syndrome (neuropathic and somatic pain). Unlike somatic pain, which comes from specialized nerve endings and warns of tissue damage, neuropathic pain comes directly from nerve dysfunction and does not imply ongoing damage. It is important for physicians to explain this distinction to patients, who will be reassured when they learn that their pain does not signal continuous damage and may not be the harbinger of a more serious illness.

A common example of this mixed somatic/neuropathic syndrome is compression of a small nerve in the spine (neuropathic), which leads to muscle spasm (somatic). The body responds to the pain of compression by protecting the area through spasms, which create muscle pain in the area as well as other inflammatory responses. While the patient feels the muscle pain, the underlying pathology can be neuropathic. In treatment, therefore, residual pain after treating somatic pain should be considered an indication of possible neuropathic pain, even if the symptomatic features of the neuropathic pain are not predominant.

There are several neuropathic pain syndromes, outlined in Table 1, that are the result of ectopic generators, nerve trunk pain, microenvironmental changes, central alterations, and changes in the balance of nociceptor and nonnociceptor fibers. At this time, it is not yet possible to determine which of these factors specifically cause an individual's neuropathic pain. However, all of these factors can result in sensory loss, paresthesias (positive numbness or tingling), dysesthesias (painful or unpleasant burning, tingling or electric shock phenomenon), hyperesthesia (increased perception of mildly painful stimuli), hyperpathia (subthreshold stimuli producing pain), or allodynia (nonpainful stimuli producing pain).

Table 1. Common Types of Neuropathic Pain*

Examples of peripheral neuropathic pain

- Carpal tunnel syndrome

- Complex regional pain syndrome
- Human immunodeficiency virus (HIV) sensory neuropathy
- Meralgia paresthetica
- Painful diabetic neuropathy
- Phantom limb pain
- Postherpetic neuralgia
- Postthoracotomy pain
- Trigeminal neuralgia
- Radiculopathy

Examples of central neuropathic pain
- Central poststroke pain
- HIV myelopathy
- Multiple sclerosis pain
- Parkinson's disease pain
- Spinal cord injury pain
- Syringomyelia

Examples of cancer-associated neuropathic pain
- Chemotherapy-induced polyneuropathy
- Neuropathy secondary to tumor infiltration or nerve compression
- Phantom breast pain
- Postmastectomy pain
- Postradiation plexopathy and myelopathy

*Reprinted with permission from A Clinical Guide to Neuropathic Pain. Galer BS, Dworkin RH, eds. Minneapolis, MN: McGraw-Hill Healthcare Information; 2000.

Treating Neuropathic Pain

Pain is a central nervous system (CNS) phenomenon, and neuropathic pain can be thought of as a loss of normal control in the nervous system, not unlike epilepsy.[3] However, because we cannot tell which mechanism is the predominant cause, treatment is currently based on assumptions about the type of input, not which transmitter, is out of balance. It has been demonstrated that the way in which pain is perceived and evaluated by patients affects their mood. Chronic pain has been shown to beget depression; conversely, depression can make chronic pain seem worse.[4]

Sections of the thalamus and the sensory cortex are the primary areas of the brain where neuropathic pain is perceived.[5] Two of the primary descending pain control systems come from the hypothalamus and the periaqueductal gray matter, and are mediated by several neurotransmitters including the noradrenergic and serotonergic systems.[6-8] Some of the first-line pharmacotherapies for neuropathic pain target these systems.[9] The noradrenergic system may also be involved in the control of pain in situations of severe danger (e.g., running into a burning building to save a child). Nociceptive nerve endings signal the pain but the brain does not register the pain. These are short-lived mechanisms that last only for the duration of the emergency but may be the same mechanisms at work during distraction therapy (i.e., shutting down the nociceptive primary afferent fibers).

Treatment Strategies

Although the science of treating neuropathic pain is still young, there are drugs and combination therapies from several different disease areas that can be used. Some of the treatment modalities are, in fact, also used for somatic pain, but some agents are CNS specific.

First-line therapy for neuropathic pain is analgesics, followed by neuroactive agents. There are several classes of adjuvant analgesics that are effective, including antidepressants, anticonvulsants, antispasm agents, local anesthetics, and a2-adrenergic agonists. In general, neuroleptics have not proven to be effective. Of note, a large number of complementary or alternative therapies have been suggested for the treatment of pain. However, they require further evaluation before specific recommendations can be made.

Antidepressants

Amitriptyline is one of the oldest and most commonly used tricyclic antidepressants (TCAs) for post-herpetic neuralgia (PHN) and diabetic neuropathy.[10-12] This drug exerts both noradrenergic and serotonergic uptake inhibition, believed to be the cause of both its analgesic activity and its association with mood elevation. Amitriptyline is also associated with significant anticholinergic side effects that cannot be tolerated in some patients, including cardiac arrhythmias in elderly patients, urinary retention, and dry mouth. Nortriptyline has been shown in controlled clinical trials to be as effective in postherpetic neuralgia as amitriptyline but with far fewer side effects.[13] The side effects most common with TCAs include dry mouth, somnolence, weight gain, constipation, and memory impairment. Less common side effects include urinary retention, orthostatic hypotension, cardiac arrhythmias, and blurred vision.

The selective serotonin reuptake inhibitors (SSRIs) are also frequently used in chronic pain patients, although they do not appear to have direct analgesic properties. With fewer side effects and effective anti-depressant effects, they are helpful in addressing the psychological sequelae of chronic pain that reinforce and exacerbate the perceived level of pain. SSRIs such as citalopram, fluoxetine, fluvoxamine, paroxetine, and sertraline cause far fewer side effects than TCAs. Other antidepressants that also affect norepinephrine reuptake or the noradrenergic system include bupropion, maprotiline, mirtazepine,

nefazodone, trazodone, and venlafaxine. Venlafaxine, in particular, has shown benefit in treating neuropathic pain in recent case reports.[14-17] SSRIs have few serious side effects but can cause somnolence, changes in weight, and some memory impairment.

Antiepileptic Drugs

Antiepileptic drugs (AEDs), are useful in the treatment of neuropathic pain and migraine. The mechanism of action of AEDs in neuropathic pain is not well understood. Their effect on cellular activity appears to include modulation of ion channels or alterations in transmitter production, release, uptake, and/or breakdown. Their effect on neuronal activity, also poorly understood, includes suppression of paroxysmal discharges, reduced neuronal hyperactivity, and suppression of aberrant discharges. AEDs act both centrally and peripherally.[18,19]

First-generation AEDs were carbamazepine, phenytoin, and valproic acid. Carbamazepine was initially used to treat trigeminal neuralgia (TN) and was the "gold standard" for treatment of TN for many years. Second-generation AEDs include gabapentin, lamotrigine, levetiracetam, oxcarbazepine (a metabolite of carbamazepine), tiagibine, topiramate, and zonisamide. In general, the second-generation AEDs have the advantage of a much improved side-effect profile.

Because each AED works, presumably, by a different mechanism, each one tends to be effective only in a subgroup of patients, as has been shown with gabapentin in the treatment of PHN and diabetic neuropathy.[20,21] This should not discourage the use of AEDs in treating neuropathic pain, because they can be extremely effective in that specific subgroup, however, it makes it all the more important for physicians to carefully manage patient expectations, avoid raising hopes, and promote compliance with an appropriate trial of therapy. Several drugs may need to be tried before the desired results are seen and results will vary among patients, even those suffering from the same underlying disease. For example, among 3 patients with similarly caused damage to the nervous system, the resulting neuropathic pain may be due to the sodium channel in one patient, the calcium channel in another, and a different channel in a third.

Severe side effects associated with AEDs include hepatotoxicity (carbamazepine and valproate), Stevens-Johnson syndrome (lamotrigine, phenytoin, and zonisamide), aplastic anemia (carbamazepine), and teratogenicity (carbamazepine, valproate, and possibly others). Mild and more common side effects include dizziness and ataxia, somnolence, cognitive impairment, nausea/ vomiting, and weight gain. However, topiramate has been associated with weight loss in some people, which may be an advantage in treating overweight or obese patients with neuropathic pain. Also, topiramate, levetiracetam, and gabapentin do not appear to cause hepatotoxicity.[22] Hepatotoxicity and anemia can be particularly problematic in treating pain in cancer patients.

Opioids

Opioids may be effective at very high doses and can offer dramatic relief for some patients treated at these levels. Patients often report that lower doses take the edge off their pain, but substantial relief may require very high does. Like other drugs used for neuropathic pain, opioids can be effective in a select subgroup of patients. Although their use has sparked controversy due to the potential of abuse by patients who are addiction prone, it is rare for a chronic pain patient to develop a true addiction. As with the other neuroactive medications, opioids should be used on a case-by-case basis, and the drugs should be discontinued if they are ineffective or if the side effects cannot be tolerated. Patients who may be candidates for high-dose opioid therapy are probably best served by a referral to a chronic pain clinic.

Topical Therapies

Topical therapy (patches or creams) can be useful for patients who have small areas that are hyperesthetic. Patches that protect the area against impact or friction and reduce sensory inputs from the area are available, with or without lidocaine. Capsaicin cream may be effective, but the patient often experiences pain at the site of application like that typically associated with eating hot peppers. This pain often abates after 3 or 4 uses, but if the patient stops regular use, the "hot pepper response" returns and tolerance needs to be rebuilt. These therapies are short acting and many of them are difficult to apply.[23-27]

Physical Therapy

Physical therapy is important for neuropathic pain management because active people heal and adapt faster.[28-30] Because muscle spasms can add significantly to a patient's pain, it is vital that muscles be kept active and loose. Training tight muscles or muscles that are in spasm (a common cause of trigger points) to relax can substantially improve a patient's level of function. In addition, patients must

maintain muscle tone and the support that muscles provide, because loss of tone and support can lead to other problems such as back instability and tight, painful joints. However, as patients begin to improve and increase their activity, they may initially request more pain medication to offset the pain related to the activity. This is a reasonable request and should be fulfilled, because renewed activity serves the primary purpose of treatment for pain: to help patients return to a more normal lifestyle. In fact, if the newly active patient requests additional medication for this purpose, the pain treatment has been a success.

Psychological Therapy

Psychological therapy should always be part of the pain-management process. Chronic illnesses, especially those associated with neuropathic pain, can cause severe psychological distress, often leading to depression, so neurologists must actively address the psychological aspects of the patient's condition and be prepared to make referrals for appropriate psychological services.[9] It is important to reassure the patient that they are not imagining or overreacting to their pain, and that you are encouraging them to get appropriate help and that you understand the difficulty of their situation.

Several therapies can benefit patients by helping them to understand the mind-body connection and take control of the pain, rather than allowing the pain to control them. These include yoga, acupuncture, biofeedback, relaxation techniques, hypnosis, imagery, and a host of other meditative techniques. In addition to the positive psychological effects of such therapies, there is growing evidence, taken from experiments in animals and brain imaging studies, that patients can increase endogenous endorphin levels and influence the brain's pain-control system.[31-35] As with the pharmacotherapeutic interventions, we cannot predict which method will work for a particular patient, so again, the therapy must be matched to the patient's lifestyle and needs.

Neurolytic Techniques

Neurolytic techniques, either neurosurgical or anesthesiological, are generally not helpful, except in some patients who have less than a 12-month life expectancy, because the pain often returns. Pain is resilient; it often finds another way around externally imposed blocks. It is important to realize that the nerve cell body for peripheral sensory nerves is in the dorsal root ganglion, near the spinal cord. One of many possible theories is that if a peripheral nerve is cut during surgery, the central pain system continues to function and adapts to the fact that no signal is being sent from the cut nerve. This may result in sensitivity to any response being increased to the point that when a signal comes in (i.e., from a different nerve), the response to the signal is picked up much more acutely. It has been demonstrated that nerves will try to grow back after being severed, although often in an aberrant manner, such as neuromas.[36,37] Another theory about the etiology of neuropathic pain is that there is aberrant cross-stimulation between these neurons resulting in painful discharges.

Counterstimulation Techniques

Spinal cord stimulators are generally wires that are inserted through an epidural needle placed in the spinal canal and appear to cause a counterirritation in the affected area. This input to the nervous system of a nonnoxious stimuli appears to reduce the amount of noxious input. Spinal cord stimulators are most useful in unilateral limb disease but can be used bilaterally, and in different areas of the body. Limitations to their use include the lack of clinical trials to support their use in neuropathic pain, a battery life of 5 to 7 years, and the risk for infection. Additionally, the lead of the wire can be covered with fibrose tissue and lose effectiveness over time.[38-40]

Peripheral nerve stimulators require a neurosurgeon, preferably a peripheral nerve specialist, to open and examine the damaged nerve. For select patients with well-defined, dramatic mononeuropathies, peripheral nerve stimulators have an 80% to 90% success rate compared with 50% for spinal cord stimulators. However, of those who are successfully treated initially, only about one half will enjoy long-term relief.[41]

Transcutaneous electrical nerve stimulation (TENS) involves applying small amounts of electrical stimulation to the skin. TENS has not been shown to be effective in treating neuropathic pain, perhaps because the electrodes are placed on the nerve endings rather than connected directly to the nerve.[42] Success or failure with a TENS unit does not predict the outcome from other types of stimulators.

Principles of Use

The principles of adjuvant medication use in neuropathic pain treatment are outlined in Table 2.

Table 2. Principles of Adjuvant Medication Use

Examples of peripheral neuropathic pain

- Believe the patients' report of their pain

- Establish the appropriate diagnosis and treatment of pain
- Choose medication carefully for both effect and side effects
- In drugs that have significant side effects, start at a very low dose to allow accommodation to those side effects
- Increase dose slowly and regularly until effective or side effects become intolerable
- Push to high therapeutic dose if possible
- Watch for and treat side effects
- Try each medication one at a time and allow enough time for results
- All potentially effective medication in a group should be tried
- Polypharmacy is often necessary

Assuring an appropriate diagnosis and treatment are important and first require addressing the problems of the patient as a whole. For example, a previously stable patient who presents with uncontrollable pain may be under the influence of several factors. While it may be true that the underlying disease process that is causing the pain has gotten worse, it is also just as likely that the absorption of previously tolerable drug therapy may have changed, the patient may have become tolerant to the effects of the drugs, or the patient may be experiencing significant personal distress (e.g., divorce, job loss, death of a loved one) that has reduced their tolerance for pain. The second step is to choose the initial medication or any change in medication based on both the desired effects and side effects. Clinicians should try to use the side-effect profile to their advantage. For example, an insomniac patient may do better on a pain treatment with a somnolence side effect, when a majority of the dose is given at night. For medications with significant potential side effects, the treatment should start at a low dose and be titrated up slowly. For newer drugs with less side effects, doses can be started at therapeutic levels. Most important, the dose should continue to be increased until there is a beneficial effect, the patient has too many side effects, or the level being used exceeds the high therapeutic range before deciding whether the treatment is working. Similarly, adequate time should be given to determine the success or failure of treatment.

Because drugs in the same class can work through different mechanisms, all drugs in a class should be tried sequentially in patients with difficult-to-control symptoms. Given the complex set of symptoms involved in chronic pain, polypharmacy is often necessary. If a medication works, it is reasonable to treat any side effects associated with high therapeutic doses when necessary. When possible, side effects should be anticipated and aggressively managed.

Conclusion

In addition to the appropriate use of the myriad pharmacotherapy choices for treating neuropathic pain, perhaps the most important clinical intervention neurologists can offer neuropathic pain patients is empathy, hope, and ongoing support. The importance of this cannot be overstated. Chronic pain inflicts significant sensory and emotional burdens on our patients and both must be addressed to ensure successful outcomes. Most neuropathic pain patients experience some improvement when physicians adopt a holistic approach to treatment.

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As most of you are aware, the TMA has been administering a survey to its members since January, 1997. We have been entering data since the inception of the study. We continue to administer and collect surveys, and we encourage each of you to fill out the survey, if you have not already

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done so. All of the respondents to the surveys are being kept completely anonymous. There is no way to identify any of the responses in the analysis and results with a particular respondent. There are no names or identifying characteristics associated with any of the data being analyzed.

We are in the process of coding the survey responses, and beginning to perform some analysis of the data. What appears in this newsletter is a very brief report of some of the preliminary results. David and I would like to thank Dr. Hisham Choueiki for his assistance in performing our analysis and for reviewing our report.

It is critically important to keep in mind that our sample is not a randomly selected sample. Our sample is composed of individuals who have found The Transverse Myelitis Association and have chosen to complete and return the survey. In addition, there is a considerable response bias, which will have an impact on the results. For instance, most of our members have found us via the Internet. From what we understand of the digital divide, that likely means that our sample is under-represented by people who are minorities, low income and elderly. Additionally, it is likely, since the survey appears only in English, that our sample does not adequately represent people who do not have some facility with the English language. When we prepare the final report, we will offer a complete discussion of response bias. For the purposes of this article, it is merely important to consider that there is response bias.

Another important shortcoming of the data is that it is self-reported. We have no way of knowing whether all of the respondents received a ***good*** diagnosis of TM. The doctors who offered the TM diagnosis to our respondents used a set of criteria to make their diagnosis; we have no idea what those criteria were and we have no reason to believe that they all used the same criteria or that the criteria were consistently applied.

Having identified some of the serious problems with the data, I will close this introduction by noting that while there are certainly flaws in the data, it remains of extremely high value for the purpose of better understanding Transverse Myelitis. There are 546 respondents currently in our sample; there is no published research that comes close to this number of TM patients.

Table 1 presents the geographic distribution of the sample. The vast majority of the sample is from the United States; the UK and Canada represent the majority of the international respondents.

Table 2 identifies the current state residence of each of the respondents in our sample. The column "No. in Sample" reports this number. One of the issues we tested was whether any of the states were either over-represented or under-represented in our sample as compared to the state's proportionate population size. This test also addressed the representativeness of our sample as compared to the general population of the United States. The United States population data was derived from the 2000 census. We generated two sets of percentages; the first was derived by dividing each state population by the total United States population and the second was derived by dividing the sample of TM respondents for each state by the total number in the sample. There were 51 pairs of percentages; we included the District of Columbia. While there are 455 US residents in our sample, only 454 were included in this analysis. One of the US respondents was serving on a military base and did not identify a state of residence on the survey.

Table 1 Geographic Distribution of Sample

Australia	7
Brazil	3
Canada	24
Denmark	2
E Malaysia	1
France	1
Germany	1
Greece	1
Holland	1
India	1
Ireland	2
Italy	2
Japan	1
New Zealand	1
Republic of Korea	1
Scotland	4
South Africa	2
The Netherlands	2
Turkey	1
UK	33
USA	455
Total Sample	546

We ran a paired T-test that compared each pair of percentages for each state. The Null hypothesis was the following: There is no difference between each pair of percentages; the percentage of TM respondents of each state versus the percentage of each state population. The alternative hypothesis states that there exists at least one state that is either over-represented or under-represented. The p -value from the T-test was 0.8042, which means that we failed to reject the Null hypothesis at the 0.05 level of signifi-

State State Pop % State Pop No. in Sample % State in Sample SampleN_Pop

AL 4447100 2% (0.0156) **8** **2% (0.0176)** 1.79893E-06

AK 626932 0% (0.0022) **2**

0% (0.0044)		3.19014E-06			
AZ	5130632	2% (0.0180)	**9**	**2% (0.0198)**	1.75417E-06
AR	2673400	1% (0.0094)	**1**	**0% (0.0022)**	3.74056E-07
CA	33871648	12% (0.1188)	**46**	**10% (0.1013)**	1.35807E-06
CO	4301261	2% (0.0151)	**6**	**1% (0.0132)**	1.39494E-06
CT	3405565	1% (0.0119)	**3**	**1% (0.0066)**	8.80911E-07
DE	783600	0% (0.0027)	**1**	**0% (0.0022)**	1.27616E-06
DC	572059	0% (0.0020)	**2**	**0% (0.0044)**	3.49614E-06
FL	15982378	6% (0.0560)	**25**	**6% (0.0551)**	1.56422E-06
GA	8186453	3% (0.0287)	**15**	**3% (0.0330)**	1.8323E-06
HA	1211537	0% (0.0042)	**2**	**0% (0.0044)**	1.6508E-06
ID	1293953	0% (0.0045)	**2**	**0% (0.0044)**	1.54565E-06
IL	12419293	4% (0.0435)	**24**	**5% (0.0529)**	1.93248E-06
IN	6080485	2% (0.0213)	**9**	**2% (0.0198)**	1.48015E-06
IA	2926324	1% (0.0103)	**5**	**1% (0.0110)**	1.70863E-06
KS	2688418	1% (0.0094)	**2**	**0% (0.0044)**	7.43932E-07
KY	4041769	1% (0.0142)	**6**	**1% (0.0132)**	1.4845E-06
LA	4468976	2% (0.0157)	**7**	**2% (0.0154)**	1.56635E-06
ME	1274923	0% (0.0045)	**3**	**1% (0.0066)**	2.35308E-06
MD	5296486	2% (0.0186)	**14**	**3% (0.0308)**	2.64326E-06
MA	6349097	2% (0.0223)	**15**	**3% (0.0330)**	2.36254E-06
MI	9938444	3% (0.0348)	**16**	**4% (0.0352)**	1.60991E-06
MN	4919479	2% (0.0172)	**2**	**0% (0.0044)**	4.06547E-07
MS	2844658	1% (0.0100)	**4**	**1% (0.0088)**	1.40614E-06
MO	5595211	2% (0.0196)	**8**	**2% (0.0176)**	1.42979E-06
MT	902195	0% (0.0032)	**1**	**0% (0.0022)**	1.10841E-06
NE	1711263	1% (0.0060)	**3**	**1% (0.0066)**	1.75309E-06
NV	1998257	1% (0.0070)	**3**	**1% (0.0066)**	1.50131E-06
NH	1235786	0% (0.0043)	**3**	**1% (0.0066)**	2.4276E-06
NJ	8414350	3% (0.0295)	**11**	**2% (0.0242)**	1.30729E-06
NM	1819046	1% (0.0064)	**4**	**1% (0.0088)**	2.19895E-06
NY	18976457	7% (0.0665)	**27**	**6% (0.0595)**	1.42282E-06
NC	8049313	3% (0.0282)	**16**	**4% (0.0352)**	1.98775E-06
ND	642200	0% (0.0023)	**1**	**0% (0.0022)**	1.55715E-06
OH	11353140	4% (0.0398)	**27**	**6% (0.0595)**	2.3782E-06
OK	3450654	1% (0.0121)	**3**	**1% (0.0066)**	8.694E-07
OR	3421399	1% (0.0120)	**8**	**2% (0.0176)**	2.33822E-06
PA	12281054	4% (0.0431)	**28**	**6% (0.0617)**	2.27993E-06
RI	1048319	0% (0.0037)	**1**	**0% (0.0022)**	9.53908E-07
SC	4012012	1% (0.0141)	**9**	**2% (0.0198)**	2.24326E-06
SD	754844	0% (0.0026)	**2**	**0% (0.0044)**	2.64955E-06
TN	5689283	2% (0.0199)	**8**	**2% (0.0176)**	1.40615E-06
TX	20851820	7% (0.0731)	**21**	**5% (0.0463)**	1.00711E-06
UT	2233169	1% (0.0078)	**0**	**0% (0.0000)**	0
VT	608827	0% (0.0021)	**1**	**0% (0.0022)**	1.6425E-06
VA	7078515	2% (0.0248)	**12**	**3% (0.0264)**	1.69527E-06
WA	5894121	2% (0.0207)	**12**	**3% (0.0264)**	2.03593E-06
WV	1808344	1% (0.0063)	**3**	**1% (0.0066)**	1.65898E-06
WI	5363675	2% (0.0188)	**11**	**2% (0.0242)**	2.05083E-06
WY	493782	0% (0.0017)	**2**	**0% (0.0044)**	4.05037E-06
Total	281,421,906		**Total: 454**		

cance. In other words, our sample is representative of the United States population. Additionally, there are no states that are either over-represented or under-represented in the population. There are more people from the state of California with TM in our sample, because this state has the highest population of any state in the country. When comparing the percentage of people who live in each state to the percentage of people in our sample from each state, the similarities are remarkable. We know that there are communities that have disproportionately high numbers of people with TM; far higher than can be explained by their population size. From this analysis, however, there does not appear to be any

higher frequency of TM in one state as compared to another that cannot be explained by the size of the population.

