❖The Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

I hope that you are all doing well. With the publication of this fourth newsletter, we are closing out the second full year of our regular communication to our Association members. We are grateful that so many people are finding us from all over the world. By the time this newsletter is in the mail, our membership will have grown to well over thirteen hundred people. As our numbers grow, so too do the responsibilities of the Association.

We are continuing to collect and enter the TMA survey information. I would like to extend special thanks to Jessie Danninger for all of the hard work she has performed in entering survey data. It is a very laborious and time-consuming task. Jessie is a SAS expert, for those of you who understand the world of statistics. She is going to be conducting our statistical analysis once we have the information entered and coded. Until then, we are making progress on the data entry phase of the research. If you have not completed a survey, you may get a copy of the survey and instructions from Deanne or you can download a copy from our web site. Please take the time to complete a survey and mail it to me, if you have not already done so. If you want doctors to understand TM, you are going to have to be willing to share information about your experiences; it is the only way they are going to learn about this condition. If you would be interested in assisting with the research project, I am in need of help with the data entry. If you have a computer with MS Excel loaded on it and if you have some time to enter information, please get in touch with me. I would greatly appreciate the help.

There are two other important continuing projects that were initiated by the Association this past fall. We are collecting information to build a database of neurologist referrals. We asked you to consider whether you would refer your neurologist to other members from your area who have TM. If you would make that referral, we asked you to contact their office and to be sure that they have an open practice and that they would consent to your sharing their name with the Association and other members. We have, thus far, had an underwhelming response to this request. If you are satisfied with the care you are receiving from your neurologist, please consider taking the time to get permission from them to send us their name, address, and phone number. A referral to a good neurologist, and one who has had some experience with TM, is one of the most frequent requests the Association receives. At this stage, you are our best and only source of information regarding neurologists who treat TM patients. Please help each other out by sending me this very important information.

The Association is also collecting information in order to publish a children's directory. At present, I have received very few responses. Children with TM often have different physical and emotional issues to deal with than an adult with TM. There are certainly differences in family issues that arise. We often have parents who are seeking out other families who have a child with TM. We maintain that one of our most important goals is to offer a support network to people with TM and their families. To achieve this goal, again, we need your efforts and support. We know that a considerable number of our 1300 members include children with TM. We would like to facilitate the support network between children with TM and families of children with TM by making a children's directory available. We will take every precaution to limit the distribution of the directory. It will only be mailed to families who identify that they have a child with TM and who share their own information with the Association. Please take the time to send me your child's name and age, and your name, address and phone number, if you are interested in being listed in the children's directory.

Both the neurologist information and the children's directory information can be sent to me on the TMA response form that you received in the last newsletter. You do not need the form, however, to send me this information. You may also send me the information through e-mail.

There are some important and exciting events scheduled for the near future that should increase the public's awareness of Transverse Myelitis and our Association. This education and recognition is so

important for the Association's goal to be a catalyst for research into the causes and treatments of Transverse Myelitis. Pam Schechter, a TMA member from Flushing, NY, has advocated in the State of New York for a Transverse Myelitis Awareness Day. There is going to be a resolution sponsored by the New York Legislature in Albany this June. If you are a resident of New York, you should be contacted regarding this special event. Pam is preparing an article for the next newsletter that will describe the events in New York. The Transverse Myelitis Support Group of Australia is planning a similar event in the near future. We will also provide you with a description of the events taking place in Australia.