The next issue we analyzed concerns the frequency of TM by latitude in the United States. There is a higher prevalence of Multiple Sclerosis in the more northern latitudes as compared to the central and southern latitudes. We performed a very preliminary study to test whether there was a higher prevalence of TM in the more northern latitudes in the United States. This analysis was also based on the data, which appears in Table 2.

We divided the United States into three regions. We did not attempt to divide states in this analysis; the entire TM state population was counted in one of the three regions. The northern region is composed of people from the following states: WA, OR, ID, MT, WY, ND, SD, MN, WI, MI, NY, MA, RI, VT NH, ME and CT. The central region is composed of people from CA, NV, UT, CO, NE, KS, IA, MO, IL, IN KY, OH, WV, PA, VA, NJ, DE, and MD. The southern region is composed of people from AZ, NM, OK, TX, AR, MS, LA, TN, AL, GA, FL, NC, and SC. In order to make a valid comparison of the regions, we created a variable called SAMPLEN_POP which took the number of TM patients for each state and divided it by that state's population. This new variable removes the bias effect of the population factor, i.e., normalizes the data. The ***E*** identified in this variable stands for ***exponent***; thus, E-06 represents 10 to the negative 6th power. We ran an Analysis of Variance (ANOVA) test using SAMPLEN_POP as the dependent variable and Northern Region, Central Region, Southern Region as the independent variables. There were 48 observations. Hawaii, Alaska and the District of Columbia were excluded from the analysis. In addition, we ran a Tukey test on the means.

The Null hypothesis was the following: There is no difference among the means of the three regions. The p-value from the F-test was 0.3587, which means that we failed to reject the Null hypothesis. In other words, there was no difference between regions. The results from the Tukey test indicated that there were no significant differences at the 0.05 level for the three combinations of paired means. Basically, this test supports the results of the ANOVA test. Consequently, from our preliminary analysis, there does not appear to be a relationship between the frequency of TM and latitude.

The remaining analyses are based on the entire TM sample of 546 respondents. Table 3 presents the age of onset of TM for each of the respondents. The largest numbers of people contracted TM between 35 and 49 years of age. There are 202 persons or 37% of the total sample represented by these three age groups. For those under the age of 20, there are two distinctively larger groups; for those who contracted TM under the age of one year, and for those between the ages of 11 and 15.

Table 3 Age of TM Onset

Age at Onset	Frequency
0 to 1	31
1 to 5	3
6 to 10	10
11 to 15	32
16 to 20	14
21 to 25	18
26 to 29	30
30 to 34	42
35 to 39	81
40 to 44	55
45 to 49	66
50 to 54	36
55 to 59	48
60 to 64	27
65 to 69	30
70 to 74	11
75 to 79	9
80 to 84	3

Table 4 presents the gender of the respondents.

Table 4 Gender

Gender	Frequency
Female	358
Male	188

Females compose 65% of the sample, while males only compose 34% of the sample.

Table 5 presents the number of respondents who reported multiple episodes of TM. The survey did not ask respondents if they had experienced multiple episodes. The survey asked the respondent to identify when they had contracted TM. For six of the respondents, they identified multiple dates of onset which reflect multiple episodes. It is quite possible that if we had asked for whether people had experienced multiple episodes, these numbers would have been higher. It is possible that some people only reported the date of their first episode of TM. This is an area that will be given great attention in our next survey.

Table 5 Number of Episodes

Number of Episodes	Frequency
1	534
2	5
3	1

There were six people who reported multiple episodes of TM; five reported two episodes and one reported three episodes.

Table 6 presents the month in which the respondents contracted TM. We were interested in identifying whether TM onset might be seasonal or if there was a pattern of TM onset that might coincide with "flu season."

Table 6 Month of Onset

Month Contracted TM	Frequency
January	60
February	49
March	43
April	41
May	54
June	49
July	35
August	43
September	45
October	38
November	38
December	43

There does not appear to be any particular pattern in the months in which people contract TM. The largest number of people contracted TM in January. The second highest number contracted TM in May. Table 7 groups the months by season in order to analyze the seasonal onset of TM.

Again, there does not appear to be any distinctive pattern in the results. The lowest numbers of people contracted TM during the fall season and the highest during the winter season. Of the 538 valid responses to this question, 121 or 22% contracted TM during the fall months, and 152 or 28% contracted TM during the winter months.

Table 7 Seasonal Onset of TM

March	43	
April	41	
May	54	
Spring	**138**	
June	49	
July	35	
August	43	
Summer	**127**	
September	45	
October	38	
November		38
Fall	**121**	
December		43
January	60	
February	49	
Winter	**152**	

We also analyzed the monthly and seasonal onset of TM among the children who contracted TM. We were looking for a similar pattern of onset that might coincide with a "flu season" for those children who could be in daycare facilities, a preschool or in schools.

Tables 8-12 present the children from five different age groupings and the month in which they contracted TM. We have also aggregated the data for each age grouping using the seasons as identified in Table 7.

Table 8 Month of Onset Age: Under 1 Year

	Frequency		
January	5		
February	2		
March	2	Fall:	8
April	1	Winter:	9
May	3	Spring:	6
June	1	Summer:	7
July	4		
August	2		
September	2		
October	3		
November	3		
December	2		

Table 9 Month of Onset Age: 1 to 5

	Frequency
February	1
August	1
November	1
Fall:	1
Winter:	1
Summer:	1

Table 10 Month of Onset Age: 6 to 10

	Frequency		
February	2		
March	2		
May	1	Fall:	1
June	1	Winter:	3
July	2	Spring:	3
October	1	Summer:	3
December	1		

Table 11 Month of Onset Age: 11 to 15

	Frequency		
January	8		
February	3		
March	1		
May	2	Fall:	6
June	1	Winter:	15
July	4	Spring:	3
August	3	Summer:	8
September	2		
October	1		
November	3		
December	4		

Table 12 Month of Onset Age: 16 to 20

	Frequency		
February	2		
March	3		
April	2	Fall:	3
May	1	Winter:	3
July	1	Spring:	6
August	1	Summer:	2
November	3		
December	1		

We were unable to identify any pattern in the data regarding the month or season of onset of TM and the children's ages. The highest month of onset was in January for children who are under one year and between 11 and 15 years of age. The only other notable characteristic in the data is that there were 15 children between the ages of 11 and 15 who contracted TM during the winter months. From this preliminary analysis on the data, there does not appear to be relationship between a particular month or season and the onset of TM.

The last table presents the length of time the respondent had TM when they completed the survey. This number was calculated by the difference between the respondent's current age (when they completed the survey) and their age at the onset of TM.

Table 13 Length of Time Had TM

Years	Frequency
0	143
1	138
2	47
3	36
4	32
5	19
6	12
7	11
8	10
9	5
10	14
11	8
12	8
13	4
14	1
15	2
16	4
17	4
18	3
20	2
21	2
23	4
24	2

25	6
26	1
27	1
28	2
29	2
31	1
33	1
34	2
35	1
37	1
38	1
47	1
51	1
74	1

There were 533 respondents who provided valid responses to the questions regarding their current age and their age at the onset of TM. Of the 533 respondents, 143 or 27% had TM for less than a year when they completed the survey. There were 138 or 26% of the respondents who had TM for between 1 and 2 years when they completed the survey. This means that more than half of the respondent sample is composed of people who had TM for less than two years when they completed the survey. There were 396 or 74% of these respondents who had TM for less than five years when they completed the survey. When discussing response bias, this is, perhaps, one of the more significant considerations to keep in mind. Our sample is significantly over-represented by people who are recently diagnosed with TM, and under-represented by people who have had TM for longer than five years.

A thorough analysis of the TMA survey data will continue. The results will be reported to our membership and to the medical community. It is critically important that if you have not completed the survey, you should do so. You can find the survey on our web site at: http://www.myelitis.org/survey1.htm. Please do your part to help the medical community better understand TM!The following information is offered as a general response to questions related to Transverse Myelitis and is not to be construed as a specific medical recommendation for any individual. This information is based on the information provided in a brief question and is without the benefit of a complete history or an examination. Any decisions regarding diagnosis or treatment should be made in consultation with your personal physician who is best suited to make appropriate medical recommendations for you.

Member Questions and Answers from D. Joanne Lynn, MD

Assistant Professor of Neurology, Multiple Sclerosis Center, The Ohio State University; TMA Medical Advisory Board

1. What is the purpose of steroid treatment at the onset of TM? Is there a point after onset when the steroid treatment is no longer useful? Is there a difference in how steroids are used between patients who have an acute onset and those who have a slowly progressing form of the condition?

Corticosteroids may be administered in acute TM in an attempt to cut down inflammation of the spinal cord. There are no controlled studies of the treatment of TM with corticosteroids, but they are given in the hope that they may decrease tissue damage and hasten neurologic recovery. Corticosteroids have multiple actions including:
1) redistributing lymphocytes or white blood cells that may be involved in the autoimmune attack on the spinal cord into other tissues of the body, 2) inhibiting the functions of macrophages, a type of white blood cell that may be involved in the production of spinal cord inflammation, 3) reducing the abnormal activation of lymphocytes, and
4) reducing the production by white blood cells of chemicals that participate in tissue damage.

We have the most information about the use of pulses of high dose steroids during acute inflammation of the central nervous system from studies of the use of high dose intravenous methylprednisolone (IVMP) in acute attacks of multiple sclerosis. Several studies in MS have shown that IVMP shortens the duration of a MS attack. The standard treatment of an acute severe MS attack is 1 gram of methylprednisolone every day for 3 to 5 days. This is a regimen that is often given to people with acute TM. There are no studies available to give information about when steroid treatment is no longer useful in acute TM. In general, it is assumed that typical acute TM is a transient process with acute inflammation and tissue damage occurring over a period of three weeks or less. It is reasonable to consider a course of IVMP after initial diagnostic studies if there is no evidence of an infection of the spinal cord that might be made worse by steroid treatment that suppresses the immune system.

We have few controlled scientific studies of the window of opportunity for treatment of an acute attack of MS, and some worsenings of neurologic function in MS develop more gradually than TM. However, there is some evidence that suggests that IVMP is most likely to be beneficial in the treatment of optic neuritis (demyelination/inflammation of the optic nerve – one type of MS relapse) if it is started within 10 days of the onset of neurologic symptoms.

The above discussion referred to patients with typical acute TM that does not progress after 3 weeks and either stabilizes or improves. Many of these patients have a post-infectious etiology for their TM. The small subset of patients who have a more subacute course with worsening that

continues on for longer than one month are already different than the average TM patient. There is a higher likelihood that there is some sort of underlying systemic autoimmune disease, such as Multiple Sclerosis, Systemic Lupus erythematosis or something else. These patients need careful evaluation for such underlying diseases. When one of these underlying diseases is diagnosed, progressive inflammation of the spinal cord may be treated with more chronic use of steroids. Unlike acute TM where it is assumed that the duration of inflammation is relatively limited, in subacute TM that continues to worsen past one month, it would be logical to assume that the underlying inflammatory process in the spinal cord is chronic. That is the reason that steroids are used differently in the situation of subacute TM - it might respond to longer term suppression of the immune system/ anti-inflammatory agents. In that case, there is again very little medical literature to guide treatment. Neurologists may start with a pulse of IVMP and then follow with oral steroids at a gradually tapering dose or just skip the IVMP and start with the oral steroids (usually prednisone, sometimes Decadron). The problem with this is that there are many side effects to the use of long term oral steroids that are not a problem with a short burst of high dose IV steroids. The physician will watch carefully for improvement and attempt, gradually, reduction of steroids often to avoid these side effects. In some cases such as a definite diagnosis of SLE-related myelitis, it is frequent that long term steroids are required. In that case, the neurologist may decide that additional immunosuppressive agents should be added to the treatment regimen to reduce the need for steroids.

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Beck RW, Cleary PA, Anderson MM Jr, et al. A randomized, controlled trial of corticosteroids in the treatment of acute optic neuritis. The optic neuritis study group. N Engl J Med 1992:326:634.

2. What is the purpose of IV Immunoglobulin therapy for TM? (What is it and how does it work)?

Intravenous immunoglobulin (IVIg) refers to the infusion of human immunoglobulins or antibodies in an attempt to modulate the immune system. Blood is obtained from pools of 3,000 to 10,000 donors and the immunoglobulins are extracted from the plasma fraction of that blood. The immunoglobulin preparation is then treated in several ways to kill or inactivate viruses, including human immunodeficiency virus (HIV) and the various hepatitis viral agents. HIV has never been transmitted through IVIg. There are cases of hepatitis transmission via IVIg in the past, but newer methods of treatment of the IVIg have proven safe in prevention of the transmission of hepatitis virus.

IVIg is currently used to treat many autoimmune diseases. The exact manner in which it works is unclear. However, each batch is a mixture of human antibodies directed against a wide spectrum of human and foreign proteins. Many of these antibodies actually bind to the antibodies in the patient who receives them as a treatment and may inactivate antibodies that cause autoimmune diseases. IVIg has also been shown to interfere with the function of macrophages and other white blood cells which are involved in autoimmune and inflammatory attacks on many tissues. IVIg readily crosses the blood-brain-barrier and enters into the central nervous system gaining access to the brain and spinal cord.

IVIg treatment has been tried in many autoimmune neurologic diseases. The best scientific evidence for beneficial effect exists for the following diseases: Guillain-Barre syndrome and chronic inflammatory demyelinating polyneuropathy – two autoimmune diseases affecting the peripheral nerves – and dermatomyositis – an inflammatory autoimmune disease of the muscles. There have been small trials of IVIg treatment in myelopathy (spinal cord disease) related to infection with human T-cell lymphotropic virus-1 infection (a relatively rare viral infection in this country), paraneoplastic diseases of the central nervous system and multiple sclerosis.

Administration

Various regimens are given. The typical dose is 2 grams/kilogram of the patient's body weight. This may be divided into 1 gm/kg each day for 2 days or into 5 daily doses of 400 mg/ kg each. Maintenance therapy is often given as a single dose every few weeks as needed for control of the autoimmune disease. IVIg has been tried in most autoimmune diseases of the immune system. This treatment has been shown to be especially useful for management of chronic inflammatory demyelinating polyneuropathy (CIDP) which is a chronic autoimmune attack on the peripheral nerves. Some small studies have suggested benefit for relapsing MS. There are no significant studies of its treatment in transverse myelitis. Intravenous steroids would be the usual first choice treatment for typical acute monophasic transverse myelitis.

However, IVIg might be tried in more atypical subacute, progressing cases. Potential complications are relatively uncommon, but can include severe allergic reactions, kidney failure, infections, triggering of migraine headaches, rashes, aseptic meningitis, and rarely stroke.

References

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3. What is the purpose of Plasmapheresis for TM? (What is it and how does it work)?

Plasmapheresis or "therapeutic apheresis" is a procedure in which blood is removed from the body and "cleansed" of circulating antibodies, complement, cytokines and other plasma proteins that may participate in an inflammatory attack. Apheresis is derived from a Greek term that means "to remove" or "to take away by force." One session usually removes 3-5 Liters of plasma and fluids are then replaced with albumin. Therapeutic apheresis is very costly and there are very few well-controlled, rigorous studies to assess its benefits in autoimmune neurologic disease. Plasmapheresis is a standard treatment with proven benefit for several autoimmune diseases affecting the nervous system including Guillain-Barre syndrome, chronic inflammatory demyelinating polyneuropathy and myasthenia gravis. Plasmapheresis may be done through a regular intravenous catheter in a peripheral vein at the elbow in people with "good veins." However, for many people, a larger catheter may need to be placed in the central veins in the chest (a "central line"). Complications of pheresis range from mild to potentially fatal: muscle cramps, electrolyte imbalances, hypotension (low blood pressure), nausea and vomiting, and bleeding due to depletion of clotting factors. Complications related to catheter placement may include infection, pneumothorax (collapse of the lung), and bleeding.

Weinshenker's group performed a randomized controlled trial of plasma exchange in 22 patients with acute severe inflammatory demyelinating disease of the central nervous system. This was a mixed group of patients (12 had MS, five with TM, and five with acute disseminated encephalomyelitis ADEM or variants). All patients were first treated with at least five days of IV corticosteroids but had failed to respond. Patients were not immediately treated with PE or sham (pretend) PE, but were observed 14 days from the onset of IV steroids or 12 days from the onset of the neurologic deficit, if the patient continued to worsen despite the IV steroid treatment. The patients were then treated with either active PE (7 exchanges over 14 days, 54 milliLiters/kg body weight, 1.1 plasma vol/exchange) or sham PE. If a person did not improve with 14 days of sham PE, they were crossed over into 14 days of active PE. Moderate or greater improvement of neurologic disability occurred with 8 of 19 (42.1%) of patients after active PE and only 1 of 17 (5.9%) after sham treatment. This suggests that there is a subset of patients with acute demyelinating events who may respond to PE. Obviously, this study involved only a small number of patients, but it has generated new enthusiasm for PE as a treatment for severe acute TM and for the need for additional larger studies. However, this is an invasive and expensive (up to $18,000) form of treatment and the current recommendation would be that PE should be considered in catastrophic episodes of acute demyelination with significant neurologic disability that has been refractory to treatment with conventional high-dose corticosteroids.

References

Weinshenker BG et al. A randomized trial of plasma exchange in acute central nervous system inflammatory demyelinating disease. Annals of Neurology 1999;46:878-886.

Weiner HL et al. Double-blind study of true vs. sham plasma exchange in patients treated with immunosuppression for acute attacks of multiple sclerosis. Neurology 1989;39:1143-1149. (an interesting related article regarding the use of PE in combination with other immunosuppressive therapy in acute attacks of MS – some immediate benefits but no clear long-term benefits).

Clark WF et al. Therapeutic plasma exchange: An update for the Canadian apheresis group. Annals of Internal Medicine 1999;131:453-462. (PE does not help progressive MS much. Good review of literature on PE in neurologic disease).

The Transverse Myelitis Association will be holding a Children's and Family Workshop in Columbus, Ohio from Thursday, July 18 – Sunday, July 21, 2002. The TMA Workshop will focus on children from infancy to their early twenties and will include their brothers and sisters and their parents. Most of the parents have never met another child or a parent of a child with TM. These parents and the families often feel isolated, frightened and alone. It is imperative that we offer them this opportunity to make connections with others who can offer them emotional support and encouragement.

Children with TM face special challenges in their lives, as do their

The Transverse Myelitis Association Children's and Family Workshop Columbus, Ohio Thursday, July 18 – Sunday, July 21, 2002

families. The TMA Children's and Family Workshop has two primary purposes. The first is to provide information and strategies to parents regarding the various treatment issues required by the symptoms of TM. In addition to the many physical symptoms parents need to address, they are also faced with significant social and emotional issues, which surround having a child with a devastating illness. The Children's and Family Workshop will also attend to these important issues through presentations by experts from a variety of medical and other disciplines. TM is a rare condition, and the parents with children who have TM are spread out in communities all over the country and all over the world. Offering them an opportunity to spend time together to share information and support is one of the most important benefits that will result from the workshop.

The second major purpose of The TMA Children's and Family Workshop is to offer children an opportunity to have a fun weekend and to meet other children who have TM. Most of these children have never met another child who has their condition; most of these children feel very isolated in their experiences. The Workshop will provide them with the opportunity to meet other children with TM and to foster relationships and support that can last a lifetime.

We have assembled a parent planning committee that has been working on a program agenda. Cathy Dorocak and Paula Lazzeri are heading the group, which is composed of Cathy and Dan Dorocak, Paula Lazzeri, Jack and Joanne Callahan, Jeanne and Tom Hamilton, Deanne and Dick Gilmur, Mary Troup, Neil and Wendy Ross, Steve and Colleen Blandford, Gail Hirsch, Pam and Morgan Hoge, Judy Baker and Shelley and Cody Unser. We have begun the process of inviting experts who will be making the presentations to parents; Friday and Saturday will be the primary presentation days. A tentative program agenda is included in the newsletter. We are already very excited about the physicians, therapists and psychologists who have committed to participate in the workshop.

We want the workshop to be an opportunity for parents to learn and to find support relationships in this very special community of families. We want this weekend to be a great time for the kids! We are in the process of arranging to have occupational and physical therapy students serve as companions for the children who have TM during the weekend while parents are in the workshop presentations. These students would assist your children during the fieldtrips and the other activities that we are planning for the children over the weekend. We are also arranging to have nurses available on the fieldtrips and the other activities to perform catheterizations and to assist with any other special needs for the children. Additionally, we have requested that a physician go on these fieldtrips with the children. Every effort is being made to assure that the children have a fun and a safe time, and that parents can enjoy the presentations with peace of mind.

Our tentative plans are to have Thursday, July 18th be a travel day for the families. The registration and a dinner will be held Thursday evening. We are hoping that we can have the occupational and physical therapy students attend this dinner and be assigned as the companion for each of the children with TM. This dinner would provide parents and children the opportunity to meet their companions and to exchange information. In this way, the children would also not be meeting this person for the first time as they were leaving their parents on Friday. Again, brothers and sisters will be included in all of the activities. We are sensitive to the issues that surround time and attention for these very special siblings; we are going to work very hard at being inclusive, and providing them with lots of care, love, and attention.

The Friday, July 19th fieldtrip will be to The Center of Science and Industry. This is a wonderful science museum for children. You can learn about the museum and show it to your children by visiting their web site at http://cosi.org/html-site. Dr. Kathryn Sullivan is the President and CEO of COSI Columbus. Dr. Sullivan is a former astronaut who has logged more than 500 hours in space. She is a specialist in deep-sea geological research. We are certain that your children are going to find the museum a really fun and fascinating experience.

Our fieldtrip on Saturday, July 20th is going to be to the Columbus Zoo and Aquarium. It is a great place. Jack Hanna was the Executive Director of the Columbus Zoo from 1978 – 1992; he remains the Director Emeritus. I have requested that Mr. Hanna meet the children during our visit; we'll find out how many of your children are staying up to watch the David Letterman Show! His secretary told me that he is in Los Angeles during the summer. I asked her to put it on his calendar. When he finds out how important your children are maybe he

will come back to Columbus to meet them. The web site to show your children the Columbus Zoo and Aquarium is http://www.columbuszoo.org/.

We are going to offer some alternative activities for some of the older children and young adults. We have a group of recreation therapists from Children's Hospital, The Columbus Parks and Recreation Department and The Adaptive Adventure Sports Coalition (TAASC) who are developing an agenda of recreation activities for the children. We would like for the children to be exposed to a wide range of activities; we want them to observe and experience all of the possibilities. We will also arrange for the recreation therapists to have activities for the children who go on the field trips later in the day when they return from COSI and from the zoo.

The summer time in Columbus is filled with riverfront festivals, concerts, sporting events, and fairs. We will keep a close watch on the calendar, and if we identify any fun opportunities for the older children and young adults, we will attempt to arrange for some of these activity choices, as well.

Sunday morning promises to be a very special time for both the parents and families who attend the workshop. The parents are going to have the opportunity to engage in a roundtable discussion; and the doctors will be present to participate in the discussion and answer your questions. We are arranging a separate roundtable discussion for the teens and young adults. The younger children will have some really fun activities to participate in on Sunday morning.

The parent planning committee is also organizing an adaptive equipment exchange. We will provide you with more information about this activity later in the year. They are going to arrange for an exchange of equipment in Columbus. Perhaps more importantly, they are going to establish a virtual equipment closet so that parents can offer and look for different pieces of equipment as their children outgrow or out-develop certain items, while other parents may identify the need for those same items.

We are currently negotiating a contract with the Clarion Hotel in Worthington, Ohio; this is a northern suburb of Columbus. They have offered us a rate of $74.00 per night. The TMA will handle the registration and billing process for all of the members attending the workshop. As the TMA will be direct billed for the rooms, there will be no taxes paid on these rooms; your rate will be $74.00 per night. Additionally, if you arrive early or stay after the workshop, your room rate at the Clarion will be $74.00. The Clarion has established this discounted rate for TMA members for any time you stay at the hotel. As the TMA is going to be handling the registration process, it is important that you do not contact the hotel to register. We will begin the formal registration process in January. If you are interested in reading more details about the Clarion, please go to their web site at: http:// www.alliancehospitalityinc.com.

It is our hope that we are going to be able to raise sufficient workshop funding that we will be able to provide for all of the meals. The children will be provided lunches at COSI and at the zoo. We are also hoping not to have to charge a registration fee. We would like to raise enough money to cover all of the expenses of the workshop. That is the goal.

The Clarion has been wonderful in providing us with a great deal of flexibility. The location of the Clarion is also great. It is located just fifteen minutes from the airport and is also close to the Columbus Zoo. The hotel is located just off of the Columbus outer belt and is close to a lot of shopping and entertainment. There is a shopping mall directly across the street from the hotel. Also, the Clarion has four vans; they do not charge a fee for transportation to and from the airport. If the numbers warrant, our workshop will be held in their large ballroom and they will be providing us with four breakout rooms. Three of the breakout rooms will be used for activities for the children. The fourth room is going to be used as a hospitality room. It is located directly across from the ballroom. The room has two bathrooms, a sink, and it is possible that we will move a bed or beds into that room, as well. Parents will be able to take care of any needs their children may have during the workshop activities during the day or evening without having to return to their rooms.

The Clarion has four accessible rooms. We are going to offer those rooms to people who do not have a companion to assist them with transferring through doorways or to assist them with transferring in the bathroom. We are also going to give priority for these rooms to the young adults. Thus, it is critically important that if you are a young adult that you travel with a companion who can assist you with transferring. Almost everyone who attends the workshop is going to be in a regular room. The doorways into these non-accessible rooms are 35 inches wide. The bathroom doorways in these rooms are 27 inches wide. Please come with a companion and please attend with a companion who can assist you in the bathroom. We have enclosed a form, which asks you to identify any special

needs. Please provide us with a thorough response and include any equipment that you might require, such as a shower bench, for instance. I do not believe that there are grab bars near the toilet or shower. You are going to need to be with a companion with whom you are going to be comfortable assisting you in this environment. I am sorry for this inconvenience. We would never be able to find a hotel to accommodate all of the members who are going to attend the workshop. We are going to communicate as much detail as we are able about the hotel accommodations. We are hoping that if you are prepared, it will be less inconvenient.

There is one set of elevators in the hotel. We are holding the rooms on the main floor; the floor on which the workshop will be held. Hopefully, all of the TMA members will be accommodated on the first floor. If we need additional rooms in the hotel, we will attempt to locate people on other floors who are not in wheelchairs, and we will attempt to locate you in rooms near the elevators. We will do the best we can to accommodate your needs and to create a great experience for your families.

We want to make it possible for as many families to get to Columbus as possible. One of the concerns people will have is the long-distance travel for your child with TM. Please consult with your doctor about these issues. The other concern people will have is the financial burden associated with transporting your families to Columbus. We share this concern for those who are going to have to fly into Columbus from around the country and from around the world. We have a small group looking at the possibility of finding discount airline rates for the families, and perhaps, having the airlines donate the flights for children who have TM. If you are able to assist us in this critically important activity, please get in touch with me. If you work for an airline, if you have some experience in this area, we would greatly appreciate your help. Finding an affordable way to get people to Columbus is going to be one of the most important factors determining the level of participation we will have for the workshop. Please help us in this effort.

While the Workshop may seem like a long way away, it isn't. The time is going to fly. We want to get as many families to Columbus as possible – from all over the world. That is going to require a great deal of planning for all of us! So, I am asking that we start all of this planning now. I am asking those of you who are interested in attending to fill out the registration form that is included with this newsletter mailing, and get it returned to me immediately. Please do not procrastinate; our planning efforts require that we have some sense of the numbers of family and the numbers of children who will attend the workshop, and any special needs we should be prepared to accommodate.

The Children's and Family Workshop promises to be a wonderful experience for everyone. To make it happen, we are going to need to raise a great deal of money. There are many people involved in fundraising for this event and for TM research. Please get involved. As you read in my editor column, I am on a mission. I do not believe it is mission impossible – not even mission improbable. But our success depends on you. Please make a difference for these beautiful children; and make a difference for yourself.

Children's and Family Workshop Expert Workshop Presentations to Parents (Tentative Program)

Friday, July 19, 2002

Updates on TM treatment and cure research and results

Pain: developmental assessments of pain from preverbal infancy to young adulthood; and medical strategies for the management of pain

Pain management: behavioral strategies

Management of bowel and bladder symptoms

Management of spasticity symptoms

Physical, social and emotional issues and strategies surrounding sexual dysfunction

Selecting the most appropriate and most effective adaptive equipment in pediatrics for mobility

Use of Electrical Muscle Stimulation: TES (Threshold Electrical Stim) and NMES (Neuromuscular Electrical Stim)

Pediatric physical therapy: effective techniques and expectations

Pediatric occupational therapy: effective techniques and expectations

Strategies and informed decision-making regarding childhood vaccinations

Pediatric nutrition and diet: developmental issues and the immune system

Pediatric pharmacological issues: the use of medications in childhood and the long-term use of medications

Saturday, July 20, 2002

Alternative therapies in pediatrics: aquatic, equestrian, yoga, martial arts

Self-esteem and disability: helping our children with TM build a healthy

self

Managing stress and a marriage when you have a child with TM

Managing a family when you have a child with TM: sibling issues

Appropriate and effective clothing and shoe choices for children with TM: finding what works and what they will wear

Recreation choices for the disability community: national organizations, camps and adaptive recreational equipment

Active and passive entertainment choices (gaming, computers, art and music) for the disability community, including the role of technology

Children with TM and the educational system: working with the school system, working with teachers and support staff, advocacy and legal rights, setting expectations

Community, state and national resources for the disability community: Medicaid, Medicare, state entitlements, funding support for equipment and supply needs

Sunday, July 21, 2002

Adaptive equipment swap: developing an inventory and strategies for setting up the virtual equipment closet

Roundtable discussion and Q&A (for parents) with the doctors

Roundtable discussion for older teens and young adults with a facilitator

Children's and Family Activities

Thursday Evening, July 18, 2002: Family dinner; movies for children
Occupational and physical therapists and OT and PT students will serve as companions for the children with TM over the weekend and particularly on the field-trips. The OTs and PTs will have dinner with the families, providing an opportunity for everyone to meet and exchange information.

Friday, July 19, 2002: Children's Tour of the Center for Science and Industry (luncheon for the children at the museum)

Friday Evening, July 19, 2002: Italian dinner; family games and movies for children

Saturday, July 20, 2002: Children's Guided tour of the Columbus Zoo
(luncheon for the children at the zoo)

Saturday Evening, July 20, 2002: Pool Party/ Picnic Bar-B-Que/ Karaoke
movies for children

Kung Fu and Tai Chi Demonstration
Storytelling
Music
Arts and Crafts
Games
Sporting events, festival on the riverfront, county fair, concerts, if scheduled – for older children, young adults
As you know from the previous article, one of the major concerns we have about the Children's and Family Workshop is making it affordable for the families to get to Columbus. For those having to travel by air, and particularly for those families having to fly long distances, the airfares could be the determining factor as to whether or not a family is able to attend. We need to make this Workshop affordable for families. They need to be able to get to Columbus. They need the opportunity to learn about new treatments and coping strategies. They need the support and encouragement that they can only find from other parents. The children need the opportunity to meet other children with TM. We need your help!

Please donate your air miles for the Children's and Family Workshop!

Please consider making a donation of your frequent flyer miles to the TMA to be used by families to attend the TMA Children's and Family Workshop. You can make the difference for some very special children and their families. If you are interested in making this donation, please contact Debbie Capen. Debbie will work with you to arrange the transfer of your miles to the TMA and these families.

If you have a relationship with a travel agency or one of the airlines, please consider making a request for a donation of an airfare for one of these special children. If you work for a travel agency or one of the airlines, if you have a family member or friend who works for a travel agency or one of the airlines, please consider requesting a donation. It would be a wonderful way to make a difference in the lives of these children and their families.

Thank you so much for your generous support of this important program!

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The 2nd International Transverse Myelitis Symposium was held at the Holiday Inn – Inner Harbor, in Baltimore, Maryland. The Symposium ran from Thursday, July 12th through Sunday, July 15th 2001. The Symposium director was Dr. Douglas Kerr from the School of Medicine, Johns Hopkins University. The purpose of the workshop was to foster an understanding of the clinical and research features of transverse

The 2nd International Transverse Myelitis Symposium Baltimore, Maryland July 2001

myelitis and to facilitate interaction and discussion among patients with TM and caregivers. The Transverse Myelitis Association is so grateful for the hard work performed by Dr. Kerr in planning and coordinating the Symposium. The physicians from the Johns Hopkins Transverse Myelopathy Center, as well as the Staff from the Center and Office of Continuing Medical Education should also be recognized. A special thanks to Philis Carbonell and Carol Kowarski for all of their hard work in preparing for the Symposium. Finally, the Cody Unser First Step Foundation provided a grant for The 2nd International Transverse Myelitis Symposium. We appreciate the support that Cody and Shelley offered to make the Symposium possible.

Dr. Kerr assembled a distinguished group of presenters for the Symposium. There were two major focuses of the presentations. The first couple of days of lectures were focused on research. There is some really important and wonderful research being preformed that offers great hope for all of those who have transverse myelitis. The second focus of the presentations centered on the issues of symptom management and treatment. The presentations in this area were very informative and helpful.
In addition to Dr. Kerr, the other members of the TMA Medical Advisory Board attended the Symposium and made presentations. Drs. Bowen, Levy and Lynn continue to make a most valuable contribution to the TMA. Words cannot adequately convey our deepest gratitude for the support and work they offer to the Association.

There were approximately 140 members from the TMA in attendance at the symposium. TMA members came to Baltimore from all over the United States, from Ireland, Australia, England and Canada. As the vast majority of our members were not in Baltimore, we have established a number of different methods for providing you with the information from the presentations. Most of the lecturers have provided or will provide an article from their presentations to be included in this and future newsletter publications. Additionally, if the lecturers provided handouts or prepared a slide presentation, Jim has posted this information on our web site. Finally, all of the presentations were videotaped. You may order a set of these videotapes using the form that was included in this mailing, or you can download the order form from the web site. You may also watch the presentations as streaming video from the web site. Jim has digitized and loaded all of the presentations to be viewed as Real-video. A free copy of RealPlayer may be found from a link on our web site. The web address for The 2nd International Transverse Myelitis Symposium is: http://www.myelitis.org/baltimore2001/index.html

In addition to the informative presentations, the weekend offered a number of wonderful social events. The Symposium began with an early registration and reception on the rooftop of the Holiday Inn. Most of the TMA members were in attendance at the reception. It was the first of many opportunities for us to renew old friendships and to develop new relationships. We also had a chance to meet many of the physicians who would be presenting over the weekend. There were many interesting discussions between TMA members and the research scientists and physicians during these social events. A dinner and tour of the National Aquarium was held on Friday evening. During the dinner, Cody Unser delivered a very inspiring and beautiful speech. A wonderful banquet was held on Saturday night. There were a number of really eloquent speeches made by TMA members during the banquet.

As in Seattle, the Sunday morning roundtable discussion was very helpful for the participants. There was a wide range of topics covered and most everyone had a chance to ask questions, to offer opinions and to share experiences about the issues in their lives with transverse myelitis. A number of physicians participated in the roundtable, which offered the opportunity to solicit expert opinions on some important subjects. We would like to offer our special thanks to Drs. Bowen, Kerr and Kaplin for their participation in the roundtable discussion and for their informative responses to all of our questions. During the Roundtable, Ann Moran took the opportunity to unveil her beautiful international quilt. It is truly a work of art, created with the skill and care of a very special person.

The 2nd International Transverse Myelitis Symposium was a tremendous success. Our members left with a great sense of hope for their futures, based on the amazing research that is being conducted by this group of scientists. We left Baltimore with a greater understanding of our conditions and more effective ways to treat the symptoms of TM. And we left with a renewed sense of fellowship, which derives from sharing this incredible journey with such very special people. Deanne, Debbie, Paula, Maureen, Rich, Drema, Heather, Phil, Pauline

and myself met for the first time in May of 1998. We were guests of Dr. Charles Levy, the National Organization of Rare Disorders and the International Fybrodysplasia Ossificans Progressiva Association. It was an enlightening weekend in Columbus, Ohio. Spending a few days with a group of people with FOP offers a lifetime of perspective on the blessings we have when our bodies are in working order. Beyond the experience of learning from a group of very courageous people with FOP, there was this small group of us associated with TM who saw first hand the social and emotional power that evolves from the opportunity to share in the personal experiences which surround having a rare disease. FOP is a disease that affects just hundreds of people, and they have merely a few doctors who have developed an interest in performing research on the causes and treatments for this truly amazing condition. We readily observed that their gathering was a catharsis for their souls, it was an awakening of spirit and it was a celebration of hope.

Welcoming Remarks
Thursday, July 12, 2001
Sandy Siegel

It was during that weekend that the officers of The Transverse Myelitis Association vowed to each other that we would bring together people with TM and offer them this important opportunity; to share in experience, to help people with TM feel less isolated, to encourage education and research on this condition, and to offer people great hope for their futures. It was through that promise that we came together in Seattle in 1999 for the First International Transverse Myelitis Association Symposium.

Today, it is my great pleasure to welcome you to the Second International Transverse Myelitis Symposium. We greatly appreciate the attendance and participation of the medical community and are grateful for your taking time from your busy schedules to share information with us about your exciting progress in transverse myelitis research, as well as sharing treatment information with those of us who have TM and our caregivers. Most importantly, we are grateful for your interest in Transverse Myelitis. It is through this interest, and your concern for the well being of the people who have this condition that we derive our greatest hopes for the future.

I would like to thank Debbie Capen and Paula Lazzeri for all of the work they perform as officers and board members of the TMA. They make time in their busy lives filled with family and work to devote hundreds of hours to keep the TMA running. And both of them perform these duties in spite of the many physical challenges they face with TM. We love you, both, and are so grateful for all of what you do for all of us.

We would also like to thank all of the members of The Transverse Myelitis Association who have come here from all over the country and from all over the world. We understand the great sacrifices you have made to be here; and we are grateful for your being able to share in this wonderful and important experience.

For many of you, this will be your first opportunity to meet others with the TM diagnosis. Over this weekend, many of you will begin special relationships with each other that will last a lifetime and will provide you with comfort and support through difficult times. For who else will know what you are going through better than they.

For all of us, we heard the words 'transverse myelitis' for the first time when we were diagnosed with this condition, or when our loved ones were given this diagnosis. None of us had ever known anyone who had this condition; we did not have any experience or context through which to consider a prognosis. And the information we received from our physicians was confusing and ambiguous. The result for all of us was that we felt so isolated, we were frightened and we were so confused. There was no one to turn to and there was no information to help us understand what was happening to our bodies or to help us understand what our futures might hold.

Well, we are here this weekend and you can look around the room -- you are not alone. And we are here with a room full of physicians and scientists who are trying to better understand transverse myelitis. They are interested in what is happening to us and our loved ones. We are all very excited about the possibilities that your research holds for us – and it does provide us with great hope.

I would like to thank the TMA Medical Advisory Board for being here and for participating in the symposium: Dr. James Bowen from the University of Washington, Dr. Douglas Kerr from The Johns Hopkins University School of Medicine, Dr. Charles Levy from the University of Florida, and Dr. Joanne Lynn from The Ohio State University. The TMA would like to offer our deepest gratitude to Dr. Charles Levy for initiating our Medical Advisory Board. He came forward to offer his help without solicitation and at a time in the Association's development when we needed expert guidance and support. He is a wonderful doctor and a very special person. The physicians on our board offer us advice and counsel, they help us educate our membership, and most importantly,

they help us by providing excellent treatment and care for people who have TM. We are excited about the expanding role of our medical advisory board as we look toward raising significant dollars to fund TM research in the future.

We would also like to thank Cody and Shelley Unser from the Firststep Foundation for helping to sponsor this symposium and for their great efforts in motivating the development of the TM consortium. Cody has selflessly and generously worked to bring awareness to TM and to help educate the public about this condition. We are very proud and grateful for her work on behalf of all of us whose lives are impacted by TM.

I would like to recognize two very special people who are not in Baltimore with us this weekend, Deanne Gilmur and Jim Lubin. Both Deanne and Jim are board members of the TMA. In 1994 Deanne very courageously founded the TMA. She and her husband, Dick, experienced the isolation, fear, and uncertainty when their 18-month-old daughter contracted TM. It takes a very special person to go through these challenges and maintain a positive attitude about life. It takes an even more special person who can reach beyond their own challenges to want to help others. That is Deanne. We are glad that Dick is here with us representing the Gilmur's, but Deanne will be missed. We love you, Deanne, and will look forward to seeing you next summer in Columbus for the TMA Children's Workshop.

I found Jim Lubin on the Internet; it is the perfect place to meet Jim. Pauline and I typed the words 'transverse myelitis' into the Yahoo search engine, and Jim's disability resources page appeared on our screen. We began corresponding with Jim; he was the first person we had ever met who had TM. He had recently started the transverse myelitis internet club, a list group for people with TM. The synergies between a support and advocacy group and the Internet were obvious. We enlisted Jim's help and he became an officer and board member of the TMA. Jim is our Information Technology Director. Today, we have more than 350 people from all over the world who participate in our internet club. The exchange of information and support goes on 24 hours a day, 7 days a week, and every single day of the year.

We are very proud of our web site. We know how important that site is for people who are recently diagnosed with TM and for people who have had TM for years. The positive response we receive from people and from organizations about our site is truly gratifying. In 1997, the TMA had 187 members. Today, we have 3200 members from every state in the United States and from more than 40 different countries; and we have support groups in Australia, England, Ireland and South Africa. Jim's creativity, technical skill and compassion account for much of our outreach and advocacy success.

We are so proud of the wonderful and important work that Jim does for all of us. He is such a remarkable person. Jim contracted TM in 1991; he is a full quadriplegic and is ventilator dependent. He performs all of his computer work by sipping and puffing Morse code into an adaptive device. Jim has created a way for his mind and heart to reach well beyond the tremendous physical limits that have devastated his body. There isn't a day that goes by that I don't think about Jim and his dependence on the ventilator for his very life. I am here this weekend to listen to the research and the progress you are making in understanding TM. We need to get Jim off of his ventilator – that is how I will measure the success of the research. And it is with all of my heart and with all of my prayers that you are able to accomplish this progress soon.

Finally, I would like to thank Dr. Douglas Kerr and The Johns Hopkins University Medical School for hosting the transverse myelitis symposium. Dr. Kerr has worked tirelessly to organize a wonderful symposium and has brought together such a distinguished group of physicians and scientists as presenters. We know that it is going to be a very exciting and informative weekend.

Words just cannot adequately convey our sense of gratitude for all of what Dr. Kerr has accomplished in the past two years for treatment, research, education and awareness of TM. By starting the Johns Hopkins Transverse Myelopathy Center, Dr. Kerr provided a focused approach to TM treatment and research. The center has seen more than 200 TM patients. In addition to the strides made in treatment and research, the center also brings hope to people with TM for they can now see that there is an organized and concerted effort to deal with their problems. Dr. Kerr is a skilled and compassionate doctor, but most of all, Doug is a mensch. We are so proud of our association with you, and so blessed to have your interest and your support. It is my great honor to introduce to you, Dr. Douglas Kerr.

Morgan Gertz was a 12-month-old twin who presented with Transverse Myelitis ten days following a HepB, HIB and VZV Vaccination. He experienced a sudden onset of quadriplegia and areflexia. Morgan had no other medical issues and his fraternal twin, who had received the same vaccinations, was not affected. There were no antecedent infections

nor was he exposed to other sicknesses at home. Morgan suffered a complete loss of both sensation and motor function. Morgan was cognitively unchanged.

Morgan died on May 12th 2000. His parents, Bill and Kelly, are allowing

Opening Remarks of Douglas A. Kerr, MD, PhD
Thursday, July 12, 2001

me to honor the memory of Morgan as we open the 2nd International Transverse Myelitis Symposium. Bill and Kelly have offered us these words in the memory of their son, Morgan.