Much of our work this year has focused on the Symposium scheduled for this August in Seattle. The Association has expended a great deal of effort in our first serious fund-raising activities. We are learning how competitive the market is for worthy-cause dollars. It has been an uphill battle, and there have been very few successes, but we are not discouraged. We are learning the ropes, we are meeting with and telling our story to the right audience, and we believe we are laying a good foundation for future efforts. Deanne, Dick and Paula have also been working feverishly making the logistical arrangements for the Symposium and putting together an interesting and educational program. The Symposium weekend is also going to offer many of us an opportunity to meet in person for the first time after years of communicating over the phone, by letter and by e-mail. It will certainly be a very emotional and important occasion. If you are on the Internet, you can monitor the progress of the Symposium plans through a link Jim has created from the TMA web site. Jim will update the Seattle Symposium web site as new information becomes available. Pauline and I had the opportunity to meet Sarah Ferguson, the Duchess of York, in January 1999. We were guests of Dr. Charles Levy, the world renowned Physiatrist who serves on the Medical Advisory Board of The Transverse Myelitis Association. Sarah was invited to The Ohio State University Medical School, and was involved in an all-day tour of the facilities. Dodd Hall, the rehabilitation facility at OSU, was a part of her tour. Dr. Levy had invited a number of Dodd Hall "alumni" to be a part of the tour. As the doctors and dignitaries escorted Sarah around the building, they were able to introduce her to people who had gone through rehabilitation. In this way, she had the opportunity to learn something about the importance of rehabilitation, and not just see a bunch of equipment in a building. Pauline lived at Dodd Hall for six weeks and went through an intensive rehabilitation program there. She was also in outpatient rehabilitation at Dodd for almost a year. Dr. Levy regularly calls on Pauline to come and "visit" with patients at Dodd who might be having a difficult time with their therapy and with their illnesses. She has met with TM patients at Dodd Hall. Dr. Levy wanted Pauline to attend and to meet and talk with Sarah. I was invited to attend as an ornament for Pauline; and a lovely ornament I was indeed. (There is a picture of Pauline, Sarah and myself posted on the TMIC recreation and activities page, the link from which may be found at the bottom of the TMA web page).

We did meet Sarah and had a very good conversation with her. Pauline described Transverse Myelitis and what had happened to her. When she had completed her explanation, Dr. Levy very generously described our work with The Transverse Myelitis Association. I also explained to Sarah that we had quite a few members from England in our Association. At that point, she asked if she might not be of assistance to us -- and I immediately responded that she certainly could. I offered to give her a call. She did not give me her telephone number, but she did give me a way to reach her. And I will send her a note about the Association with a few suggestions for how she might be able to help us out. Pauline and I were very impressed with Sarah Ferguson. She is a very down-to-earth, caring, compassionate and kind person. She is very bright and very honest. Sarah was also impressed with the group of people who were in attendance -- the Dodd Hall alumni. And with good reason. There were some very courageous people in that room -- and, of course, I believe that Pauline is at the top of that list.

The Association is grateful to those who continue to support our efforts by donating their time and expertise to write articles for our newsletter. This issue of the TMA Newsletter contains a wonderful article by Dr. Norman Uretsky and Cheng-Huan Chang from the College of Pharmacy of The Ohio State University. Medications make up such a significant element of the treatment regiment for people with TM. We thought this was an important subject to begin to explore with our members. Dr. Uretsky has also very graciously consented to write a regular question and answer column for the newsletter. If you have any questions about your currently prescribed medications, those you have read about others taking, or those medications that your doctors have considered prescribing for you, please send those to me and Dr. Uretsky will attempt to provide you with answers in the next newsletter. Drs. Arnett and Rabold provide us with their second in the series of articles about the process of

adaptation to the effects of severe injury and illness. Dr. Lynn has offered some very thorough and helpful responses to the interesting questions that were sent by our members for her question and answer column. Finally, the *In Their Own Words* stories for this newsletter are remarkable. We have a very special collection of stories, and some from people who have had TM for decades. The experiences you will read about are quite emotional and thought provoking. The stories and experiences from the *In Their Own Words* column continue to demonstrate the resiliency and courage of our members.

The next communication you receive from the Association will be the registration materials for the TMA Symposium. Not everyone is going to be able to make the trip to Seattle. There will be a multitude of reasons why people are unable to attend the Symposium. For those of you who cannot afford the cost of making the trip, there is a wonderful article by one of our members who describes some of the ways she has planned personal fund-raising to make this Symposium possible for her. Please read Drema's thoughtful and creative article and consider how you might be able to put into action some of the suggestions she has offered us. We are surrounded by friends and family who would help us, if we only knew how to ask. Drema offers us some wonderful ways to make it easier to ask.

I hope that you are able to make it to Seattle. If you are not able to attend, we will find ways to share the experience with all of you. We will certainly find ways to share any educational and research materials that are made available at the Symposium. I am looking forward to meeting all of you who are able to attend. Take good care of yourselves and each other.