Morgan Gertz

March 18, 1999 - May 12, 2000

God watched you as you suffered and knew you had your share. He gently closed your weary eyes and took you in his care. Your memory is our keepsake, with that we will never part. God has you in his keeping, we have you in our hearts. Nothing could be more beautiful than the memories we have of you.

I want to thank everyone here for your energy, input and dedication that have made the Symposium so informative and helpful.

I got TM in February of 1999. They say talking about a problem helps. And since I got TM, I haven't shut up.

I didn't start out knowing where my journey would take me. I was 12 years old, in a wheelchair, and trying to make sense of why things were happening. I started out very scared, very confused, and very annoyed that nobody seemed to know what was going on except for the TMA.

Cody Unser's Speech at the TM Symposium Dinner, National Aquarium, Friday, July 13, 2001

My story is fairly typical of what a lot of people with TM experience. I got sick and went to a hospital where my symptoms were misunderstood. I was short of breath, my legs felt numb and tingly, I had a blinding headache and I was kind of sick to my stomach. I couldn't go to the bathroom. The ER staff pronounced my condition as being some kind of "stress" event. ***I*** was just hysterical. ***I*** should go home and relax.

"Take two aspirin and call me in the morning."

In the morning, I couldn't walk.

Within a day a doctor at another hospital picked up on what was going on and within a day or so of that, we had the diagnosis of Transverse Myelitis. What followed was a journey. I had gotten sick in Albuquerque, was diagnosed there, and after a few weeks was transferred to Barrow Neurological Institute in Phoenix to start rehab and learning about my new life on wheels.

That all went fine. I got pretty good at doing wheelies. Over time, my friends came to understand that I was in a wheelchair. I had the good fortune to go see other doctors in other clinics in other cities in different parts of America. I saw Dr. Spetzler at Barrow. I went to see Dr. Barth Green at the Miami Project. I came to Baltimore and met Dr. Kerr. My mom had other discussions and consultations with other doctors in other places. And in all those conversations, here is the one thing we learned for sure.

Nobody treating Transverse Myelitis in one part of the country was talking to anyone else treating TM in another part of the country. OK, there were obviously some discussions, but every place you went, you mainly got the idea that they saw TM so rarely that there was no really good network in place for sharing information. And that was in the medical community. At onset, everybody did something different.

For the outside world, the public at large was utterly clueless about TM.

So that was why the Cody Unser First Step Foundation started. To build public awareness of TM and encourage the medical community to share information about TM. And more than I can tell you, the activities with the media, support groups, other foundations, government officials and public appearances have helped me see transverse myelitis not so much as a barrier but as a unique opportunity.

Let me say a word about barriers. The most restrictive barriers are the ones you place on yourself. They are also the easiest to overcome because your attitude, which is something you control, can beat any barriers. Whether or not you think you are handicapped is what makes the real difference. Once I figured out that my wheelchair was just a new accessory, and my friends saw I was the same old Cody only sitting down, things got back to "normal," if you can call any of this "normal."

But like I was saying, awareness of TM was a big thing, and getting the medical community to aggressively share information about research and their patients was another important thing. I've been very fortunate to be in a position to share my story in the media, build a website, distribute information brochures and interact with TM patients all over the world. I

think the world is a little more aware of TM than it was two years ago.

On getting doctors to work together, I'm a little bit of a nag. I get that from my mother. But when I saw all these wonderfully smart doctors and therapists in different places who really knew what they were doing, but didn't know what anyone else was doing, that was a real problem. So I made a point to bug all my doctors and therapists about calling other doctors and talking not only about me, but all their TM information and sharing their knowledge.

Thanks to Dr. Kerr and Johns Hopkins, we now have a national consortium that will be the most important advancement in TM research and medical awareness, because information from the best and brightest TM doctors and researchers will be shared.

I suppose this is a good time to say that I really hope stem cell research can go forward, ethically, with government funding. I don't see this as just something the government can do, it is something that all of America can do. And the government needs to be a part of it. They are Americans too, right?

Let me also say that Dr. Kerr's work in this area is just so exciting to me. I think this research is the best chance I have to walk again. And I appreciate the Christopher Reeve Paralysis Foundation efforts to affect government policy. I hope if you feel as strongly about this research as I do, you will figure a way to let your congressman know of your support. This is a fight we need to win.

My foundation has been pretty successful so far, but we're only getting started. It is neat I've gotten a couple of awards, but honestly getting awards is kind of a pain. My real inspiration comes from you, all my fellow "TM-ers" who have shared stories, encouragement and provided your own strength. We are all in this together.

And in closing let me say that life is good. Whatever normal is, this probably isn't it. But, if you can't be normal, be spectacular.

I love you all.

Dr. Kerr asked me to speak with you this evening and share with you a bit about my journey. Like many of you, transverse myelitis changed my life in ways I never knew possible. After ten years as an IBM marketing rep and another three years as director of marketing for a career transition firm, I found myself stuck in a wheelchair after a visit from TM. I also found that I enjoyed writing. I now have a monthly column in one of our local newspapers entitled, "From Where I Sit" and am working on a book. I share with you an excerpt from it called, "Unchosen Paths and the Spirit of Nevertheless."

It was Wednesday. Ash Wednesday, to be exact. The date was February 12, 1997 -- a date so painful to remember, yet too important to forget. The mental tape rewinds and plays in slow motion. Every time, I shake my head in disbelief. Every time, I shut my eyes in horror. Every time, tears trickle in outrage and grief. But the tape still plays. And, the ending is still the same.

Rebbeca Galli's Speech at the TM Symposium Banquet, Saturday, July 14, 2001

I awakened in the early morning hours with a dull ache in my lower back. Strange shooting sensations rifled through my legs. I had had the flu for about a week, but had no idea that this seemingly ordinary bug would put me in a wheelchair, possibly for the rest of my life. Six hours later, the knife-like bolts of pain twisted their way up to my waist, permanently relaxing every muscle along the way. The paralysis stopped just inches short of the need for a ventilator.

With this life-altering event, I joined the journey of the rare 1 in 1.34 million people who go to bed with a flu-like illness and wake up with Transverse Myelitis, the cause of my paralysis. In the intensive care unit as I fought the pain with a morphine drip, I said to my father, "It's going to be OK, Dad. I just know it's going to be OK. I've been in the wilderness before. Fact is, I've been here so many times I have paths down here!" I managed to smile.

Paths in the wilderness – I've learned to seek them out as I have dealt with the difficulties that have come my way. At the age of twenty, I lost my only brother in a water skiing accident. In my thirties, parenting presented its own challenges, as I became mother of four children, two having special needs that included cerebral palsy, epilepsy, mental retardation and autism. And, my divorce was final nine days before my paralysis. To say the least, I have become a veteran of "unchosen paths."

Yet as unique as I am, and as you are, I realized that we still share the common experience of handling adversity. Everyone faces "unchosen paths." Ironically, I discovered the word "unchosen" is non-existent. There is no listing according to Webster. Yet "unchosen" crisply describes any unwanted or unwelcomed circumstance. Think about it. We are the "choice" generation, bombarded with advice from parenting experts on giving

choices and consequences to the People's Choice Awards. We like choices. Choices are freedom.

"Unchosen?" We literally don't even define it.

Yet, we all experience the pain of unchosen events and the imprisoned feeling that can follow. Each of the following statements reflects the beginning of an unchosen path:
"I want a divorce."
"You've miscarried the baby."
"Your job has been eliminated."
"The tumor is cancerous."
"There's been an accident."
"Your child has a serious condition."
And yes, "You have Transverse Myelitis"

Pain and anger are the sidekicks of unchosen paths, inevitably intruding into our lives, our plans, and our dreams. Chaos often results; with shock so deep we can't feel anything for days. We hear the words. The color drains from our vision as our heads spin while we try hard to focus and make our mouth and mind connect again. The moment is immersed in the devastating news, dipping our world into horror, retrieving it, and then freezing it in time. As life stubbornly moves ahead, as it must, reality cracks the icy crust of this life-altering event, forcing chips and slivers of our world to be discarded with the falling wreckage. Dreams for the next ten years vanish. Next month's trips disappear. Tomorrow's appointments are canceled. Frozen fragments crash like glass, sending splinters of pain back to the mind that remains unharmed as it idles in neutral, numb.

Maybe God puts us together like that. Our bodies won't let us feel the pain. Shock is the buffer that protects us from the pain and destruction that reality holds. We go on automatic pilot, reacting as we normally would but without registering our actions in the "purposeful department" of our minds.

We flow. We smile and nod. We keep moving at a conscious level while our insides freeze -- and sink. Yes, sink. There is a falling feeling, too. That frozen moment of incomprehensible news is wrapped in the denials of "this can't be!" and slowly starts a downward spiral of disbelief.

And we sit still.

Life is full of unchosen paths. Once we find ourselves on a path we did not choose, we have a huge decision to make: How are we going to handle the new reality? What can we learn? What can we teach? What can we love? What can we let go? Unchosen paths can lead to hand-wringing, shoulder-slumping, hair-pulling bouts of self-pity -- if we let them. Unchosen paths whine, "Why me?" They shout, "Not my life, please!" They scream, "Life is not fair!"
But with effort, we can shift our minds into a different gear of attitude. We can go deep within ourselves and touch the solid bottom of our souls, returning to shout back with vengeance to that path unchosen, "Nevertheless, I'll master you anyway!" and choose to move from pity to power. The spirit of "nevertheless" lets us shift our anger and pain at life, to an energy seeking more from life despite our circumstance.

"Nevertheless" accepts a given situation, yet refuses to be passive. "Nevertheless" takes pity and moves it to power.

If I had to be paralyzed, I am glad it is now when technology has opened my limited world from the wheelchair to the unlimited world of cyberspace. I hate being in this wheelchair and know one day I will no longer need it. "Nevertheless," I will live in the moment I have today.

I am determined to live a full and complete life, even if it is on unchosen paths.

I come from Australia. A country famous for it's bikini clad meter maids, and Steve Irwin – "The Crocodile Man."

My family consists of Steve (not the crocodile man!), Emma our three and a half year old tornado daughter and Luke, my 20 month old son with TM.

I am an Air Traffic Controller, and I am used to having some control over things and making them happen. But in Luke's situation, I had absolutely no control over anything.

This is Luke's story, and nothing could have prepared us for the turbulent path that our lives have followed over the last 15 months.

On the sixth of April 2000, Luke had his scheduled DTP, diphtheria, tetanus, and whooping cough

Alison Alderton's Speech at the TM Symposium Banquet, Saturday, July 14, 2001

immunization. On the 19th of April 2000 Luke had his third and final Hepatitis B immunization. The very next day we all flew to New Zealand after being in Australia on a three-year posting with the Royal New Zealand Air Force. We were to return for two weeks to organize our affairs before moving the family to Australia, where Steve was to start a new job.

Luke was five and a half months old.

The first time I was aware that something was not quite right with

Luke was on the 29th of April. Luke had a weak cry, he was unsettled and appeared tired and a little floppy – as all children are at times.

Luke had a bad night's sleep, waking and crying, but not moving around very much. I fed him and comforted him and he fell asleep next to me. Early the next morning, he hadn't improved, so we took him straight to see a doctor. The doctor couldn't diagnoses what was wrong, but was unhappy (as I was) with his weakness.

Luke was admitted to Palmerston North Hospital directly from the doctor's surgery on that day (30th April). The hospital was a small hospital, servicing a city of 40,000 people.

The doctors thought he may have either encephalitis or meningitis, and Luke was commenced on a course of antibiotics. A spinal tap was also preformed. The doctors were still unable to come up with a diagnosis.

Luke's breathing appeared laboured and I mentioned this to the nurses. Finally, I got to see a pediatrician who reassured me this was a normal breathing pattern for a baby. I was concerned.

Later that evening Luke started to salivate and went in to respiratory failure. His eyes were fixed straight ahead and his body was completely floppy. Luke was resuscitated and then went into respiratory failure another two times.

The emergency doctor was out of his depth. He was hesitating and was unsure whether to incubate Luke, as he had no pediatric training. When the pediatrician arrived, he incubated Luke and gave Luke some drug to relax his jaw, as he was also having a seizure.

Somewhere in the middle of all of the chaos, I managed to call Steve who joined me. Together we stood in disbelief and shock, wondering what was happening to Luke.

On the first of May, Luke was transferred, by aircraft, to PICU, a cute name for a very serious place – The Pediatric Intensive Care Unit of Starship Hospital in Auckland. This was the biggest and most capable hospital in New Zealand. We felt Luke was in good hands.

On the second of May, the doctors felt Luke was stable enough to be taken off the ventilator. He was abdominally breathing – but he was breathing!

He was completely paralysed from the neck down and we still didn't have a diagnosis. Luke appeared to be in pain and was given pain relief. I expressed milk and Luke was fed through a tube, as feeding was too exhausting for him.

The doctors talked to Steve and I about Luke's quality of life. They expected him to fatigue and have to go back on the ventilator. They discussed turning the ventilator off. This was without a doubt the worst day of our lives.

We still had not had a definite diagnosis, but Gillian-Barre and TM were hot contenders. A CT scan revealed nothing. Luke was given a course of Methyl Prednisone.

On the fourth of May, Luke had an MRI scan. This was five days after the onset of Luke's illness. We were expecting the scan results to reveal TM – by now my husband was an expert having read all the medical reference books he could get his hands on. We were advised the MRI scan showed a lesion from C2 to C7 and a long syrinx. It was almost certainly a tumour and Luke would have two weeks to live. Steve and I had had better days.

Over the next few days, Luke remained paralysed – reaching out to the world only with his tongue.

On the 11th of May, Luke had a second MRI scan. This showed a reduction in the size of the lesion, a significant reduction of 50%. It was now thought by the doctors that TM was more likely than a tumour. We felt so blessed to still have Luke, and there was the occasional small flicker of a finger. The chance of life was so much better than no life at all.

And how is Luke now, 15 months later?

Luke is a very happy boy. He is a quadriplegic. He has limited movement of his arms and hands. Enough now that he can just feed himself by balancing pieces of food on his thumb. He has returning sensation in his lower limbs. He still abdominal breathes. There is some small independent and conscious movement in his legs.

While Luke is faced with more challenges than most people, we focus on what Luke ***can*** do – not on what he can't. We see a bright, independent and satisfying future for both of our children, and as a family, we will ensure that happens.

I came to this symposium believing I knew what TM was – I leave realizing I know nothing. Luke's rehabilitation will be greatly improved by what I have learned here.

I hope to increase the awareness of TM and the importance of early intervention with steroids and early diagnosis with MRI scans.

For whatever reason it happened, and I'm not sure why, what I do know is that we are on a different flightpath to the one I'd filed. This doesn't mean a worse flight – just a different one, and the destination might even be better than the one we'd originally planned, who knows?

Just as Luke has adapted, we also have made adjustments, got used to the changes, and got on with life. What else is there?

When Luke was in PICU and it looked likely he would die, my husband wrote a list of wishes for Luke, and I'd like to share them with you now:

When it was just life or death, nothing more, this is what I wished for Luke.

I must always remember this.

Things I wish for my son:

To feel the warmth of sunlight on your face.

To reach out, and feel the accomplishment of grasping.

To marvel at the mystery of life.

To sense the vastness of the universe and the smallness of one's self.

To give love. To feel love.

To know peace and comfort.

To wonder. To be in absolute awe.

To feel rapture/pure joy.

To know faith.

To simply dream.

To see the first rays of the morning light.

To sense the uplifting spirit of music/song.

To feel contentment and happiness.

To create.

To feel the first sharp intake of breathe after diving into fresh cold water. The invigorating sense of being alive.

At the end of it all, to have been a good person.

San Diego, Here I Come! Or How I Contracted TM and then Won the Canadian Handcycling Nationals

Andrew Reid

It was seven months after I moved from Ottawa, Canada to the good ole US of A -- Austin, Texas to be exact -- that I ended up in a wheelchair. Life couldn't have been better. I was 28 years old, working for a great software company, kickboxing 40 rounds per week, and chillin' out in the sun 300 days a year.

It was November 24, 1999 that I took off to San Diego, the land of beautiful waves, for a four-day surfing adventure. I had planned the trip several weeks before for my first American Thanksgiving weekend, and now the date had arrived. I couldn't have been more excited since it had been about a year-and-a-half since I'd danced on the waves. I wish I could tell you that the trip went without glitches, but then you wouldn't be reading this article, if it had.

I had caught several waves at Pacific Beach (PB) that day before trouble arrived. I began to feel a little "numb" but that is standard stuff really when you are surfing in 55 F water. In fact, most of the local surfers only stay out an hour at a time, because it's so cold, even with a wetsuit. I had already been out there a good hour-and-a-half and planned to catch as many waves as possible that weekend. So, though I was having difficulty feeling my feet, I soaked it up, paddled out and caught another wave. I timed it perfectly, hopped up, and felt almost a "pop" in my lower back, nothing traumatic, but enough to make me wipe out. It was at that point that I decided to take a breather and go into shore and warm up. I lied in the sand and hoped that my feet would come back, but they never did. In fact, I got up to clean the sand off after lying there several minutes and fell down. I staggered down to the water like I was drunk and could no longer stand by myself. Onlookers saw what was happening and the next thing I know I'm in emergency. It probably wasn't more than 2 hours before I was paralyzed at T11.

The next few days were a blur. My mom and dad got that fateful call in Canada and, of course, my mom thought "why does he have to do all that crazy stuff" (surfing, snowboarding, kickboxing, rock-climbing)? Of course, they didn't know at that time that it wasn't so traumatic.

I guess it was about a week before they moved me out of emergency and into rehab, Scripp's Memorial to be exact. By the way, my mom had arrived as soon as she could and either my mom or dad never left my side until my return to Canada, which was a month later when I got out. All the staff at Scripps was fantastic. At that time I wasn't ready to accept anything to do with being in a

wheelchair so when the physical therapists (PTs) told me that life is not over and there are plenty of great wheelchair sports, I'm like, "Yeah right! How the heck will I ever kickbox again?"

It was December 24th, my birthday, that I got out of rehab. I flew back to Canada with my dad and I don't think I need to tell you how horrible Christmas was for me and the family. I also can't tell you that I didn't suffer from depression for the first few months. I had never spent a day in the hospital and now my life seemed to be pretty much over.

I'm proud to say that those negative thoughts didn't last very long. I've always been a warrior and nothing will change that! I knew the best thing for me was to get back to Austin with the warm weather. My body just doesn't seem to be good with the cold weather now. So, I moved back to Austin less than a month after being home in Canada. Work had been so supportive (and continues to be) and that made my life so much easier. The president of our company even flew down to see me when I was in rehab.

I started doing home therapy and slowly got back to work and "on my feet" so to speak. I knew I had to stay active since sports have always been a huge part of my life and I've always been in great shape. I think doing crazy stuff keeps me sane. I heard about a sports program through my PT. She said it was St. David's Fitness Center for people with disabilities and that they were always doing crazy stuff.

I went in there over a year ago and said to the dude who appeared to be in charge, "what is the baddest thing I could be doing in a wheelchair?" He told me that triathlons were the way to go and handcycling is the future. I said, "where do I sign up?" That was really the turning point for me. The person I talked to that day was Mike Haynes, the supervisor at the center, and he immediately got me swimming and handcycling.

I'd like to tell you about all of my initial adventures and could probably go on forever, but the length of this article might scare you and you won't read it. As I mentioned, that was a little over a year ago that I started handcycling. I have participated in many cycling events since then. In June, I came in fourth in the handcycling division of the toughest ½ Ironman in the country. This is the qualifier for the full Ironman in Hawaii and is a grueling 1.2 mile swim, 56 mile bike, and 13.1 mile run (push in my case). I have logged many miles and rides since then and am very proud to say that I just won both the 13 km time trial and the 40 km road race by a landslide at the Canadian Cycling Nationals.

I next began preparation for The European Cycling Championships in Zurich, Switzerland. I arrived on September 6th and met the other Canadian team members. We stayed in Zurich until September 12th where we trained on the lovely farm roads everyday, and then proceeded to Neuchatel, a French village about 2.5 hours drive for the actual road competition. I competed in a 12.9 km time trial on September 14th and a 53.2 km road race on September 15th. It was a wonderful experience racing against the best people in the world. After recovering from a wipeout at approximately the 23rd mile by taking a corner a little too fast, I managed to finish 13th, which isn't so bad for the world ranking and my first year of racing.

I certainly learned a lot from the trip. The Europeans are very strong and have a large group. I plan to do at least 100 miles a week here in Austin until the 2002 season begins and then I will be racing probably at least once a month around the country preparing for the World Championships in Germany in August of 2002.

I guess the training in the hills and 100 degree weather is starting to pay off. After all, there is nothing like being in good health. Hopefully, next year I will compete in the Ironman in Hawaii, and then who knows. It's hard to believe that I'm a better swimmer now then before, even without the use of my legs.

This summer I had the pleasure of attending the Cody Unser First Step Foundation Golf Fiesta. My wonderful brother, Buddy Peltier, attended the tournament with me. The tournament invited athletes from all sports. They included Darrell Lamonica, Jim Kelly, Al Unser Jr., Luc Longley, Pedro Guererro, just to name a few. Fortunately, my brother got to play in the tournament along side Pedro Guererro. Cody's mother, Shelley, and I decided it would be fun to surprise Cody and not tell her I was coming. It was hard to keep it a surprise, because I had to lie in every e-mail we exchanged leading up to the event. She was pleasantly surprised.

The tournament was at a resort in the beautiful setting of Albuquerque, NM. The weekend included an auction where they had all sorts of sports memorabilia up for bid, a two-day golf tournament, and a banquet/ concert as a finale. As a special fundraiser, they set up the 18th hole where the teams had to hit their approach shot onto the green from a wheelchair. Marilyn Hamilton, the founder of Quickie wheelchairs, played the role of the bill collector. Teams then had the option of playing the "wheelchair" shot, or buying a second, standing approach shot for

The Cody Unser First Step Foundation Golf Fiesta
Paula Lazzeri

$40. It was comical, challenging, and gave each team a glimpse of just how difficult life can be from a wheelchair.

Overall, my brother and I had a wonderful time. Throughout the tournament I was continually reminded of how much Cody Unser was meant to be an advocate for all persons with Transverse Myelitis. She was out there each day raising money while telling her story to the attendees and press. I can honestly say that I am truly lucky to have Cody Unser as a friend.

The following is the speech I gave at the banquet.

Hello everyone. First let me say how happy I am to be here, both as a fellow person with TM and as a friend to Cody and her family. It was two years ago at the first International TM symposium when I met Shelley and heard about Cody. Seeing and meeting other TMers for the first time brought back many feelings. It was 22 years ago to be exact. I was a happy go lucky, healthy 12-year-old girl. In a few short hours, I went from running around doing cartwheels to a c6-7 paraplegic bound to a wheelchair. It took a month before my parents, family, and I heard the words Transverse Myelitis. That month was an agonizing time of seeing my family through a glass window for the docs were afraid I was contagious. I went through many tests, and no one would answer my question, "am I going to die?" Hearing a diagnosis of TM didn't seem to clear the uncertainty of what my future held, instead it only gave me that feeling of being on a desert island. My experience is not unique, many other fellow TMers are at first thought of as, "it is all in their head" and do not get diagnosed right away.