From the President
Deanne Gilmur

Happy 1999! This year will be an important one for the TMA. We are, as many of you know, taking a significant step towards our goals by instituting our first Symposium. While there is much work that lies ahead, the Symposium program is rapidly coming together – and it looks very informative and worthwhile.

The 1999 Transverse Myelitis Symposium will offer a platform to accomplish a variety of goals and to reach a wide-ranging audience. The Symposium will be an opportunity to gather together as many people with TM and their families as possible to exchange ideas, network and develop further supports; to share coping mechanisms and resources in order to maximize independence and function; to hear from professionals regarding new and best practices; to share information about accommodations and adaptive equipment; and to hear what research is being done that might impact those with TM. The Symposium will also offer a focussed setting to provide enhanced educational opportunities for medical providers about TM and persons with TM.

Perhaps most importantly, the 1999 Transverse Myelitis Symposium will provide an organized opportunity for people with the TM diagnosis and their families to come together to discuss issues and problems specific to this diagnosis. It also offers an opportunity to educate and involve physicians and other members of the medical community regarding the needs and issues of TM patients. The increasing numbers of TM patients identified in the TMA membership clearly speaks to the need for providing more education, information, support and partnerships amongst providers and patients specific to TM.

The ability for the TMA to continue to act as the catalyst for dialogue on TM related issues and the dissemination of information necessary to increase TM awareness is paramount for the needs of TM patients. Far too many TM patients contact our organization with disheartening tales of misdiagnosis, months until a diagnosis, lack of information about the condition from their providers upon diagnosis, no or limited recommendations for rehabilitation (physical or occupational therapy), lack of compassion regarding pain issues, and even expressed belief from medical providers that the symptoms experienced are "all in the patient's head". More often than not, a person with TM is being cared for by a provider that has not seen a TM case before or "only one a long time ago". TM patient experience seems to indicate that many providers, perhaps since they do not have many cases, do not have the time or motivation to pursue knowledge of the condition or to develop an aggressive treatment team for the patient's best care. TMA believes that patients need to be informed and empowered so they can manage their needs and be an active participant in their care and treatment team decisions so as to ensure the best possible outcomes.

We have identified three basic stages of the condition that require knowledgeable care and response: 1) TM onset, 2) TM recovery/rehabilitation period (time for partial or full recovery usually extends two years beyond onset), and 3) TM long-term living and care. All of these stages, like any spinal cord injury or dysfunction (SCI/D), require specialized attention as they each can bring new issues and

concerns. In addition, the need to be informed about relevant research that is underway and the prognosis for viable "cures" is important to many persons with TM, as well as providers.

We believe that this Symposium will meet the needs of persons with TM and providers by focussing on these many critical and pertinent topics.

The Symposium will be held August 12-15th at the DoubleTree Guest Suites and Inn at Southcenter near the Seattle-Tacoma Airport in Washington State, USA. Thursday evening (August 12) will consist of registration/check-in and an informal reception for participants and their families.

The Symposium's formal program will begin on August 13 opening with a review of current literature on TM. There will be medical specialists to speak about pain management, sexuality, electrical stimulation, medications and future treatments and research. We will also discuss Multiple Sclerosis and the interrelationship that seems to exist between MS and TM and the diagnostic issues relative to these conditions.

Additionally, there will be a variety of displays by companies and providers specializing in resources, programs, equipment and adaptive devices pertinent to persons with TM (e.g., orthotics, recreational equipment, assistive technology, etc.).

The following day will focus on presentations on issues and problems experienced by individuals with TM and their families, redevelopment of a healthy self, and disabilities resources. The afternoon session will include a facilitated discussion group in which participants will have opportunities to develop supports and share coping strategies.

A TMA banquet is planned, as well as other social opportunities, for TMA members to develop supports and build friendships. The Symposium will conclude Sunday morning with a state and country representative meeting and general membership meeting.