When I met Cody face to face, which was only a month ago, I couldn't help but notice so much of myself in her. Her sheer determination to "make a difference" shows through. I, too, decided at a young age that I wasn't going to let this defeat me. I went on to graduate from high school and college, got married, had a baby, and have worked as a tax accountant for the past 12 years. Seven years ago the TMA was founded by a couple whose daughter got TM at 18 months. Our membership now reaches over 3300 people worldwide. As the treasurer of the TMA, I am proud to be a part of an organization that has educated many doctors, caregivers, and TM victims on the basics of TM and given moral support to all. We had our first TM symposium two years ago, and, as I mentioned earlier, last month the 2nd TM symposium was held. Next summer we are planning a Children's Workshop for children with TM and their families. Our mission is to educate, give moral support, direct fellow Tmers to physicians, and ultimately find a cure. Watching Cody and her Foundation these past few years has only aided our cause! Their Foundation has been remarkable at making changes at a national level.

Let me end by thanking all of you for being here and helping us "make a difference." Cody, I know someday soon we will both be walking. Until then, I'm right here with you, in the same fight, with the same hope!

There is much to be gained by improving communications between family caregivers and health care professionals, especially physicians. Positive outcomes include: better care for the patient, less stress and illness on the part of the caregiver, more efficient use of doctors' time, reduced costs for the health care system, and more satisfaction for all concerned. In order to reap these benefits, caregivers and physicians need to gain a better understanding of each other's worlds. They need to try, as hard as it is, "to walk in each other's shoes." The following guide is offered as a path for doing just that.

Tips for Doctors from Family Caregivers

- Be open and forthright.
- Think about the practicality of the treatments you suggest and consider their effect on the entire family, not just their medical efficacy.
- When you prescribe medications, be sure caregivers understand potential side effects so they know what to expect.
- In non-life threatening situations, assure caregivers that every decision doesn't have to be made on the spot. Respect the right of the caregiver and the patient to think things over.
- Now and then ask the caregiver: How are you? Let them know you understand that illness and disability are a family affair.
- Be accessible – especially when a caregiver is opening his or her heart.
- Reach out to the caregiver – literally. A simple touch can mean a great deal.
- Be sensitive about where you talk to caregivers about difficult subjects – waiting rooms and

A Guide to Improving Doctor/ Caregiver Communications: Suggestions from the National Family Caregivers Association

corridors are not appropriate.
- Always explain as completely as possible all of the legal ramifications of life-saving actions.
- Be prepared to tell caregivers about helpful resources. Living with a chronic illness or disability requires more than medicine has to offer.

Tips for Family Caregivers from Physicians and other Healthcare Professionals

- Write questions down so you won't forget them.
- Be clear about what you want to say to the doctor. Try not to ramble. If you have lots of things to talk about, make a consultation appointment, so the doctor can allow enough time to meet with you in an unhurried way.
- Educate yourself about your loved one's disease or disability. With all the information on the Internet it is easier than ever before.
- Learn the routine at your doctor's office and/or hospital so you can make the system work for you, not against you.
- Recognize that not all questions have answers – especially those beginning with "why."
- Separate your anger and sense of impotence about not being able to help your loved one as much as you would like, from your feeling about the doctor. Remember, you are both on the same side.

10 Tips for Family Caregivers

1. Choose to take charge of your life, and don't let your loved one's illness or disability always take center state.
2. Remember to be good to yourself. Love, honor, and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. Watch out for signs of depression, and don't delay in getting professional help when you need it.
4. When people offer to help, accept the offer and suggest specific things that they can do.
5. Educate yourself about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
7. Trust your instincts. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Stand up for your rights as a caregiver and a citizen.
10. Seek support from other caregivers. There is great strength in knowing you are not alone.

Reprinted from the NFCA Website with permission of the National Family Caregivers Association, Kensington, MD, the nation's only organization for all family caregivers. 1-800-896-3650; www.nfcacares.org.
The Transverse Myelitis Association is a proud member of the National Family Caregivers Association (NFCA). We have established a link to the NFCA from the bottom of the main page of our web site. A recent survey from the NFCA reports that during the past year, more than 54 million people were family caregivers. Providing care to a loved one who is ill, disabled or elderly is a devastatingly difficult job.

We support NFCA's effort to "Share the Caring" and acknowledge National Family Caregivers Month (NFC Month) as an opportunity to provide community-based activities in support of family caregivers. NFC Month is designed to raise awareness that will help people recognize and appreciate the caregivers' vital role. The goal is to build caregiver self-esteem, expand caregiver self-awareness and teach caregivers to become their own advocates.

NFCA recognizes that one of the most difficult challenges for family caregivers to overcome is the ability to effectively communicate with the medical world. Educational materials available through NFCA will address this topic.

Please join us in celebrating National Family Caregivers Month this November. For information on how to obtain a list of activity ideas, a

Share the Caring This November As We Celebrate National Family Caregivers Month 2001

media communications kit, educational materials and/or background information on NFC Month, contact NFCA.

Call NFCA at 1-800-896-3650 or visit www.nfcacares.org

The TMA does not endorse any of the medications, treatments or products reported in this newsletter. This information is intended only to keep you informed. We strongly advise that you check any drugs or treatments mentioned with your physician.

In Their Own Words

In each issue of the newsletter, we will bring you a column that 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.

Experience with TENS Unit
Conrad Brown

I have no way of knowing how many Tmer's who suffer from spasms may or may not be familiar with the effectiveness of a TENS unit, but I thought it would be helpful to others for me to communicate about my experiences.

Though few physical therapists and seemingly fewer physicians know this, painful spasms can be stopped cold with a Transcutaneous Electrical Nerve Stimulation (TENS) unit - at least mine can be. An L2-4 incomplete paraplegic following a mysterious ten-minute attack 28 years ago, I've been using a TENS unit for the past 15 years for pain-producing nocturnal spasms, usually stopping them instantly the moment they appear. As a consequence, I take no pain medication other than an occasional Tylenol.

Every evening before dinner I wipe a skin barrier across two areas either side of the spine about waist level. Then I apply 1-3/4" x 3-1/4" Encore

National Family Caregivers Month
November 2001

Tantone re-usable electrodes one on each side of the spine oriented vertically about eight inches apart. I use the snap-on type snapped onto a double lead wire, having found that the slide-on type can pull apart, and the free end of a charged TENS lead can be like having a snake in bed with you.

I get my electrodes from Electro Devices (1-800-762-5969), a mail order supplier *par excellence*. The two large electrodes I use deliver a broad flow of stimulation from one electrode to the other, which is a set-up I have found far more effective than the standard four small electrodes, whatever their placement. To keep from getting tangled with the lead wire, I wear a light T-shirt under my pajama top and run the wire around and up across my chest next to the skin; the TENS unit goes in my pajama pocket.

I tried several different brands of TENS unit (available only by prescription) before I came upon the EMPI (1-800-328-2536), which I use every night, removing the electrodes when I get up in the morning. Experimenting with different EMPI configurations, I long ago discovered that a pulse rate of 60 and a top-side control set on R were most effective and I have used these settings ever since.

Some folks may shy away from the idea of a TENS unit because it sounds like some kind of shock wave therapy, which it most decidedly is not. The TENS unit produces rather pleasant vibrations under the skin, vibrations which, when you press your fingers on the site, surprisingly you cannot feel at all. As to how it works, I have never been able to get an answer that is nontechnical enough for me to understand. I can only say, the TENS stimulation seems to interrupt either the pathway or the message itself between the spasms and the brain.

And I shall never cease to be amazed at how instantaneously it works if I turn the TENS unit on within the first few seconds of an attack of spasms, although if the spasms start while I'm asleep, relief may take a little longer. There have even been a few times, I must admit, when I have wakened in the night to find the spasms have a long head start and are going full blast. Then the TENS unit has not been effective at all.

I understand that some people are not helped by a TENS unit. Nevertheless, I urge any reader-sufferer who may not have tried the device to give it a real chance. Without mine I think I'd have gone over the abyss years ago.
Sincerely,
Conrad Brown
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I just recently found out about the TMA while I was doing some research on an existing problem. I was delighted to discover the TMA. While sitting at the library reading all that I could, I suddenly realized, G-d didn't only do this to ***me***, but to others, as well. I didn't feel all alone. In 1975 I was told I was the only person in the USA to have TM.

I just received my first issue of the

TMA newsletter and my membership directory. I was so excited that someone other than myself and family knew anything about TM. I immediately had to write, and say, "Hello, I'm Tammy and I'm another victim of TM."

Well, this is my story, but please excuse me if some of the details are not clear. In November of this year, it will be 26 years that I have suffered from TM and its everlasting affects.

It started a few days after Thanksgiving in 1975. I was eleven at the time of the onset. I remember feeling like I was getting the flu, along with a horrible headache. I didn't go to school that entire week. I was still feeling terrible at the time, but this is something I'll never forget. My family and I were watching television in the living room; we were watching *All in the Family*. I began to have pain in my back. At first I didn't think too much about it. I thought it was a flu-like symptom. However, the pain became more severe. I thought if I lay on the floor, maybe it would relieve the pain. It did

Tammy Morrison
Anderson Indiana

not! The pain was getting worse. My Mother gave me a pain reliever and I went to bed. The pain continued throughout the night. In the middle of the night, I started noticing a numbness feeling around my chest and back. Then my left foot and leg was becoming extremely weak.

The first thing Monday morning, my Mother called our family doctor and they said, "bring her in immediately." By this time I could barely walk; my left foot and leg was completely paralyzed. My Mother had to carry me to the car. On the way Mom stopped at my Grandmother's house for some help to carry my lifeless body into the doctor's office. By the time we arrived, I was totally paralyzed around my chest and back, both legs and feet (excluding my arms and neck). My bladder was so full, it would have burst if I had arrived any later. I had no sensation that my bladder was full; granted I was only eleven years old and I didn't understand what was happening to my body.

The doctor had no clue what was wrong other than my bladder needed to be emptied immediately. He called an ambulance and they took me to our local hospital. I was there two days. Plenty of tests were taken, but no one had any answers. Then on December 3rd I was transported to Riley Children's Hospital in Indianapolis, Indiana. When I arrived, there was a team of physicians waiting for me. I only can recall just a few of their names.

I had spinal tap after spinal tap and test after test. Twice daily I had shots given to me in my legs; and I don't remember the reason for these shots. The team of doctors still didn't have a clue at this point. When all of my tests came back, they had to send them to California for more 'testing.'

Meanwhile, I was taking intense physical therapy twice daily and occupational therapy three times a week. I clearly remember the PT. At first, I despised my PT; she would make me so mad at times for forcing me to get my legs in use again. Now, looking back, I'm immensely grateful to her for keeping me focused on my outcome, which was to walk again.

When the test finally arrived, the team of doctors called my family in for their 'three' inconclusive diagnoses. The doctors 'suggested' it 'may be' MS or muscular dystrophy or Guillian Barre. When I saw my Mom cry, I knew it was something awful. Being only eleven, I really didn't know what MS or muscular dystrophy or Guillian Barre were. Then the doctors told me that I would never walk again. I 'never' would comprehend the fact that I would spend my life in a wheelchair. I was 'determined' to walk and to prove the doctors wrong. However, they didn't know any more than I did!

Although I disliked my PT, I decided to use my anger against her in a positive manner. My 'only' focus was to walk again and to go home. I asked my neurologist at the time, if I could go to the PT four hours a day instead of two hours per day. He reluctantly said, yes.

As the days went on, my legs began getting stronger and some of the numbness was somewhat starting to diminish. Then my legs started to jerk uncontrollably (but at least they were moving). I took it as a sign from G-d that 'I will' walk again. That gave me more ambition and faith. I 'am' going to beat this horrendous disease.

Christmas was only a few days away and all I wanted was 'not' to be in the hospital on Christmas and I desperately wanted to go home. Granted I was not 'ill.' I was 'disabled' and getting somewhat stronger. So, I pleaded with my attending physicians to let me go home for two days. After doing a lot of praying and pleading, he gave me approval, but with one stipulation. That my parents drive me to our local hospital twice daily for those 'unknown' shots in my legs.

I flew in that wheelchair like a bullet, getting to the phone to call my dad and have him come and get me. If I can correctly recall, he had already been to visit that day, as both my parents visited every day, even though we lived about forty miles one way. Within a couple of hours, Dad and his

best friend finally arrived. Luckily, his friend had a van for my wheelchair and I.

It was a great Christmas except for the four unwanted wheels I was affixed to. However, I was thankful and happy to be home with my family that had taken remarkably good care of me. And to this day, my family is caring and understanding when it comes to my health.

Meanwhile, back at Riley, I continued my strenuous PT. It was finally starting to help.

I distinctively recall one particular evening. I had learned the routine of the nurse's duties down to a science. After lights were out, I decided to see if I could attempt to walk to a chair, which was about four feet away. I quietly sat up and put my legs over the side of the bed. I remember saying, "I ***can*** do this!" My legs were very heavy when I placed my feet on the floor. I started to lift myself up, my legs began to tremble, but I was not going to give up. Slowly, I made it to the chair. At the same time, a nurse passed by the door. I was so happy that I had done it that I didn't hear a word she said while she was scolding me. Although later that evening she said, "Good job!"

The next morning, I could not wait to show and tell my PT. For the next few weeks, I was getting stronger and stronger everyday. I was slowly but surely starting to walk again. Finally, after all the prayers and my determination to walk, it happened.

By this time, the doctors determined that it was TM, and that was when I was told I was the only person in the United States to have this disease. I was released but continued to have problems. And ***still*** do have problems due to TM.

Then at the age of 14 I was diagnosed with severe scoliosis and was the first person here in my hometown to have the surgery; just my luck. That was also a horrible experience. If any of you have ever experienced being on a Striker Frame, you will completely understand. Also, wearing a non-removable full body cast for nine months. Then I wore a removable body cast for nine months, twenty-three hours a day. I understand the surgery is much more advanced. I hope so, anyway; although that was a long time ago, 23 years. I would never want anyone to ever go through that unforgettable treatment.

Meanwhile, I have had a pretty long period of "decent" health, except for the everlasting affects of TM. No one has yet to help with these problems, because most neurologists know little or nothing about TM.

I started to go to college at the age of 33, and began having severe lower back and buttocks and leg pain. I eventually had to drop out of school, and had to break down and apply for Medicaid. And as of July 2000, I was diagnosed with spinal stenosis. I had surgery in September. It seemed to ease the pain at first, but now the pain is worse than ever. But I'm not going to give up until I'm out of pain, if ever. I'm awaiting an appointment with a neurosurgeon in July. Hopefully, he can help.

Well, that's just a fraction of my story. I realize that I am very lucky to have come this far. I hope my story has somehow helped or inspired you and your family. For those of you with TM that have not been as fortunate as I was, my prayers are with you ***all***. Remember, you are not alone – like I thought for the past 26 years.

In closing, I will do whatever it takes to help the TMA, especially getting TM awareness out to the public. Also, I will help with fundraising for the TMA. I would also like to thank Dr. Levy and Dr. Lynn for their remarkable efforts and for actually knowing about TM. Thank you!

I would like to add that I have applied several times for social security disability benefits. I am fighting for something that I am legitimately entitled to, along with all others with TM.

Your TM friend,
Tammy Morrison

Hi, my name is Phyllis and I live in Sutton, Ontario, Canada. I am 54 years old and I have been diagnosed with TM.

On June 23, 2000 my husband and I had gone out to dinner. When we returned, I was drinking a cup of tea and watching the ball game on TV when my fingers on my right hand started to tingle (that falling asleep feeling). Within half an hour, the tingling and now numbness was moving up my right arm to shoulder level. It then started in my left hand and traveled up my left arm to shoulder level. Within two hours I couldn't move my arms and my husband helped me into my pajamas. I had a nagging pain in my shoulders and arms and they felt like lead. I couldn't get comfortable in bed, on the couch or on the floor that night. I don't think I slept at all.

Saturday morning I got to see my doctor who immediately sent me to the ER at the nearest hospital about 25 miles away. Because I had a fall the day before down three cement steps landing on my butt, the ER doctor ordered a CAT scan and x-rays of my spine, but they showed nothing unusual. As it was Saturday and no MRIs are done at this hospital, I was sent by ambulance to St. Michael's hospital in Toronto to see a neurosurgeon in the ER there. I had my first MRI on my spine at 8:00 p.m.

that night and by midnight I was told by the neurosurgeon (who had been in surgery) that I didn't need his services as there were no fractures in my spine. He said that a neurologist would see me Sunday morning in the hospital. I was admitted to the hospital.

Phyllis Pollock
Sutton Ontario Canada

Things were a little fuzzy for the next few days as numerous tests were done, including blood tests, a MRI on my head which was normal, evoked potentials which were normal, and a lumbar puncture which revealed oligoclonal banding. The MRI on my spine showed a lesion starting at C2 to C5. In the hospital I was put on an I.V. drip of Solumedrol for four days. Because my arms didn't work, I was completely helpless except I could walk the corridors. I even had to be fed my meals and have my teeth brushed. I think I heard the terms multiple sclerosis and transverse myelitis while I was in the hospital.

I was asked if I would give the history of what had happened to the whole neurology department in the hospital, because my case was so unusual. When I did, they asked me all sorts of questions, but I received no direct answers as to what was wrong with me. Shortly after the meeting, I was discharged from the hospital. I was glad to be on my way home, although I had not been given a diagnosis. I was just told I was very unusual. I was given a two-week taper of prednisone to be taken at home.

I have since had another MRI on August 9, 2000, which showed the swelling had narrowed a bit. On November 10, 2000 I had an EMG and the doctor who performed it didn't think I had MS. She said the nerves in my shoulders were regenerating, but that it was a slow process that could continue for about two years. I am scheduled for another MRI on May 22, 2001.

I had been employed as a legal secretary for 17 ½ years for the same lawyer. I haven't been able to work since June 23, 2000, as I can't use the computer for any length of time. My boss has been very supportive and has told me I still have a job, if I can ever come back. My neurologist has told me he doubts I'll ever be able to work again.

I have a wonderful husband, Brian, who has pitched in and does most everything at home. Thank goodness he likes to cook. Preparation of all meals, cleaning the house, showering, dressing and feeding me fell on him, as well as his continuing to work a four day work week and doing all the yard work at our home. We have two grown children, a daughter 28 who lives in Colorado and a son 26 who lives in Texas. My sister-in-law, Lillian, was a godsend in those first weeks last summer, as she would come each morning to see if I needed anything while Brian was working. There is a therapeutic pool not far from where I live that Lillian started taking me to about a week after I was out of the hospital. It is great as a person can do many more exercises in the water due to the buoyancy.

By November my husband had cut back his work week to two days and he started taking the pool classes with me. I go three times a week. I also do arm exercises on my own at home and I walk a lot, but not in the snowy winter. I walk 2 ½ miles, three or four times a week.

From time to time I do get a banding feeling across my rib area on my left side. My upper front legs sometimes feel cold from the inside out, but are not cold to touch. My knees sometimes have a throbbing feeling. I don't know if that is TM or age. I had no paralysis in my legs. My worst symptoms are still the numbness and tingling in my hands and lower arms. I am unable to lift objects more than a pound and not very high. I take no medications. It is hard to get comfortable in bed, because no matter where I lay, that part of my arm falls asleep very easily.

I have not driven a car since June 23, 2000 and I may never be able to again. I live about five miles from the nearest town. I do like to read a lot, do jigsaw puzzles and crossword puzzles. Prior to contracting TM, I did knit and sew, but not anymore so far.

From what I have read on TM on the Internet, I think I am very lucky. However, I haven't been able to find many other people with similar symptoms to mine where the paralysis hit my arms and not my legs. I would be interested in hearing from anyone who has similar symptoms.

Phyllis Pollock
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I am a 70-year-old physician and cardiologist from the UK, but I am also a patient of TM. I had read about TM during my student days. I listened to lectures and lectured myself during my stay at the university on this subject, but had never seen one case during my professional career. I never thought I would see one, let alone become a victim of TM.

I retired early at age 61 and continued to work six to eight months a year helping my friends. I enjoyed my work and had a good life. My wife, Beryl, and myself spent a lot of time with our three children and eight grand children spread over three continents. Life was good and I was hoping to continue to work for a few more years and continue visiting

friends and relatives. Just before my 68th birthday on the 31st of January my whole life was going to change. I had two attacks of bad cold in the months of Dec 97 and Jan 98 and I also had taken the Flu Vaccine in Oct 97. I was working that Saturday and returned home after a busy ward round. I have been a health and fitness fanatic, strict with my diet, regular exercise in the gym and yoga. I also played golf as often as I could. In spite of a busy day, I had been to the gym and done yoga that morning. I was going for a quick game of golf that evening and my wife thought I should take it easy. I had not passed water since noon and all my efforts failed. My wife wondered why I was visiting the toilet so frequently. I told her the problem and thought at my age, enlarged prostate was the usual problem.

Beryl drove me to the hospital at midnight and it was thought that there was a slight enlargement of prostate with retention of urine. A self-retaining catheter was put in and I was admitted for observation. The next day the urologist came and said I could have the catheter out the next

C.R. Rao
Birchington Kent UK

morning and go home on some tablets and he would assess me in the next week or two. That morning I observed that the slippers were shooting off of my feet every time I tried to walk. I thought it must be the loose slippers. Beryl observed that I was a bit unsteady when I tried to shower; we thought maybe because of the previous late and restless night.

I was sitting on a chair all the evening watching TV and at midnight when I tried to stand up, my legs became numb and wobbly and I fell on the floor. I thought it was numbness due to sitting too long on the chair. I did not call the nurse or any body else. I just crawled and then climbed on to the bed. In the early hours of the morning, I found I could not move my legs and they were numb and heavy. I felt as if it was like the trunk of a big tree. I thought all sorts of things and finally scratched my legs with my fingernails upward towards my tummy. There was dulling of sensation up to mid-chest and pain around at that level. Then I realized I must be having an attack of transverse myelitis and called the nurse and told her my problem was neurological and not urological and it was an emergency. The surgeon came to see me and after brief examination, managed to get a neurologist within the hour. They all agreed with the diagnosis of TM. As the hours went by, I was getting weaker and weaker and now my arms were also numb, weak and unsteady.