The Symposium will include the participation of experts within the local region, as well as at the national level. Contacts have included: Dr. Stephen Groft, National Institute of Health, Bethesda, Maryland; Dr. Brian Weinshanker, Mayo Clinic, Neurology Institute, Rochester, Minnesota; Jim Bowen, M.D. and Steven Kramer,
M.D., University of Washington, Department of Neurology, Seattle, Washington; Linda Yates, Director, Children's Treatment Unit, Good Samaritan Hospital, Puyallup, Washington; Heather Hepdon, Assistant Director, Washington State PAVE (Parents Are Vital in Education), Tacoma, Washington; Augusto Odone, President, The Myelin Project, Washington D.C.; Maria Amador, Program Coordinator, Information and Referral, The Miami Project, Miami, Florida; Douglas Kerr, M.D./Ph.D., Chief Resident Neurology, Johns Hopkins Hospital, Baltimore, Maryland; Nancy Hylton, PT, Children's Therapy Center of Kent, Kent, Washington; Don Bethune, CPO, Cascade Prosthetics, Bellingham, Washington; Doby Hall, Director of Field Services, NORD, New Fairfield, Connecticut; Dianne Wagener, SKI-FORALL (non-profit), Bellevue, Washington; Charles E. Levy, M.D., Department of Physical Medicine and Rehabilitation, The Ohio State University, Columbus, Ohio and Joanne D. Lynn, M.D., Multiple Sclerosis Center, The Ohio State University, Columbus, Ohio. Some of the above will be presenting, others will provide displays, and others have provided vital information and direction to continue this successful effort.

Your TMA Board of Directors has established several goals for 1999, most of which will be accomplished through the Symposium. These include the following:

Goal 1: Disseminate educational information and resources about TM and issues related to this condition.

Goal 2: Facilitate support and networking opportunities for persons with TM, their families and providers.

Goal 3: Increase awareness of TM and its impact and the need for additional research.

Goal 4: Develop partnership opportunities between the TMA and the medical community/providers.

Goal 5: Expand the Medical Advisory Board.

The TMA 1999 Transverse Myelitis Symposium is of national and international significance because there have been no other previous events that have been specifically planned to meet the needs of persons with TM, their families and medical providers who diagnose and treat TM. The TMA membership consistently communicates isolation, lack of useable information, dissatisfaction with treatment, and a lack of supports. This Symposium will be an opportunity to positively impact the needs of persons with TM by meeting the Symposium outcomes and disseminating Symposium end products as listed below:

1. Increase information, support and condition management mechanisms available to participants of the Symposium;

2. Increase awareness of TM to

the professional/medical community and to increase knowledge of supports, resources and treatment needs;

3. Increase the partnership of the TMA with the medical community by increasing Medical Advisory Board appointments and by developing ongoing relationships to include research; and

4. Develop ongoing local supports.

Registration materials will be forthcoming in the very near future. Symposium registration fees will cover minimal expenses; participation in planned dinner/lunch programs will be optional with separate costs identified in the registration packet. A block of rooms will be reserved for Symposium attendees with special event rates ($119.00 per night for single/double occupancy, $124.00 per night for triple/quadruple occupancy). The facility has 13 accessible rooms available (11 at the Guest Suites event site and 2 at the adjacent Inn). Specific bath and toilet adaptive equipment will be available for those needing such accommodations. The facility provides regular shuttle service from the Seattle-Tacoma International Airport. Wheelchair accessible shuttle service will be available from an independent provider for a small fee. These details and more will be provided with the registration materials. This first Symposium will be an important opportunity for participants to become involved in the continued growth and development of the TMA. I hope that many of you will be there to join in this process. We need you! Throughout these past four years, I have been overwhelmed by the courage, strength and graciousness that you have exhibited during difficult times. To meet many of you face to face will be a gift to look forward to. Your participation in this Symposium will be significant to the future of the TMA, the treatment of persons with TM, and our partnership with the medical community. I hope to see you in August!

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:

srulyosef@aol.com or
ssiegel@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 TMA Officers' e-mail addresses:

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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.

Drugs Used for Symptoms Associated with Transverse Myelitis

Norman J. Uretsky
and Cheng-Huan Chang

Norman J. Uretsky, Ph.D. is a Professor of Pharmacology in the College of Pharmacy at The Ohio State University. Dr. Uretsky's research interests include neuropharmacology, neurotransmitter release in animal behavior and neurological diseases. Cheng-Huan Chang is a Senior Student at The Ohio State University College of Pharmacy. He will graduate with a BS in Pharmacy in the Spring Quarter, 1999.