I was transferred to a teaching hospital in London where I had a MRI of the spinal cord which showed some patchy signal change in the dorsal region which enhanced with gadolinium. There was no meningeal enhancement. A MRI of the brain done the next morning was normal with no abnormal enhancement. Lumbar puncture showed 82 lymphocytes, pressure normal and proteins slightly raised at 675m.gmper litre. All blood results were normal; viral studies normal. The neurologist thought that it might be tuberculous in origin, as I came from India and have had some temp off and on for few weeks (whether it was due to severe attacks of cold). If I agreed, they would start me on anti-tuberculous therapy. By that time I was too ill to think, agree or disagree. In retrospect and with further results in hand, we agreed at the follow up, it was not tuberculous in origin, however it was worth continuing the treatment for the whole year as it involved only oral therapy, which I did.

This was the third day in the hospital and I was going down fast. My wife and children were told that they should not expect much and, at the most, I would be in a wheelchair in a year's time. You can imagine the distress this caused. From that day I started meditation, more or less all the time, when I was without any audience. I visualized my brain, spinal cord and peripheral nerves and started sending signals asking the cells to regenerate. On the 7th day, I was bed-bound and could sit in a wheelchair with help. The body was limp, legs were weak and numb, arms were weak and there was no coordination. I could not sit or stand and my hands could not hold anything. I needed help to empty my bowel and bladder. Overnight, from an active professional man, I had become a vegetable almost.

The nursing staff was ignorant of my condition or indifferent to it. I had a different nurse every few hours, mostly agency nurses and there was no continuity of care. I was never given a face/mouth wash before breakfast. I was too ill to walk to the wash hand basin. Food and tablets were left on the table and I was asked to get on with it. When I spilled or dropped a tablet, I was told off. Beryl was worried about my back and nothing was done to prevent bedsores. Beryl was a nurse, so she brought the necessary things and took care of my back. This 7th day, it took two physiotherapists and a helper and my wife to get me up and sit and they had to hold me and without support I would fall back into bed. They tried to make me stand with help and made me do some exercises. After they left, I tried doing the same every hour.

Next morning, I was feeling a little

better and I was taken to the physiotherapy department where I had some more physiotherapy and I practiced it every hour in my ward with help of my wife. Next day, I was a bit stronger and was able to walk in parallel bars. I returned to the ward and practiced with the wall railings. Following day, I had more walking practice and this day with a stick. By this time the hospital routine was getting me down and I asked if I could go home for the weekend as nothing much was going to happen with physiotherapy. They all agreed. I was going to my daughters and the bedrooms were upstairs and I had to use the stairs. The physiotherapist asked me if I would like to try the stairs and I said yes, and we did. I became more confident. I went to my daughters and I went to the nearby church with my grandchildren and then to the supermarket with my wife and managed to walk with a stick. My daughter's neighbors had heard I was seriously ill just a few days ago and now to see me walking, they just could not believe it.

I went back to the hospital on Sunday night and after further lumbar puncture, blood tests and more physiotherapy over the next three days, we returned to our own home. I had more physiotherapy locally and was told that I was doing fine and that I could continue at home. Now I needed to empty my bladder with self-intermittent catheterisation four to six times a day. I continued meditation, added yoga bit by bit and even went to the gym.

Everyone says that I look great and my physicians say that I have done very well, but I feel that a small fuse is missing somewhere. However, with continued improvement, we decided to go on a cruise to Norwegian fjords. After our return, we went to see our daughter, son-in-law and two grandchildren in LA. While in LA, my daughter and son-in-law wanted me to see an acupuncturist for the urinary problems. I did see one and I am not sure if it helped. I did start passing water myself, at times, which has slowly improved. I continue meditation and exercises. I feel this has certainly helped me.

When I was seriously ill, all my family, friends and even the classmates of my grandchildren requested their teachers to put my name on the sick list to be mentioned in the daily prayer for blessings. I am sure these good wishes and prayers helped me too.

Right now, I am independent, self-caring, and need intermittent self-catheterisation a few times a day (if I am home, I can manage without it). I still travel a lot, planning to add yoga and restart gym. We have been around the world by air visiting daughters and family in the USA and Australia and son and family in India. While I look well and generally feel well, the little fuse somewhere is still missing.

Dr. C. R. Rao
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My Experience with Transverse Myelitis June 17th 2001

At the age of 27, living by myself with two children (seven and nine), I have gone back to school to progress in life and I am really active. April 15th, 1991, afternoon, I feel pain in my lower back, numbness under my arms. I'm feeling very loud. Walking is hard, I can't write my name, and I don't have any strength. In the evening, I go to the emergency room, because the pain is still there. I saw a doctor who performs a radiological test (cervical spine). Result: nothing . He gave me a painkiller and put me to rest for ten days. I go back home, take my pills and go to bed. I didn't sleep well. In the morning, I try to get up to send my kids to school. Nothing moves. I don't have the choice; I have to go back to the hospital, but this time by ambulance. I have pain through all my body and I feel more and more weak. To the emergency room. They install me a catheter because I can't walk.

I see a neurologist. He performed a lumbar puncture and other radiological tests (cervical and back spine) to find what's happening to me. He gives me a room for the night. I have so much difficulties to breathe and nobody can hear me.

April 17th in the morning, my doctor gave me a test to know my oxygen level. After that, I go to the intensive care. He tells me that the nurses will be closer to me. Then I realize that it was something worse than I thought. Doctors don't know what I have. They think about Gillian Barre syndrome or multiple sclerosis. Afternoon, they put me on a ventilator. I can't breath by myself anymore. I receive blood plasma and nurses turn me every two hours. The pain is awful, even a little touch is terribly painful. I receive: netilmicine (anti-infectious), flagyl (antibiotic), zinacef, solumedrol (against inflammation). I pass an electromyography, a cervical and thorax scanner, a myelography, a nerve conduction test, and a neck soft tissue x-ray.

Danielle Ruest
Rimouski Quebec Canada

A few days later, doctors make their diagnosis: transverse myelitis, C2 C3. Nothing moving from my neck to my toes. The pain is like burning everywhere in my body. I'm on a ventilator from April 17th to May 25th. I had a stomach hemorrhage. I also

had a tracheotomy from May 10th to October 11th. I had my catheter from April 16th to September 18th.

Since the beginning of my hospitalization, an occupational therapist and a physical therapist come see me everyday to help me move my arms and my legs to make my muscle react. A big thank you to those who take their time with me to help me get better. They support me really well.

On December 4th 1991, I took a nuclear magnetic resonance to confirm my diagnosis. On December 9th I left the hospital for a readaptation center. My first goal is to get an apartment and to take care of my kids. On June 17th 1992, I have reached my goal: I have an apartment and my daughter is living with me. I spent 14 months in the hospital. I miss my kids so much. My pain was worse than a regular pain, there was physical pain and the pain a mom can feel when she misses her kids.

One day, my doctor told me that I was so badly touched by the disease that it was a miracle that I could walk and move like this. The after effects that the transverse myelitis have caused:

My left side is still weak; my upper body is still atrophied; I have less sensation from my thoracic cage to my feet; I don't feel hot and cold in many places; I have a lazy bladder (it causes me many urinary infections); I need to use a laxative and suppositories to help my bowel move; when I have flu, I can't expectorate, so I've got to take antibiotic; I've got to take many rests in a day; I can walk for short distances (after 3 minutes, my legs get weak); I can't stand up and if I fall, I can't get up; and when I sit down, I need to put my legs up or they turn blue.

I still have pain. It feels like my body is burning inside. When I go down to sleep at night, I hope that tomorrow the pain will be gone, but I just have to move a little bit to feel it. Sometimes it's so painful that I have to change positions many times. I have tried lots of painkillers: tegretol, mexillecitin, neurontin, celebrex, vioxx and naproxen.

The sun's heat helps me a lot. I feel more supple and I can move more. Hot baths help me, too, but I can stay in too long because it makes me feel weak. Now I'm taking: baclofen (10mg x 3 times a day), detrol (2 mg x 2 a day) amitriptyline (75 mg 1 time a day), atasol (2 x 500mg each 4 hours), bisacodyl (10mg), bricanyl and pulmicort (when I have flu).

April 2001, I'm living with this disease for ten years now. I made my bereavement of what I was before. Now I'm rebuilding my life with what I am now. I understand after many years that the past is the past and I have to live with it. I thank with all my heart, all my family members who helped me for those 10 years. I thank also the men who take care of my kids from the first day; my friends who stay but I also understand those who leave because I know it's not easy to live with someone sick. Someone comes every week to do my cooking and my laundry.

My story ends here. Thank you for taking your time to read it and I hope it gives you some hope. Live one day at a time. I want to let people know that I'm open to receive questions and communication from people having this disease or from people living with those who have it in Quebec. Since I know the Association, I feel less alone and it helps me to continue.

I would like to introduce myself as a new member of the TM Association.

My name is Marsha. I was stricken with TM on February 11, 2001. It was an acute onset, rather than taking a week or more to manifest itself. I was getting into the car with my son at 10:30 a.m. to go to the store when I was suddenly gripped with a severe pain in my left mid-back region. I waited for a few minutes to see if it would go away, but it remained as severe as when it started. We went ahead and drove to the supermarket and to rent some movies. As we did our errands, the pain worsened and spread to my right side, and then around to my abdomen, so that I had a band of severe pain all around my torso, up above my waist.

When we got home, I was doubled over in pain. I told my son that I was going to go in and lie down for a while to see if it would go away. I thought I might be having a problem with my kidneys, gallbladder or pancreas. I put heating pads on my stomach and back, and went to bed. The pain did not let up, but continued to worsen. After two hours of suffering, I had my son call a friend of mine to take me to the emergency room. We arrived there at approximately 1:00 p.m., and triage took me right in to a bed. The ER physician came in and examined me. I was given a shot of Demerol. The nurse asked me to get them a urine sample, but when I went to the restroom, I found that I could not urinate. I thought I couldn't go because of the severe pain. After a period of time, the doctor told me that they were going to take an ultrasound of my abdomen. I was given three bottles of barium to drink. I was then taken for an ultrasound with contrast, and then X-rays. I was still in severe pain, and was then given a shot of Morphine, which also did not really help.

By this time, I was suffering from muscle cramps in both legs. I just

Marsha E. Scholes
Sacramento, CA

thought it was "restless leg syndrome," which I have suffered from time to time. It kept getting worse, so that I couldn't lie still. My legs were driving me crazy, even with all of the pain medication they had given me. I kept trying to get up and urinate (I never could get myself to go), but by then, my legs had started feeling wobbly and weak when I would try to get up and go to the restroom. I attributed that feeling to the Demerol and Morphine. Then the transporter came to get me again, and I had a CT scan. I don't know if these tests showed anything other than an extremely full bladder, but at 9:30 they decided to admit me. I received another shot of Demerol.

By 10:30 they had arranged a bed for me, and wheeled me upstairs. They wanted me to get on the scale and weigh myself before getting into the bed, but by now, I could hardly stand at all. Two nurses had to assist me in getting on the scale, and then help me to climb into bed. I still thought the weakness was from all of the pain medications I had been given. An IV was started once I was situated, and I fell asleep after receiving more pain medication. I awoke in the middle of the night to two legs, which refused to move at all. I buzzed the nurse, and told her that I couldn't move my legs. They made note of the fact, and I guess I fell back to sleep. The next morning a neurologist was called in. He examined me, and ordered a MRI. My legs were so painful, as were my back and abdomen that I couldn't lie still. They had to give me Valium in order for me to go through the long MRI. It took over an hour, and thank G-d, the valium made me fall into a sleep. I awoke just as the test was nearly finished.

The days ran into each other, but not too long after, I was informed that I probably had TM. I asked what it was, and was told in layman's terms about the lesions on the spinal cord, of which I had two in the T-spine. They then decided to do another MRI of my brain, and to do a lumbar puncture to see if I had elevated protein in the spinal fluid. That came back positive, but my brain MRI was negative. They ruled out MS and Epstein-Barr, and the diagnosis of TM was confirmed. I was in the regular hospital for nearly a month with severe pain and paralysis. The neurologist put me on IV steroids, and after a few days, I started to regain minute movement in my toes, and gradually, was able to move my right leg slightly. My right leg was definitely less affected than my left. The legs were still quite spasmodic, pulling up and doing as they would. I had no bowel or bladder control at all, and a foley catheter had been inserted so that I wouldn't develop reflux in my kidneys.

The first part of March, the physicians felt that I had recovered enough to be moved to the acute rehabilitation facility in the hospital, so I was transferred to a different room in that ward. They began to work on me as far as rehabilitation was concerned. I still couldn't even sit up by myself, as I had no sense of balance from my ribcage down. Gradually, with steroid intake, I improved so that I could sit up, and move from bed to wheelchair. I then was able to shower every other day with the assistance of a therapist. I remained in acute rehab for two weeks, and was released to go home on March 15, 2001. I could barely stand with the aid of a leg brace on my left leg. I was taught how to catheterize myself.

Once I got home, I was terrified. I have improved over this period of time to be able to walk short distances. I have to be very careful as I have fallen quite a bit due to the instability of my legs. I have regained enough feeling to know when I am going to have a bowel movement, so if I can get to the bathroom in time, I am safe. I still have not regained the use of my bladder. I have severe neuropathy from the waist down, so that I have no feelings of pain to injury, hot, cold, or wet. I do have feelings of pain in my back and abdomen in the areas that were painful at the onset of my disease. I feel pressure in most areas from the waist down, but suffer from severe muscle spasms, which are very unnerving. I have to be catheterized every few hours. I am able to drive on good days, so that my son, who is my caregiver, and I can go to the store, or run other errands. He wheels me to the car in my wheelchair, and we go from there. At least on those days, I feel I have a modicum of freedom. A great deal of the time I am depressed. It is very hard to get used to being infirm. I hope in time I will adjust, and will be able to find a purpose to my life. Right now, I am still trying to get used to having TM.

Every morning, I awake and the first thought in my mind is that my life is altered forever. I am trying to get in touch with other sufferers of TM, so that I can have someone to talk to who knows what I am going through. I have five children, and most of them really don't understand the seriousness of this illness. My two daughters actually think that most of this is in my head, and that I could function as usual if I wanted to! I look forward to the day when I can deal with this and have a smile on my face, and be able to get on with my life. Right now, I am still trying to deal with the finality of my diagnosis, and to get through each day. I look forward to hearing from any sufferer who would like to exchange information, and perhaps help me in

knowing I am not alone.

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My Adventure with Acute Transverse Myelitis

July 2nd 1992 my husband of six months, Gary, and I took my grandchildren home after a short visit. While we were at my daughter's house, I began to feel a tingling in my left leg. I did not think too much about it at the time. I just thought it was from sitting and riding in the car for four hours. I had no pain, just discomfort. On the way home, I could not get my left leg and foot to relax. I could not keep them still; they would move by themselves. After we arrived home, I sat in a tub of hot water hoping it would help. It did not. I slept only a little while that night.

The next day, July 3rd, both of my legs were tingling. They felt as if they were trying to wake up or thaw out. There was still no real pain, just discomfort. I could not sit still. I felt as if I was in a bed of ants; not the stinging kind; the kind that just crawl all over you. I thought I was losing my mind. I was worried and scared. I could not see my regular doctor until Monday because of the holiday. I did see a doctor and he gave me a muscle relaxer and told me to see my doctor on Monday.

July 4th, the muscle relaxer hadn't helped. I had a lot more tingling. I was beginning to have some numbness in my left foot and leg. I was very tired and weak. My husband and I had only known each other six months. We met on a Friday night and were married on the following Saturday (one week later). I was afraid there was something wrong with me that would make him not want to stay with me. Looking back on it now, I believe G-d had a plan for us. He knew I was going to need him in the near future, because my life as I knew it was about to change. I thank G-d each day for Gary and my children.

July 5th was Sunday. I was getting weaker in my legs. I felt heavy. My

Minnie E. Todd
Mobile AL

feet would not go where I wanted to put them. I had a lot more tingling and more numbness. I could not sit. I could not stand without a lot of discomfort. My entire lower body was tingling. I still had no real pain. I had a hard time breathing. I felt out of breath all the time.

July 6th, Monday, I made it through the weekend, now it was time to find out what was wrong with me and get it fixed. I saw my doctor that morning. He took x-rays. The x-rays did not show anything wrong. He gave me more relaxers and sent me to a neurologist. By this time I was really scared. I never thought about being paralyzed.

July 7th, I made it out of bed and got dressed. To this day I do not know how. On the way down the steps while leaving home to see the doctor, I was on the last step and I felt my lower body melt and I just sat down. I did not know it at the time; I would not stand or feel the seat beneath me again. My husband put me in the car and took me to the doctor's office. The doctor said it was MS. I prayed that I did not have MS. I knew that was bad. I was hospitalized. They ran every kind of test they could. They did a spinal tap, a MRI, everything. On the second day of tests, I heard the words, Transverse Myelitis. What in the world is that? I did not know what it was, but I knew that I did not want it.

That was seven years ago. I spent nine months in the hospital. I have had all kinds of therapy. I cannot control my body functions or move anything from breast-level down. I am grateful for my arms and my speech. My life is fuller now than before. I have my husband and my children. Above everything else, I have my G-d.

Without Acute Transverse Myelitis I would not have ever stopped to hear Him talking to me. I am truly blessed. G-d loves me, and he loves you too.

I wrote this last year. I never could get up the nerve to send it to anyone. It has been nine years now. I do not have any feeling below the breast. I still have my husband and children. Above all I have Jesus to speak to G-d on my behalf. I thank you for your newsletter, it helps.

Minnie E. Todd
Minnieherrell58@aol.com
On March 13, 2001 I noticed that my feet were numb and that the front of my thighs burned. I just figured that I had taken too hot of a shower. When my wife and I looked at my legs, the skin looked like it always did. It wasn't red or irritated. I began having trouble urinating. It would take forever to get it started and when it did start, it wouldn't go long enough to empty my bladder. The next day my legs had also gone to sleep. I could shuffle along, but I couldn't walk normally. I was in a lot of pain from not being able to urinate. My right arm was tingling and felt like it was going to sleep. My daughter drove me to the emergency room of our local hospital. I was looked at immediately by the staff doctor. He told me that he didn't know what I had, but whatever it was it was serious.

Several other doctors stopped by to

poke and probe me. A doctor poked his head into my examination room and asked me if I had recently had the flu. I told him that my whole family had been sick about two weeks prior. My wife and grandson had gone to the doctor. I figured that I would get well on my own. Another doctor poked his head in and asked me if I had taken a flu shot. I said yes. The attending doctor came back in and asked me if I ever "imagined" being ill. He apologized for the question, but said he was required to ask it. To cut the doctor a little slack, I have been troubled with depression and obsessive compulsive disorder (checking things) and have taken 250 milligrams of elavil and 45 milligrams of buspar every day for the last 15 years. I hate to go to the doctor so being a hypochondriac is not my cup of tea. Another doctor came in and poked her finger up my behind to see if my prostate was keeping me from urinating. A catheter was installed on me.

After a couple of hours a neurologist arrived. He was concerned, because of my arm being involved, that it might be MS. I was admitted to the hospital and rolled down to the MRI machine to look at my upper spine.

Joe Wilson
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That evening the neurologist came to my room and said that the MRI picture didn't indicate MS, but he would need further tests before he would feel comfortable diagnosing my condition. He mentioned transverse myelitis.

Upon awaking the next morning, I found that my knees had lost all of their strength and my abdomen felt asleep from a couple of inches above my belly button down, but my arm felt normal. I knew that I had a butt, but it might as well have been someone else's. It was numb and I had no control of it. I would get the feeling I had to poop about ten seconds before it came out. A guy from physical therapy came and loaded me into a wheelchair and rolled me into a room full of exercise equipment. He lifted me up into a standing position and I took a stiff legged step or two (I felt like I was on wooden stilts), but I couldn't control my legs and feet. He had me hold onto a waist high horizontal bar and squat down. I had to pull myself up using my arms, as my knees had no strength. When I was in a sitting position, I couldn't even lift my legs an inch. I had never felt so helpless in my life.

Over the next couple of days, I had a MRI of the rest of my spine, as well as a spinal tap. My wife would help me out of my bed and I would slide stiff legged down the hall as she kept me from falling over. On the fourth day, my neurologist told me that the spinal tap had indicated inflammation in my spinal cord and diagnosed what I had as transverse myelitis. He said I could go home the next day provided that I could go to the bathroom without the catheter. When the catheter was removed, I managed to urinate on my own.

I went home the next morning armed with a prescription for Prednisone. I could shuffle from the family room sofa, with the help of a cane, to the bathroom and back a couple of times a day, but that was about it. When I would take a shower, I wasn't able to lift my legs high enough to put on my pants. It was after coming home that I felt a terrible tight "constriction band" running around my body just above my bellybutton. It was as though someone had put a belt around me and then pulled it five or six notches too tight. It was more aggravating than painful. The only position that minimized the band feeling was to lay on the sofa with my upper body propped up to a forty-five degree angle. At times, especially after eating, I felt as though I was being cut in two by the "band."

After two weeks of lying on the sofa, I began to feel something happening. It started at the top of my legs. It was as if I had a six-inch cuff day by day being slid down my legs. Six inches of my legs felt as though they were on fire. Any pressure or touching caused severe pain. The next day the pain would be gone, but that area would feel as though there was an electrical firefight going on in it. It was as though every nerve in that six-inch area was test firing and looking for what it should connect to. A day or two later that "cuff" of pain would move down. Over the period of a week, it moved all the way down my legs, firefight and all. But the day after the areas woke up, they would go back to sleep.

My first glimmer of hope came a week later when my ankles flushed warm. For lack of a better description, it felt as though that area was sweating. As each part of my legs and feet began to flush warm, I did what I could to exercise them. I might push my feet against the coffee table or hold onto a chair and try to do deep knee bends. I usually ended up pulling myself up with my arms as my knees were terribly weak. I could stand for awhile, but not long. My knees always felt weak.

From week eight through week ten my body would buzz from my constriction band down to my feet. It was as if I was hooked to an electrical power line. It didn't buzz all of the time, it would turn itself on and off. I would have my wife feel my legs to see if they were vibrating on the outside; they were not. At 11 weeks I

began to get terrible backaches, radiating from my back on the same level as my "constriction band," perhaps because I had become more active. Sitting on a chair and leaning forward until my upper body was against my legs helped to ease the pain.

At 12 weeks I was feeling much better. I could run short distances and help the coach of my grandson's baseball team a little. The balls of my feet felt as if they had duct tape wrapped around them and my toes still didn't feel right. I wasn't sure that I even knew what feeling right felt like anymore. My constriction feeling was still with me. One humorous note is that if I would hit my leg, it would vibrate down to my toes. It's as if you stretched a spring and then hit the side of it. I considered myself to be very lucky. I had heard somewhere that if things didn't work after 12 weeks, they probably never would. The only thing that was still out of order was my sexual equipment. As I write this, 15 weeks, my sexual equipment has just come back on line. I am glad that the 12-week cutoff wasn't absolute. I consider myself very lucky to have recovered as well as I have.