This article will describe some of the drugs that are used to treat the symptoms that are associated with Transverse Myelitis. The drugs were identified through a process of reviewing the surveys that have been administered to the TMA members. This article does not attempt to discuss all of the medications used by TM patients, but rather, focuses on the medications that were most frequently noted on the surveys. For each of the drugs noted, there is a discussion of their therapeutic effects and the pharmacological mechanism for those effects, some of the more common possible adverse effects and some of the reactions with other drugs.

When your physician prescribes you any medications, it is important that you know any possible side-effects that may be caused by those medications. If you are not told the possible side-effects, you should ask your doctor to identify them for you. Should you experience any of the side-effects, these should be reported to your physician. When you are prescribed any medications, your doctor also needs to know all other medications that you are taking and their dosages. It is important that you share this information with your doctor, particularly if you are being prescribed medications by more than one physician. It is also important that you openly share life-style information with your physician. For example, no one should consume alcohol in combination with any of the central nervous system depressants that are identified in this article. Since life-style issues are unique to each individual and the combinations of medications are quite diverse among the TM population, it is not feasible to discuss all of the possible life-style issues that might impact on taking medications. It is incumbent on each person to be sure to communicate the necessary information to their physician so that informed decisions can be made about life-style issues and the medications that you are prescribed.

Finally, it is important that you know the name of the drug that you are being prescribed. Pharmacists can make mistakes and you want to be certain that you are taking the correct drug. Be sure that you know the name of the drug, and check it for yourself after your prescription has been filled.

If you have any other medications that you would like for me to discuss or if you have any specific questions about the drugs you are currently taking, I would be pleased to address these concerns in future TMA newsletters. Please send your questions or issues to Sandy Siegel.

ANTIDEPRESSANTS:
Classification:

Tricyclic antidepressants
Amitriptyline (Elavil)
Nortriptyline (Pamelor)
Imipramine (Tofranil)
Doxepin (Sinequan)
Desipramine (Norpramin)
Trimipramine (Surmontil)
Protriptyline (Vivactil)

Selective serotonin reuptake inhibitors
Fluoxetine (Prozac)
Sertraline (Zoloft)
Paroxetine (Paxil)
Fluvoxamine (Luvox)

Others
Nefazodone (Serzone)
Trazadone (Desyrel)
Venlafaxine (Effexor)
Maprotiline (Ludiomil)
Bupropion (Wellbutrin)

AMITRIPTYLINE (Brand Name: Elavil): We will consider this drug as representative of the antidepressant drug class. It is the prototype drug that is effective in treating depression and certain kinds of pain.

Therapeutic effects: This drug is classified as a "tricyclic antidepressant" because of its chemical structure (3 rings) and its effectiveness in treating the symptoms of depression. When used for depression, this drug is often administered concurrently with psychotherapy. The mechanism of action of amitriptyline is unclear. It is known to produce an increase in the effects of two neurotransmitters (*see glossary*), norepinephrine and serotonin, in the brain by preventing their inactivation. However, the enhancement of these neurotransmitters occurs rapidly, while antidepression may take several weeks of repeated drug administration

for its development. It, therefore, has been proposed that the increases in serotonin and norepinephrine transmission produced by antidepressants, such as amitriptyline, lead to subsequent changes in the chemistry of the nervous system that are ultimately responsible for the eventual relief of depression.

Although amitriptyline is classified as an antidepressant, it produces other effects that would be useful in patients with transverse myelitis. Amitriptyline administered together with an opioid drug, such as morphine, has been shown to augment the analgesic (pain relieving) effects of the opioid. In addition, amitriptyline, as well as other tricyclic antidepressants and possibly nontricyclic antidepressants (listed above), appear to be capable of relieving certain types of pain when administered in the absence of opioids, particularly neuropathic pain. The latter refers to pain derived from abnormal functioning in neurons that mediate pain sensation (*see glossary*). The mechanism of this pain-relieving effect of amitriptyline (and other antidepressants) is not clear. It does not seem to be related to its antidepressant effects, since relief of pain occurs at lower doses and develops more rapidly than antidepressant effects. Recent studies have indicated that neurons in the spinal cord that release the neurotransmitters, serotonin and norepinephrine, from nerve endings inhibit pain transmission. Accordingly, amitriptyline, which increases the effects of norepinephrine and serotonin, would be expected to inhibit pain transmission, causing a reduction in the intensity of pain. Recently, a hypothesis has been proposed that the ability of tricyclic antidepressants to relieve neuropathic pain is related to the blockade of a receptor in the spinal cord for the neurotransmitter, glutamic acid. More work will have to be done to corroborate this hypothesis.

Adverse effects of amitriptyline: Amitriptyline has many different actions that produce a variety of adverse effects. Amitriptyline can produce orthostatic or postural hypotension, which refers to dizziness and lightheadedness when the patient moves from a lying down to a sitting position or from a sitting to a standing position. This effect occurs mainly at the beginning of therapy, with tolerance developing when the drug is taken chronically. Patients who experience postural hypotension after taking any drug should move slowly into an upright position to avoid dizziness and lightheadedness.

Amitriptyline produces sedation, which is also most intense during the initial period of drug therapy because eventually a partial tolerance develops to this effect. However, the sedation can interfere with the performance of daytime activities. If sedation is significant, it can be minimized during the daytime by administering the drug before bedtime. The sedation produced by amitriptyline is augmented if the drug is taken together with other drugs that contain sedative action. Such drugs include many antihistamines, alcohol, sleeping pills, opioids, etc. The sedative effect of amitriptyline has been related to its ability to block receptors for the neurotransmitter, histamine, in the brain.

Amitriptyline blocks a certain type of receptor for the neurotransmitter (*see glossary*), acetylcholine, and, consequently, may interfere with the functioning of this neurotransmitter on various organs. The transmitter, acetylcholine, which is normally released from nerve endings, cannot activate receptors that are blocked, resulting in symptoms. Therefore, patients, when taking amitriptyline (or other tricyclic antidepressants), may experience such symptoms as blurred vision, dry mouth, constipation, urinary hesitancy, and increased heart rate. Patients who are distressed by these effects should notify their physician.

Amitriptyline and other tricyclic antidepressants produce a small increase in the risk of seizures, and thus, the drug should be administered cautiously to patients with seizure disorders.

Amitriptyline use can cause excessive sweating, which may require the patient to frequently change clothing. The mechanism of this effect is unclear. Actually, it would be expected that the blockade of receptors for the neurotransmitter, acetylcholine (*see above*) would decrease rather that increase sweating.

Amitriptyline may increase appetite, especially for sweets. Again, the mechanism for this effect is unclear. One theory is that the increased appetite is related to the blockade of receptors for the neurotransmitter, histamine, in the brain, as drugs that block histamine receptors in the brain generally increase appetite.

The most serious adverse effect of amitriptyline is to impair cardiac function, leading to abnormal cardiac rhythms. This adverse effect is uncommon except in patients who overdose or have a preexisting cardiac condition. Patients at risk for abnormal rhythms (arrhythmias) should have an electrocardiogram taken both before and at intervals during therapy.

Reactions with other drugs: Amitriptyline can produce adverse

interactions with several drugs. Amitriptyline augments and prolongs the effects of epinephrine (adrenaline). Epinephrine is used to delay the absorption of local anesthetics, to control superficial bleeding, to reduce nasal congestion, to elevate blood pressure, to produce mydriasis during ophthalmic procedures, to overcome atrial-ventricular heart block, to dilate bronchioles (asthmatic patients), and to counteract anaphylactic shock. However, the administration of epinephrine to a patient taking amitriptyline can lead to toxicity.

Amitriptyline blocks certain receptors for acetylcholine producing adverse effects (*see above*). Administering amitriptyline together with other drugs that block receptors for acetylcholine would worsen these adverse effects. Thus, patients should not take amitriptyline together with scopolamine (used for motion sickness), most antihistamines (used for allergies), etc., because these drugs also block receptors for acetylcholine.

Amitriptyline and most other antidepressants should not be administered together with monoamine oxidase inhibitors (Drugs used for the treatment of depression). The combination can produce a marked rise in blood pressure, called hypertensive crises. This is an emergency situation that requires that the blood pressure be reduced immediately to prevent damage to blood vessels and the heart.