After 12 years, I had a dream that I should write to all those with TM. Initially, when I was a paraplegic, and everyone gave up my future with walking, I would dream of such on a nightly basis. I have been blessed with a fair recovery, and I can walk. I will take what I have left as a gift. I wrote this poem with all of you in mind and send it to you with all due respect and my deepest admiration and future of possible betterment and healing.

Sleep-walker

Come with me into my dream, what is it that you'll see?
Would you see a wheelchair, or would you run with me?
You joined into my nightly dream it was then you realized,
we are both the same inside, but I am paralyzed.
In dreams we think of running on a warm and sandy beach,
setting goals of walking that we never seem to reach.
Daughter's wedding, promises made, to walk her down the aisle,
this I can accomplish but it will take a while.
Waking up each morning the dream still in my head,
but here I am to face again, the chair, and then to bed.
Eventually the dream came true, and God showed me his grace,
I am now without a wheelchair, a trade for cane and brace.
I travel where I want to go, I stand then set my pace,
not too far nor fleet of foot I will never win a race.
The dream that inspired me each night, and filled my twilight thought, came true for me eventually because each day I fought.

The dream I wrote above is true,
I pray tonight that next its you!

From Rick Harmon (Rickjetts@aol.com) to all of my TM family

The purpose of this article is to help others maximize their chances of forming successful support groups with a particular focus on the organization of successful support group meetings. In getting started some thoughtful and thorough planning can contribute to this success. Attention should be given to issues such as meeting time and place, whether to serve refreshments, membership selection, group composition and the goals, expectations and purpose for the support group meeting. The planning should be flexible enough to permit free play for individuality of experience and altered circumstances. For example, we held our first two meetings at a diner strategically and conveniently located at the juncture of a major and accessible highway. Unfortunately, it did not afford complete privacy for members who wished to discuss personal problems that are common to many who have TM, in a candid and open manner. Therefore, we were forced to change our meeting venue to another location. We chose a private room in a restaurant at a large shopping mall.

A poem of hope for all with TM
Rick Harmon

Pre-planning must encompass the capacities and needs of the individuals who will attend. For instance, many TM members may require that they be accompanied by a family member, spouse or friend to assist them. The chosen location should always be handicap accessible. I got started by planning a ceremony to celebrate the official declaration by the New York State Legislature of "Transverse Myelitis Awareness Day" on June 6th, 1999. Deanne Gilmur, then President of the Transverse Myelitis Association, wrote a start-up letter to members in New York State which I included in the hand-written invitations that I sent out for the first meeting. The letter stated that a luncheon and support group meeting would follow the ceremony. The first meeting was so enthusiastically embraced by the members that I decided to schedule another meeting.

I have Lupus, a chronic auto-immune disease that can attack any part of the body. In my case, I developed an inflammation of the spinal cord, which resulted in Transverse Myelitis. For four years, I have been attending a

TM Support Groups

Support Groups: Getting Started
Pamela Schechter

Lupus support group that meets bi-monthly at a local diner. The Lupus support group has served as a prototype for the one I envisioned for the TM group, because the Lupus group proved to be not only therapeutic, but also a lifeline to rely upon when the disease flared and left me down and depressed. By intentional observation, I became familiar with support groups and how leaders conducted them.

There are many reasons why a member would wish to start a TM support group. Primary among them are the very characteristics of the disease, such as its rarity and neurological deficits that remain after the
acute phase. Both of these reasons are compelling enough to ensure attendance. Members wish to gain more information about the disease and also wish to meet others with Transverse Myelitis. The member who starts the group need not be a professional or trained leader of support groups, but one who is deeply committed to the idea of starting a group. For practical reasons and for continuity of purpose, that member should be designated as the nominal leader. He or she should lead in decision making and planning.

The first step in getting started would be to determine the meeting place and time, member selection and group composition. By consulting the 2001 Membership Directory of The Transverse Myelitis Association for names, addresses and phone numbers, the initiator can focus on those members who live within a radius of a centrally located meeting place and, therefore, might be reasonably expected to attend. The leader need not restrict member selection to those who reside in his or her state, but consider members in adjacent states who would be near enough to a meeting location to attend.

I have always favored meeting at a diner or a restaurant because most of them are handicap accessible, do not require a special fee, can accommodate large and small groups, have ample parking space and provide a dinner or a luncheon to those who wish to eat. There are many other options that you may consider, such as town halls, private residences, libraries, etc. However, diners and restaurants are usually available seven days a week and are open through luncheon and dinner hours. Therefore, you can schedule a meeting either in the afternoon or evening.

It is important to call in advance to reserve the meeting location, especially at diners or restaurants, to make sure the room or space is available. Please remember that all decisions a leader makes are subject to modification or change, if necessary. In planning my support group meetings, I have always found it useful to send out invitations to the designated members. The basic content should include meeting time and place, purpose, agenda and topic discussions, directions to the meeting location (if possible), and the telephone number and address of the sponsor for members who have questions about the meeting. Another important step in setting up a group meeting is what I call pre-group contact. After sending out the invitations, I do follow-up calls to appropriate and potential attendees in hopes of securing their participation in the group. This contact can be effective and it often results in additional participants.

Hope Klopchin, who in the past year obtained her Ph.D. in counseling psychology, has been leading our group for two years. Her presence lends professionalism and authenticity and she gets rapt attention from everyone. I would suggest that you inquire at a local college or university where there are social work studies to see if they might offer the services of a fledgling counselor who is working for an M.S.W. or a degree in counseling psychology or another related field. They might be willing to lead the support group meeting in order to gain some experience. As the support group meetings continue, you will notice that there are regular attendees that form the core of the group.

There are many other important issues to discuss about support groups, which I will address in future articles. I would be most grateful to hear from any one who has initiated a support group or wishes to get started. I certainly would welcome their advice and any suggestions they may have. Please write, call or email me at:

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My best to you all,
Pam

In September, 2001 The Paraplegic and Quadriplegic Association of Queensland published the second edition of ***The Issue***, the Newsletter of the Transverse Myelitis Interest Group. Ian Hawkins is the facilitator of the TM Interest Group. For those of you in Australia who are interested in attending the next TM Awareness Day, please contact Ian. If any of the Australian members have information or an article for publication in the next newsletter, please contact Maureen McKeown. If parents of children with TM from Australia or New Zealand

are seeking information and support from other parents, please contact Steve and Alison Alderton.

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TM Support Group: Australia

My name is Ursula Mauro. I'm 38, a single mother, separated since 1998. My daughter, Isabella, is 13. I've always lived in Germany, but traveled a lot the last years. Isabella and me live since two years very good together with a French woman and her seven-year-old son.

I'm working part-time as something like an educating nurse (the profession is aimed for handicapped people) in a Center for epileptic people, as picture editor in an artist/graphic office and I am studying to become a nonmedical practitioner. My body was always weak, since I can remember; many little illnesses, some big ones, a slipped disc, a few surgeries with scar problems later, loss of one kidney. I was already often in pain, before the myelitis came.

The last years I tried after each illness more and more to balance the stress. I know now that I am not balancing the stress enough. March, polio-vaccination, a few days later a big flu, which lasted almost one month. There started my swallow problems and didn't go away until today. After an especially stressful April/May, everything became more slowly again.

June 10th, when I woke up in the morning, the first symptoms: a numb feeling in the higher stomach with a permanent high painful pressure above the liver and in the lower abdomen like a belt with often heavy pain like contractions. I felt weak also.

I went to a doctor, she assumed my brace (I wore it to hold my back pain down) would cause it and squeeze nerves, so I waited on without wearing my brace. Three days later it progressed: numbness in the right hand, little-finger-side until the third finger and up the arm, sometimes also painful, like needles, often very cold or completely hot, with movement-disturbations. One day later the same in the left hand. I went to my doctor, he assumed stress-reasons, but sent me to a neurologist and for an abdomen ultrasound. Many many examinations and everything seemed to be completely normal, also the SSEP. So, the neurologist wanted to wait three more weeks. Nothing improved at this time. I was always tired. Meanwhile, in addition, "needles" in my left leg and foot. I did slower, but I still worked and studied further, although I felt very exhausted.

1st of August, I've got the MRI - Transverse Myelitis C4/C5 and a slipped disc T7/T8. 2nd of August, a spinal tap and starting with high doses of steroids iv for five days. During giving the steroids, the tremor started, especially in arms and legs, sometimes a real body shaking, sometimes just little, also heart racing and knee pain. I stopped working and studying completely. Now, we are on research for the reason with many blood tests, x-ray lungs, etc. So far they found oligo-clonal bands in my liquor (what only proofs a local gamma-globulin-production in the central-nerve-system, which can happen during a lot of inflammatory illnesses), but we are still waiting for more results. A few days ago I've been to a specialist for my throat problem. Nothing got found (thanks heaven!). Since a few days, the stomach pain seems to get a little better. That's already a big relief, because this is the worst bearable symptom for me.

TM Support Group: Germany

I'm aware that I'm lucky to be able to walk around and doing things! Friends support me at the moment in many directions and I'm proud and happy to have such a lot of reliable active people around me. I'm also happy that I've found the TMA on the internet two weeks ago, got to know Sandy and finally the people from the mailing-list, they gave me such a friendly welcome. The possibility to communicate with other people with TM is very special. To feel not alone with this illness, to support each other in different directions, share and exchange information and personal experiences.

I am excited to announce that I will be starting a support group in Germany. We have a growing membership, and there is much we can do to help each other. If you are interested in participating, please get in touch with me; I will also try to reach out to you.

Take care,
Ursula
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Arranging a TMA Support Group Meeting in Ireland

I have sent out letters to those people I have on my mailing list from Ireland asking whether our members would like to have a meeting next year. It would be planned for early summer. I am currently waiting for responses. If you are interested in participating in a

support group meeting, please get in touch with me. Also, if you are interested in getting involved in our support group, please write, call or send me an email message.

Quilt Fundraiser for the TMA

I completed the quilt in time to bring it to Baltimore for the symposium. It was displayed for the first time at the Sunday morning forum during the symposium. If you would like to see photographs of the quilt, they are posted on the Baltimore page of the TMA web site. We are currently in the process of finding someone in the United States willing to take on the responsibility for conducting an auction or a raffle of the quilt. All of the proceeds will go to the TMA. If there is someone interested in taking on this responsibility, please get in touch with Sandy Siegel. I hope we can raise a lot of money from the international quilt. The quilt represents the international effects of TM and the international reach of the TMA. I am hoping that we can get worldwide participation in this effort. Thank you!

Baltimore Symposium July 2001 and "What I Did on My Summer Vacation"

As in Seattle I found this symposium gave a great feeling of togetherness for TM members. There was a wealth of information from the doctors, although the information from doctors was sometimes a bit "over our heads," with all of the medical jargon. We had a full schedule, so much so that we had two working lunches. These were to enable all TM members the opportunity to share experiences and information. I know I came away with a renewed spirit, hope and strength to carry on fighting this "thing" we call TM.

I really enjoyed all our time together; it was sad when Sunday came around and we had to say goodbye. It was great meeting all those who were in Seattle in 1999 and also making new friends and putting all of the faces to names from the TMIC.

I stayed on in Baltimore for some sightseeing after the symposium. I had just left to visit Washington DC when the train with hazardous chemicals crashed in the tunnel near the hotel. Thankfully, I was out of

TM Support Group: Ireland

Baltimore for the next few days. Before I left Baltimore, I had some fun with a puncture in my wheelchair tire. The security police helped me to get a loner chair for the rest of the day. I got it fixed by one of the maintenance men at the hotel. When I was going downtown the next day, it blew up. A lady walking behind me in the street screamed; she thought someone had been shot! I had to go to a cycle shop and get a new tire and tube fitted. I pushed two blocks on a flat tire. It was hard going and uphill as well. Got it done, made my way back downtown, and by the time I got there, I had a flat again! They had forgotten to put the cap back on the valve. Two ladies came to my rescue and we phoned the shop. The shop came to me this time and had to take the wheel back to the shop. These two ladies stayed with me all the time while I waited for the wheel to get back. We had a great long chat and exchanged addresses. So, now I have someone to go visit, if the next symposium is in Florida!

Washington was a great experience. I had quite a few adventures there. I decided to take a tour of the capital the next day. All was duly arranged through the hotel, and I was assured that the bus was accessible. The coach driver of the bus that I was booked on looked at me and said, "I can take your wheelchair, but you will have to walk up the steps into the coach." So, I said to him, "If I could walk up those stairs, I would not use a wheelchair." He just said, "well that's the way it is. I can take your wheelchair, I do it all the time. I can take two or three." I guess this is one point where we wheelchair users are not "cost effective;" more space for people paying for seats, when they don't have to provide space for wheelchair users.

Well, after asking other drivers where I could get other transport, which was wheelchair friendly, I was pointed in the right direction. This office didn't open for another three hours. So, here I was at 6 am, a time you generally would not find me out on the streets wandering around. But all ended well. I was pointed in the direction of the White House Centre where a security guard told me that I would not need a pass to go into the White House. Furthermore, I could go right to the front of the queue and would be escorted in before all of the people waiting!

So, I decided to go there until the tour operators opened. It was quite funny as I found myself being wheeled around by an unknown male who was very tall. I could not see his face when I turned around. I only got to see what he looked like when I had my photos developed. He had two friends with him. They just jumped on my bandwagon when they heard the guide from the White House ask me how many were in my party. They were quick to join me so that they could get in earlier.

The next part of my adventure was during the Washington DC bus tour. The tour bus was not accessible. When they brought an accessible bus, I was the only one on it. I had my own personal guided tour by two very nice gentlemen. I guess we saw about

everything. We stopped off at the Lincoln memorial. We went to President Kennedy's grave, which meant a great deal to me, as my father was also John Fitzgerald, and from Wexford in Ireland, where the Kennedy's ancestors came from. I was told about the man-made lake and all of the cherry blossom trees, which come out in the spring; it must be really beautiful to see. It was all a lovely experience and I truly enjoyed it.

Marty, my personal guide, escorted me to the train station to show me how I could get back to my hotel without using a taxi. I used the underground train and then a bus, and all accessible. I forgot to mention that I took the light rail from Baltimore to the main station and then from the Maryland rail to Washington. Again, all was accessible. I took many photos of all this to show people in Ireland how our transport system could be developed to become wheelchair friendly. To round off my great day, I went for a meal and a Bailey's' at an Irish Pub, which was right next door to the hotel that I was staying in. And even better, it had an adjoining door from the inside of the hotel!

I went to a place called Glen Burnie and found a fabric shop for quilting materials! I even dashed out the morning I was leaving to buy some more material as I had found that I still had more room in my suitcase after all my packing was done. Material is so much less expensive in the states than here in Ireland; it's about a third of the price.

To all my TM friends and family, my heartfelt condolences on the most horrifying catastrophe which fell on New York and Washington and Pennsylvania. How anyone could do that to fellow human beings, I will never understand. God Bless and give strength to all who have lost loved ones; also to the rescue workers who have such a terrible task. We did have a National Day of Mourning and Solidarity on the 13th of September; all shops and businesses were closed and a three minutes of silence was held that day. At our quilting group last Tuesday, I requested a minute of silence for the victims and loved ones. We are all thinking about the events of September in America and are praying for everyone.

God Bless,
Ann Moran in Ireland
annmoran@gofree.indigo.ie

On June 16th, 2001, we returned once again to Ben's Deli and Restaurant at the Bay Terrace Shopping Mall in Bayside,Queens for the fifth luncheon and support group meeting for the members of the New York TM Support Group. We also noted the second anniversary of the "Transverse Myelitis Awareness Day," a resolution passed by the New York State Legislature designating June 6th as the celebratory day for this annual event.

We were a diverse group of twenty-eight attendees, which included members, families and friends traveling from Long Island, Westchester County and New York City. We welcomed six new attendees to our group with the hope and expectation that they would return again. After partaking of Ben's famous Matzo Ball soup, oversized deli sandwiches and the condiments that accompanied it, we convened the meeting. As our principle speaker and leader, I introduced Ms. Hope Klopchin, who had just completed her doctorate at the State University at Buffalo, NY in counseling psychology. For this salutary occasion, and unknown to Ms. Klopchin we had ordered a cake to be presented to her to acknowledge the perseverance, hard work and intellectual ability it took for her to achieve this high honor and degree. As I have previously written, Ms. Klopchin was afflicted with Transverse Myelitis at the age of twelve and struggled through a recovery period of five or six years. Ms. Klopchin was surprised and delighted by the presentation and accepted it with her usual composure and good spirits.

Ms. Klopchin commenced the meeting by distributing a diagram that resembled a four-sided diamond. On each joining of the four-sides were printed the four components of the diagram:

1. Physical Health, 2. Emotion, 3. Thoughts, and 4. Behaviors.

She explained that the diagram is known as a "Pentagon Cognitive Behavior Therapy Model." She further explained that all four components interact with each other to produce someone's experiences. The point of the model was to show members that two components can not change directly and those two are your physical health and emotion. However, you can change these two components indirectly through changing your thoughts and behavior directly. Hope discussed briefly how thoughts and behavior can bring about this change. We also discussed the interrelationship and interaction between the four components and the ways each one can affect the others.

Fifth New York Support Group Meeting
Pamela Schechter

At the end of Ms. Klopchin's presentation, there were relevant responses and questions about the discussions. Primary among them were the concerns of the members'

families and caretakers. They spoke about how they cope and interact with the afflicted family member and about their mutual frustrations and problems associated with their respective roles. A general discussion ensued about medicine and doctors; how doctors can affect the way you feel about yourself; the doctor's impact in a positive or non-positive way and how it relates to your well-being. We discussed the way each of us has different priorities when visiting our doctors, such as seeking emotional support and assurance, future prognoses and any new treatments.

Another theme, as presented from a personal viewpoint by several new members, touched upon familiar denial of the disease, whether by a parent or a spouse. One member was visibly disturbed by her mother's refusal to accept her illness by not disclosing or discussing it with anyone. Another member confirmed that his wife had reacted in a similar manner. She has not changed her lifestyle in any way to accommodate his illness. Ms. Klopchin responded by stating that the way we think about illness directly affects the way we feel about ourselves and the things we do with our lives. This, in turn, effects our emotions and may indirectly affect our physical health. She then posed a question, "When do you accept what you have?." Answering it, she stated "When it becomes a part of you, rather than being outside of you."

She further commented that some people actively seek a cure for their illness and use this as a conduit to come to terms with it. We briefly discussed body image and self-image and how it relates to diminished physical power and ways we can cope with this loss. At some point in the meeting, I mentioned that I would be attending the symposium in Baltimore, and that I would report and comment on some of the highlights and events that occurred there. At the conclusion, many members confirmed that the discussions had engaged their thoughts, emotions and the way they felt about their illness. They also said, that by coming to the support group meetings, they felt less isolated and more connected to those in similar circumstances. They also expressed a feeling of comfort, encouragement and acceptance from their fellow members.

Congratulations again, to Hope Klopchin for achieving her goals and being our "Fearless Leader."

Our next support group meeting will be held on Saturday, November 3rd at Ben's Deli and Restaurant at the Bay Terrace Shopping Center from noon to 4:00 PM.

I would like to introduce myself; I am Mary Troup. My daughter, Danielle, was diagnosed with TM in 1996. The reason I want to introduce myself is that I would like to form a support group for new and existing TM patients who live in the Memphis area and who live in Tennessee. I would like to be able to offer support, to encourage other parents not to give up, and to offer hope and faith in the research that is going on daily. I have learned to love and be patient and have the hope that one day Danielle will be able to walk. This disorder can be a very emotional and physical challenge for family and friends. When the children get to school age, the school systems can create a whole new set of challenges. Over the past five years, I have E-mailed and spoken on the phone to several persons with TM and also to parents of children with TM.

I encourage all the parents of children with TM and persons with TM in our area to get involved. There is a great deal that we can do to help each other. I will look forward to talking to you and meeting you. I am also available to any TMA parents who are seeking information and support.

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Every year around 300 new cases of TM are diagnosed in the UK. This is such a small number across the country as a whole that it can be no surprise if the hard-pressed National Health Service does not see a need to instigate any research into it. However there are also many other uncommon neurological conditions which suffer in the same way.

This year the Neurological Alliance (a gathering of around 50 UK member organisations supporting patients with neurological conditions) carried out a survey to assess the state of neurological services in the UK. Thanks to Christine Clansey, there was a TM input to the survey. The report on the survey found an urgent need to bring all neurological specialist services to the level of the best; make access to specialist services easier; and ensure the provision of appropriate and ongoing rehabilitation. I think we would all agree with these. A shortage of neurologists is highlighted in some of the Report references. In the UK there are only 6 per million of the population whereas in Denmark the figure is 100/million! If you would like to read the report, *In Search of Service*, copies are available (price £3) from the Neurological Alliance, PO Box 31287,

TM Support Group: Tennessee

London NW2 6NL. It should also be available on their web site (www.neurologicalalliance.org.uk), but I was unable to open it. One way TMA members could help is to draw

the attention of their MPs to this report.

Another way members can help is by sharing their experiences at local area meetings for those with TM and their carers. Thanks to Jan Fox, there has been a support group in the Telford area, meeting four times a year, for five years now. Based on Jan's experience, Gaynor Eyles has started a group in Northampton and in October there will be a first meeting in Salford, which will, hopefully, cover the Manchester and Liverpool areas. These meetings really are for those with all levels of recovery. Those who have made rather better progress can provide enormous encouragement to those who are still struggling.

When I was recovering from TM in 1993 there was no accessible internet nor a TMA web site. I spent hours in the rehabilitation unit's library searching for information and sources of help. Now much of this is available on the internet. I have endeavoured to put some of this UK based information on the TMA site (http://www.myelitis.org/local/index.html). I have tried to supply some sources of basic background information on TM and B&B problems in the Introduction section. Once recovery starts, financial and mobility thoughts become important. There is good help in the UK on both of these aspects and these sections of the web site give sources of information which seem relevant. If TM leaves you disabled, you may need help in the form of therapy treatment and a range of gadgets which make life easier. Other web pages cover these and an Events page suggests where you can go to get some of this help. ***Please*** let me know of any helpful web sites you have found so they can be passed on, and do come to area meetings to provide solutions to others' problems. If you have no access to the internet, I can send you a print out of these pages if you send me a sae big enough for ten A4 pages.

TM Support Group and Web Site: UK

In some areas of the country, new regional neurological centres are being opened. We are hoping to be able to make contact with specialists at some of these centres. If you felt you received good treatment and information while you were in the hospital, do let us know where. At a recent local area meeting, complimentary remarks were made about both Addenbrookes in Cambridge and the Radcliffe Infirmary in Oxford, but I have heard scathing comments about some other well known centres where the specialists were unable to present their diagnoses in terms the patient could understand and were dismissive of the patient's comments. Keep the comments flowing in!

Finally, many thanks to those of you who have been involved in sponsored walks and/or made donations to the TMA. It will be good when we can cover the cost of the Newsletter in the UK.