Amitriptyline is metabolized by the liver to nortriptyline, an active metabolite marketed under the name of Pamelor. Nortriptyline is eventually metabolized to an inactive product that is excreted. Certain drugs, such as cimetidine (Tagamet), fluoxetine (Prozac), haloperidol (Haldol), oral contraceptives and ethanol, can inhibit the metabolism of amitriptyline and nortriptyline. This can lead to an increase in blood level of these substances, resulting in toxicity.

Overdose: Overdose of amitriptyline can produce central nervous system symptoms including agitation, confusion, hallucinations, and seizures. Amitriptyline in high doses is toxic to the heart (*See above*), producing severe abnormal rhythms of the ventricles, which can cause lethality.

ANTICONVULSANTS

Drugs in this group: These drugs are used to treat epilepsy and have been shown to be effective in certain kinds of neuropathic pain.

Carbamazepine (Tegretol)
Phenytoin (Dilantin)
Valproic acid (Depakene, Depakote, Evipal)
Gabapentin (Neurontin)
Clonazepam (Klonopin)

Carbamazepine (Tegretol):

Therapeutic effects and mechanism: Carbamazepine is used for both tonic-clonic seizures (full body seizures) as well as partial seizures. It produces this effect by inhibiting the entry of the sodium ions into neurons, and consequently decreases the ability of neurons to conduct impulses.

Carbamazepine has been shown to be effective in controlling the manic phase of manic-depressive disorder.

Carbamazepine has been found to be effective in the treatment of neuropathic pain, particularly the pain of trigeminal neuralgia. In this condition, there is a sharp, stabbing pain along the sensory distribution of the trigeminal nerve (along the face and forehead). Carbamazepine, which is not an analgesic, causes pain relief, presumably by inhibiting conduction of impulses in neurons mediating pain.

Adverse effects: Carbamazepine produces drowsiness, dizziness, and impaired coordination. The latter can be expressed as double vision or decreased ability to control the movement of the eyeballs. These effects are reversible when the dose is lowered. Carbamazepine in a small percentage of patients can produce water intoxication, leading to a variety of behavioral changes. It is recommended that serum sodium content be periodically monitored. Carbamazepine can cause more dangerous effects such as severe rashes, liver damage, and bone marrow impairment. However, these effects are uncommon but when they occur, the drug must be discontinued. Patient should be aware of certain signs indicating abnormalities in the blood. A decrease in white blood cell counts, which protects the body from invading microorganisms, can lead to infection, sore throat, and fever. A decrease in red blood cells can lead to fatigue and weakness. A decrease in platelets can lead to frequent bruising and the occurrence of small dark red spots in the skin and mucous membrane. Because of the possibility of bone marrow depression, complete blood counts are determined before and during drug therapy. Usually serum electrolyte levels and liver function tests are also performed before and during therapy.

Phenytoin (Dilantin):

Therapeutic effects and mechanism: Phenytoin, like carbamazepine, is used for both tonic-clonic convulsions and partial seizures. It is thought to act in the same way as carbamazepine, by blocking the entry of sodium ions into neurons, thereby inhibiting the ability of neurons to conduct impulses.

Also like carbamazepine, phenytoin is used for the relief of neuropathic pain, particularly trigeminal neuralgia.

Adverse reactions: While phenytoin is often effective in controlling seizures and pain from neurons, it is a difficult drug to take because it produces a large number of adverse effects when the dose of drug is too high. Thus high doses may produce such central nervous system symptoms as impaired muscle coordination, double vision, slurred speech, tremors, drowsiness, and fatigue, which can be reversed by lowering the dose. About 20% of patients using phenytoin chronically develop swollen gums, caused by an increase in tissue at that site. Good dental hygiene is thought to inhibit but not prevent swollen gums from occurring. Other side effects include certain vitamin deficiencies, particularly deficiencies of folic acid and Vitamin D. These deficiencies occur because phenytoin interferes with the metabolism of these vitamins. Phenytoin can have adverse effects on the skin. It can induce allergic rashes, aggravate preexisting acne, and stimulate the growth of coarse hair on the face and body. Phenytoin also interferes with the metabolism of many drugs.