Contact details:
Geoff Treglown, 8 Sedgwick Court, Kendal LA9 5HZ, UK
geoff.treglown@btinternet.com
Webster's Dictionary defines support as "to keep from failing, to strengthen." As people who face each day with the symptoms associated with Transverse Myelitis, we need the support of others who have the same experiences. It is difficult to explain to others the burning in your feet, the numbness in your legs, or the feeling that your extremities are not connected to your body. Only others who share these sensations can begin to understand how and what you are talking about and feeling. Only those with TM can understand the feelings of loss, the emotions surrounding life-altering change, and the reality that things will not be the way they were before the diagnosis was made. We must change our philosophies to "Don't sweat the small stuff ... and it's all small stuff." It's not easy, but necessary for us to have some semblance of control over our lives.

As Webster defines ***support***, so shall we. Hampton Roads, Virginia, including the cities of Williamsburg, Hampton, Newport News, Virginia Beach, Chesapeake, Portsmouth, Norfolk, and, Suffolk are forming a TM Support Group. Our first meeting will be on November 17th at 11:30 am at the Williamsburg Lodge in Colonial Williamsburg. Bring your ideas, your stories, your outstretched arms (if you're comfortable hugging as I am!) and your significant others, if desired. Please RSVP to:
wnew@erols.com
(757)565-6461

I am looking forward to hearing from you!
Pamela New
As we are intensifying efforts to encourage our members to become more involved in fundraising for the TMA, we have asked Lori Biehler to serve as an advisor for those seeking support and information on their activities. If you are looking for some creative ideas or guidance in planning and carrying out a fundraiser, please feel free to get in touch with Lori.

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Reading For Rachel
How You Can Help

When Rachel first got sick on October 9, 1999, we were in such a state of shock and sadness for our baby girl. She was only 6 ½ months old when TM struck, right when she was just beginning to become mobile. Life had been so good, and overnight all that changed. Now that two years have passed, we have come to the realization that this is something that unfortunately isn't just going to "go away." Two years ago, as a 1st birthday present for their sister, our sons Matthew and Kevin (ages 6 and 4 at the time of Rachel's illness) thought of **Reading for Rachel**, where all funds collected would go towards research to find a cure for TM. This continues to be our gift to her since this has become our annual fund-raising event for The Transverse Myelitis Association.

We won't stop until we have a cure - it is the least we can do for our dear, sweet Rachel as she struggles daily with the effects of TM.

The Reading for Rachel program works like this. Children are challenged to read as many books as they can during a certain time period (week, weekend, month, etc.). They then get sponsors who pledge and pay a certain amount of money for each book they read during this period. When they are done, they collect the tax-deductible contributions from their sponsors and send it directly to The Transverse Myelitis Association, referencing **Reading for Rachel**. It is that easy and it is such a wonderful learning experience in so many ways!

All of the material to learn about and participate in the Reading for Rachel program is located on our website: www.ReadingForRachel.org or via a link from the TMA website at www.myelitis.org. It includes a letter from Matthew and Kevin that talks about Transverse Myelitis and how it affected Rachel from the beginning to where she is today. In addition, children will be able to print off pledge and sponsor forms, reminder notices/receipts describing the tax-exempt status of contributions, and bookmarks to help them keep track of the books they read. They will also see pictures of Matthew, Kevin and Rachel and they can even watch a short video clip of Rachel in action!

TM Support Group: Virginia

Raising Funds and Awareness

Here's how you can help! We would like to get as many children affected by TM in some way to get involved. They can have TM or they can be the child, grandchild, sibling, niece, nephew, neighbor or friend, etc. of someone who has TM. You get the picture… we just need your help in spreading the word about this very worthwhile fundraising activity. It is amazing how many people you can reach if you simply send an e-mail to everyone in your address book or include a short note in your holiday cards, for example.

In addition, we would like as many school systems to get involved in this. It is particularly effective if students can relate to this illness, because TM affects a family in their school. Now is the time to talk with teachers, school administrators and PTA's regarding this activity. Many school systems have "Right to Read" weeks and this is a good activity to tie into the events of that week.

In our particular school system, we have designated March as "Reading for Rachel month" since it is Rachel's birth month. Please note, however, that contributions for Reading for Rachel are gladly accepted throughout the year. In addition, Reading for Rachel contributions have come from a number of other sources and I would like to share a few of those with you. The possibilities are endless, but the end result is the same…

*Monetary contributions (not tied directly to any reading activity) have been received from individuals and organizations, including PTA units.
*Contributions from pre-schools were made for every book that was read to students during a particular time period.
*Individuals have sponsored our own children's reading efforts from around the world. This year, we will read a total of 93 books - (one book for Matthew, Kevin and Rachel for each of the 31 days in March).
*School Book Fairs - A percentage of the profits have been donated to "Reading for Rachel."
*Heart Grams - During Valentine's week last year, children purchased paper hearts for 25 cents each. They wrote messages on them and they were delivered to students/teachers throughout the school.
*Penny War - This was during "Disabilities Awareness Week" and was a very fun activity. Each grade

level had a container in the lunchroom. Students brought in as many pennies as they could and they put these into their own grade level's container. Students brought in silver coins and they put these into the other grade level's containers since the value of the silver coins was subtracted from the value of the pennies. They loved sabotaging each other and the grade with the highest net penny value won! They won a pizza party, but the actual value of all the silver coins, in addition to all the pennies, more than made up for that!

Thank you in advance for helping us promote Reading for Rachel in whatever way you can. Please contact me if you have any questions or need help in any way. Remember, together - we ***can*** and ***will*** make a difference!

Cathy Dorocak
Cathy@ReadingforRachel.org
(440) 572-5574

Kevin's Cause: The Hamilton Fundraiser for the TMA

In May of 1999, my eighteen-month-old son, Kevin, was stricken with Transverse Myelitis. Immediately after we received the diagnosis, my sister, Jan, went on the TMA chat site and started corresponding with Cathy Dorocak (mother of TM patient, Rachel). Cathy was very sympathetic and helpful to our family over the ensuing months. After about nine months of coping with Kevin's illness, I wanted to follow Cathy's lead and raise money for The Transverse Myelitis Association. After all, the website was our link to Cathy and to so much information about Transverse Myelitis. Even at the best medical facilities in Chicago, we were referred to the TMA website for more information about TM. The website confirmed that Kevin was receiving appropriate treatments and gave me confidence to advocate for him.

On top of feeling indebted to the TMA, after looking at the TMA financial report, I knew that any money raised would be appreciated. Additionally, I was motivated to help Kevin and other TM victims. I was frustrated talking to so many specialists and have their answers be "I don't know" or "There are no studies on TM patients."

I approached longtime friends who had been devastated by Kevin's illness and were always asking how they could help. Once enough agreed to a fundraiser for the TMA, we decided not to reinvent the wheel. We met with another local family who had raised money for muscular dystrophy research. Out of this meeting, we came up with a game plan: a barbecue, a "Rolex watch" raffle, and a silent auction. Good friends, Eric and Lynne Carlson, generously offered their beautiful home for the site of the barbecue. Additionally, Eric and Lynne and my sister and her husband, Jan and Al Gunneson, offered to pay for the cost of the event so that everyone's donations would be 100% tax deductible. While this was extraordinarily generous, it also motivated us to keep our costs down as much as possible while having a sophisticated event. We sought donations and price cuts from all of the vendors. Additionally, we only had a portion of the meal catered: ribs, grilled chicken, and grilled vegetables. The rest of the sides and desserts were provided by friends and family. A liquor distributor donated all of the wine and other friends donated the beer. Raffle tickets were printed for free. Another printer printed our invitations at cost. A musician cut his price in half.

All of this came from several strategy sessions with about eight motivated friends and guidance from the TMA. Responsibilities for the event were broken down so that we could each focus on a separate part. Early on, we decided not to work too hard on the silent auction and to put more emphasis on the raffle. The raffle was an integral part of our event, but please be aware that there are federal and local laws governing raffles. Also, it is better to come up with a more generic prize, i.e., round trip airfare, money, etc. However, most people purchased tickets to support the cause, not to win. Why a Rolex raffle? We had the ability to get a men's Rolex watch at cost through a jeweler connection. We priced the raffle at $5 a ticket or six for $25.00. From there, the raffle chairperson had 10,000 raffle tickets printed. She was quite ambitious. Next, we immediately sent $500.00 worth of tickets to friends and family around the country. I put information in the newsletters of my children's two schools.

Once the raffle was underway, we worked hard at creating a compelling invitation and a large mailing list. Again, friends were instrumental. One friend, a graphic designer, designed the invitation. Lynne and I wrote and edited the copy. Finally, another friend came through and found a printer who printed the invitations at cost. My other sister, Kathy Cacioppo, cultivated the mailing list and the RSVPs. The time we put into the invitations was well worth it. A picture tells a thousand words. Three different pictures of Kevin, two in his stander, were on the cover with information about TM and the barbecue inside. The invitation served both as an invitation and as an educational tool about TM.

We planned to host about 125 people at the barbecue. In order to attend the barbecue, we requested minimum donations of $75.00 per person. Knowing the party was a busy weekend in June, we sent the invitations to around 300 homes. This list was generated from our Christmas card list, as well as many of my friends' friends. Additionally, my husband sent 50 more to work associates. We also included $50.00 worth of raffle tickets in each invitation to the party. Including raffle tickets was crucial as it gave people an easy and less expensive way to contribute without going to the barbecue.

The last portion of the event, the silent auction, kind of fell together. The core group of people let it be known that we needed auction items. In the end, we had over 40 items ranging from beanie babies, a week's vacation at a Colorado mountain home, airline tickets to anywhere in the U.S., to sports autographs. The range and variety of items made for a lot of fun for the whole crowd.

I also contacted other local TM sufferers. One gentleman, Bob Spielman, paralyzed from the chest down, contacted his friends and family via e-mail and was able to raise about $4,000.00 in two weeks. This was the first opportunity most of his friends had to show their support for him and his family.

In the end, we had a great event. We had around 125 guests who all had a great time. After paying for the Rolex watch, we were able to raise almost $48,000.00 for TM research. I am indebted to my dedicated friends and family who enabled this to happen.

If I am lucky enough to inspire anyone else to take on a fundraiser, I would be happy to consult with you. Even if you would like to take on a smaller fundraiser, I have many ideas and would love to help. During the TMA Symposium in Baltimore, I was introduced to many dedicated doctors and researchers. Let's give them the financial support they need to improve the quality of life for TM patients!

Pictures from the fundraiser, as well as our invitation are available for viewing on the TMA website.

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The Hop-A-Thon for Caroline Blandford and the TMA

Our daughter, Caroline Blandford, was six months old when she got transverse myelitis. Four years later she is starting her second year of preschool, and continuing the slow road of rehabilitation and recovery. Last spring, while in her first year of preschool, her school agreed to donate the proceeds of its annual hop-a-thon to the Transverse Myelitis Association. Over $4200 was raised and donated through this fundraiser, as well as increased community awareness of this condition.

Every year, St. Paul's Nursery School, in Cincinnati, Ohio selects a charity to raise money for with an Easter Hop-A-Thon. Each student hops 100 times, and collects pledges of a penny a hop, a dime a hop or a set dollar amount. We were familiar with the hop-a-thon because our 6 year old son, Zach, attended St. Paul's before Caroline. When discussing Caroline's condition with the schoolteachers and administrator, including her labored walk and her struggles to get potty trained, we decided to ask the administrator if she would consider donating the hop-a-thon proceeds to TMA. We got this idea, in part, from the information we had read about the Reading for Rachel program. Much to our pleasure, the school administrator readily and wholeheartedly agreed to allow us to use the hop-a-thon to raise funds for, and awareness of, transverse myelitis.

Thus, in April 2001 the students of St. Paul's Nursery School jumped 100 times for their friend Caroline, and the Transverse Myelitis Association. Family, friends, coworkers at Kohnen & Patton, LLP, and Caroline's classmates spread news of the Hop-A-Thon by letter, email, and word of mouth to raise money through pledges. A local ABC TV station, Channel 9 News, had a story and the local newspaper, the Northern Hills Press had a front-page article about Caroline and the Hop-A-Thon. There is a permanent link to the article at http://www.myelitis.org/articles/index.html. Even Caroline joined in the hopping, after weeks of practice and anticipation, never noticing that both feet could not leave the floor at the same time when she hopped. Through everyone's generosity, over $4200 was sent to the Transverse Myelitis Association in the name of St. Paul's Nursery School. Also, the nursery school administrator has indicated she would love to have another hop-a-thon in Caroline's honor in spring 2002.

Caroline was six months, and had been winning a two-week battle with a summer cold, when she woke up with warm legs, not moving from the waist down. Initial diagnoses of meningitis and Guillian Barre were quickly rejected. Luckily, even before a definitive diagnosis was made, doctors at Children's Hospital in Cincinnati began treatment of Caroline with high dose steroids within 12 hours of her admission, in case she had transverse myelitis.

Caroline was hospitalized for eight days before she was released. In that time she never moved her legs, and could no longer sit, roll, crawl, or do any of the baby activities she had done just days before. After being brought home from the hospital, Caroline made some small movements that gave hope for the future. However, the milestones were slow and far apart, coming only when hope would start to fade. Two years later, after Caroline finally began taking small unassisted steps, doctors and therapists admitted they never expected her to walk.

Today, Caroline is a talkative, outgoing four-year-old who loves Barbies and playing with her older brother, Zach. She attends regular preschool, and is even playing on a four and five-year-old recreational soccer team. Caroline doesn't remember a time she was any different physically than she is now, and does not see herself as any different than any of her friends. Her unfailing positive energy has tremendously lightened our concerns for her, and caused many friends to remark they forget her struggles when they are around her.

However, signs of transverse myelitis are still there. Caroline wears braces on her legs, occasionally gets botox injections, takes ditropan, and is catheterized several times a day since her bladder does not consistently and fully void. Right after the hop-a-thon, her legs were put in bivalve casts to help strengthen them as they grow. Caroline was not slowed down by the walking casts on both legs, but instead was excited because she got to pick the colors, pink and purple. She falls down often, but gets right back up without a tear or second glance. Weekly physical therapy is part of life for Caroline, a playtime she looks forward to.

Caroline's experience with transverse myelitis has opened our family to a world we never expected to visit. The recent hop-a-thon overwhelmed and touched us as so many people reached out and became involved. It is impossible to express in words what it means to have family, friends, co-workers, neighbors, classmates, and even some perfect strangers contribute to a cause they probably know very little about. I would encourage everyone to keep their eyes open for opportunities to raise funds and awareness for The Transverse Myelitis Association, so that you too might feel the warmth of others reaching out to help.

Steve, Colleen, Zach and Caroline Blandford

Throughout the Second Annual Transverse Myelitis Symposium, we held an auction to raise funds for TM research. Items were donated from various sources. Ms. Deana Green and her friend, Ralph Robinson, donated some beautiful paintings. Richard Boyle donated many items that he had collected and Beth Lekander brought us a lot of rock and roll and country items signed by celebrities.

The auction was a lot of fun to put on and all of us involved met some truly wonderful and giving people. The auction raised $2001.00 for the TMA's Research Fund.

I would like to thank the Johns Hopkins Transverse Myelopathy Center for allowing us the space at the back of the conference room, Beth Lekander for all her hard work, Richard Boyle for collecting so many wonderful items and Deana and Robbie for the beautiful paintings.

Without people donating items and people willing to purchase items, the auction would not have been such a success. Thank you to all those that helped us by bidding on the items that interested you! We hope you enjoy them.

I am currently working on the raffling of a new 2002 Harley Davidson Motorcycle. This raffle will take place in the spring of 2002. There will be 2000 tickets sold at $25.00 per ticket. The drawing will be held during a party where food and drink will be provided for all ticket holders. The proceeds of this fundraiser will go to the TMA's Research Fund. If you would like to get more information about this fundraiser, please feel free to contact me at:

Lori Biehler
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A month ago I got to be a part of the Attachmate Corporation golf tournament. It was a beautiful day at Eaglemont Golf Course in Mount Vernon, WA. It was my brother, Buddy Peltier's, 10th year in a row organizing this annual event. He and I both work for Attachmate Corporation. For the past four years, any fundraising activities done at the tournaments, such as raffles for a hole-in-one have been to benefit The Transverse Myelitis Association. This year's fundraising was specifically done for the TMA Children's Workshop to be held next summer. We employed a great fundraising event at this year's tournament; it was used at the Cody Unser First Step

Transverse Myelitis Symposium Auction
Lori Biehler

Foundation golf tournament which Buddy and I had attended in August. On the 10th hole, the teams had to tee off sitting in a wheelchair. In order for that stroke not to count against the team, they each had to pay $10. I'm

pleased to say that with the matching funds from Attachmate, the golf tournament raised over $2000 for the TMA Children's Workshop. My-sister-in law, Shauna, and I sat at the hole to encourage and collect the donations. The event was a great success.

Please join me in thanking Buddy for all the hard work he has put in these past four years organizing the tournaments in support of the TMA. You all don't get to see him everyday walking the halls of Attachmate with me, lunching with me, and helping me when I need it. Because of these efforts, combined with others, we are four years closer to finding a cure. Buddy, you are the greatest brother any girl could ever ask for … I love you!

2002 Harley Davidson Motorcycle Raffle

The Attachmate Golf Tournament to Support the TMA
Paula Lazzeri

Thank You, The Monks Copy Shops!

I first walked into The Monks Copy Shops when I was preparing to publish The Transverse Myelitis Association's first newsletter in 1996. I had been comparing prices at the various printing establishments around Columbus. Their prices were the lowest I could find. They got the job. The first newsletter was a small publication, as was the membership directory in 1997. I explained to the managers at Monks that the TMA was a not-for-profit that was just getting off the ground, and that we did not have an operating budget; I would be paying for the printing job. I also explained that I did not have all of the money, and I would need to pay it off over time. They said that arrangement was fine. And thus began a very unusual relationship between The Transverse Myelitis Association and The Monks Copy Shops.

I had to pay for the first few newsletters and membership directories as our contributions in those early days did not come close to covering our expenses. I walked out of the store with our copies of the newsletters and directories; the payments were always made later, over time. I have never been asked, "when are we going to get paid?"

As our publications became larger and more complicated, so too did the printing and publishing job. Each time a piece of paper is handled, there is a cost. Our publications tend to be quite labor intensive. The staff at Monks would show me a new way to staple the newsletter. I would tell them that it certainly looked great, but I wasn't sure that we could handle the expense. A manager would come up to the table and would tell me, "We'll assume the cost of the stapling; consider that our donation to the Association." Then as our membership directory grew in size, it became necessary to consider new bindings. The staff demonstrated a new binding for the last directory and it looked really great, but I explained that the TMA just could not assume that kind of expense for the directories. As I was disappointedly visualizing the big ugly staple in the corner of the directory, a manager approached the table and said, "We'll assume the cost of the binding; consider that our donation to the Association."

I have had to develop and publish several fundraising booklets and brochures. It has been my own goal not to spend any money from our operating budget for the purpose of fundraising. I don't know if it is realistic or even effective for the TMA to have this policy, but it has been my own approach since our inception. Color printing is very expensive. I have explained to them while we are costing out a job that this one is going to be an out-of-pocket expense. The last words of our negotiation belong to me, and they are always, "please be gentle." What I always hear back is, "Sandy, you know we take good care of you." And they do. They do in so many different ways. They have always given us better than comparative pricing on our printing jobs. With all that they throw in "as a contribution to the Association," I often wonder whether they are making any profit at all from the jobs that we bring them.

And what we get from Monks is so much more than a really great deal. It has always been a priority of our Association to produce professional publications within the constraints of our budget. Monks works really hard for us to accomplish that goal. And I am not an easy customer. My printer does not print a perfectly straight page. That means that they have to realign every single page on the surface of the printer to correct for my mayhem. They print electronically when we work with smaller documents, but the newsletter is not amenable to this type of printing. They also deliver all of our printing jobs to my home. This is no small chore as the boxes now fill up a truck. It takes the driver and myself about a half-hour to move the load from the truck to my living room.

Over the years the managers and staff of Monks have come to know me and they have learned about the Association. They have begun to learn about our cause. It is not just a job anymore for these people at Monks. I know that they care about what we are doing.

I walked into Monks a couple of weeks ago, and one of the managers walked up to the counter. She said that one of her best friends was just diagnosed with Transverse Myelitis. My jaw dropped onto the counter. Now, what are the odds of that happening? I called her friend. She is now a member of the TMA and has initiated some communications through the Transverse Myelitis Internet Club. Her friend knew how to find her help; she certainly knew who had all of the newsletters.

The people at Monks do a wonderful job. We always get the best product from Monks, we get the best service and we get the best price. But we really get so much more than that from these people. We get a group of people who care about those who have Transverse Myelitis. Diann, Jim, Margie and Ken – thank you! And thank you to the wonderful staff at Monks. You have all made such a wonderful difference in my life. And you have made a tremendous difference in the lives of the people who receive and use the publications that you produce. We are grateful for your conscientious and generous support of our Association and our members.

TMA Newsletters Enter the 21st Century

http://www.myelitis.org/newsletters

When Andrew Reid sent me his really inspiring story for the newsletter, he included a great photograph of himself on his handcycle. I thought it would be really great if we could afford to pay for a higher quality print job and include color photographs in our newsletter. Then it occurred to me that while we are a long way from affording color or photographs in our printed newsletter versions, we could certainly include color graphics and photographs in our website newsletter versions. And, thus, with our Volume 4 Issue 2 version of the TMA Newsletter, we have included photographs and color graphics.

In your future submissions of articles, if you would like for us to include a photograph, please either send it to me via an email attachment or you can send it through the postal service and I will scan it and return it to you. Please be sure to provide me with a caption for the photograph. Please consider submitting a photograph with your In Their Own Words articles.

We Don't Want to Lose You

Please notify the Association of any changes to your postal address, your phone number or your e-mail address. You can notify the Association by sending a letter or postcard to Sandy Siegel or by sending the information through e-mail to membership@myelitis.org. If you identify any errors in the membership directory, you may also notify the Association with the corrections in the same manner.

The 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 refer new members to TMA by using our Internet addresses. You can also use the Internet to submit your surveys and to send questions for the Dr. Lynn and Dr. Uretsky Question and Answer columns for the newsletter. Please send your e-mail to:
ssiegel@myelitis.org

Membership related:
membership@myelitis.org
Newsletter related:
newsletter@myelitis.org
TMA Survey related:
survey@myelitis.org
Web site related:
webmaster@myelitis.org

The following are some of the TMA web pages:

http://www.myelitis.org
TMA Home Page

http://www.myelitis.org/tmic
TMIC Home Page

http://www.myelitis.org/tmic/archive
TMIC Message Archive

http://www.myelitis.org/tmic/members
Members' photos and links to members' home pages

The Transverse Myelitis Association

Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065

The Transverse Myelitis Association announces the Children's and Family Workshop in Columbus, Ohio July, 2002