As if a large number of adverse effects do not produce enough problems, the degree of absorption of phenytoin after oral administration and the metabolism of phenytoin by liver enzymes is variable. This leads to marked variations in the blood levels of this drug and its therapeutic effectiveness. Therefore, patients taking this drug are usually told not to change brands of phenytoin if it is effectively controlling seizures.

Valproic acid (Depakene, Depakote, Evipal):

Therapeutic Uses and Mechanism: This is a broad spectrum antiepileptic drug that is effective in controlling many different types of seizures, including absence, tonic-clonic, myoclonic, and atonic seizures. It is also used to control the manic phase of manic-depressive disorder. The drug seems to work in three different ways. First, it acts like phenytoin and carbamazepine and inhibits impulse flow by blocking the entry of sodium into neurons. Second, it inhibits a specific type of channel (T-type calcium channels) in the neuronal membrane for charged calcium ions, thereby preventing the entry of calcium ions through this channel into the neuron. Finally, it seems to enhance the effects of the inhibitory neurotransmitter, GABA.

Recent studies have shown that valproic acid can relieve neuropathic pain, and so while not approved for this indication, it is used for this condition.

Adverse effects: Valproic acid is a relatively safe drug. However, it is irritating to the lining of the gastrointestinal tract, producing nausea, vomiting, and indigestion. These symptoms can be controlled by taking valproic acid with food or using an enteric coated preparation (divalproex sodium - Depakote), which releases valproic acid in the intestine but not the stomach. Valproic acid has been associated with liver damage during the initial period of therapy. This effect is very uncommon but can be very severe. Patients at high risk for this disorder are children younger than 2 years of age who are taking other antiepileptic drugs. Patients should be aware of signs of liver toxicity, which consist of loss of appetite, nausea, abdominal pain, and jaundice. Patients who develop these symptoms while taking valproic acid should notify their physician. Liver damage leads to an increase in enzymes normally found in liver cells in the blood. Therefore, liver function tests are usually performed before and during treatment. Other adverse effects produced by valproic acid are lethargy, tremor, weight gain, skin rash, and sometimes a loss of hair. Valproic acid can decrease platelet count, which can cause bleeding. It, therefore, should not be taken with aspirin, ibuprofen (Nuprin, Advil, Motrin), or naproxen (Aleve), as these drugs inhibit platelet aggregation and intensify the bleeding tendency. Almost all the adverse effects of valproic acid are reversible.

Gabapentin (Neurontin):

Therapeutic Effects and Mechanism: Gabapentin is classified as an anticonvulsant that is useful in treating a variety of different types of seizures. It is approved by the Food and Drug Administration for use as an adjunct to other drugs for the control of partial seizures (seizures that begin at a focal brain site, usually the cerebral cortex, and exhibit limited spread to other brain sites). As one would expect from the name Gabapentin, the drug is a chemical analog of the inhibitory neurotransmitter, GABA (*see glossary*). However, the drug does not seem to interact with receptors for GABA, and the mechanism of action of gabapentin is unclear. Perhaps it stimulates the release of GABA from nerve endings, increasing free GABA. The free GABA could then activate GABA receptors that would inhibit nerve impulses.

Although gabapentin is not approved for the treatment of neuropathic pain, it has been shown to be effective in the treatment of this condition. The mechanism of this effect is unclear.

Major adverse reactions: sleepiness, dizziness, impaired coordination.

Clonazepam (Klonopin):

Therapeutic Uses and Mechanism: This drug is a benzodiazepine derivative. Therefore, it is in the same chemical family as Librium, Valium, Ativan, and Xanax, drugs that are often prescribed for anxiety. It is considered one of the most potent benzodiazepines and has a long duration of action. It is used to treat certain types of seizures. Recently, it has been used to treat neuropathic pain. The mechanism of action of clonazepam in producing this effect is unclear at the present time.

BENZODIAZEPINES:

Definition: The term, benzodiazepine, refers to the chemical structure of a variety of drugs that can relieve anxiety, inhibit convulsions, produce muscle relaxation, and promote sleep. Generally, the reduction in anxiety is produced by lower doses of drug, and the promotion of sleep occurs at higher doses. Below is a list of the drugs in this class.

Alprazolam (Xanax)
Chlordiazepoxide (Librium)
Clonazepam (Klonopin)
Chlorazepate (Tranxene)
Diazepam (Valium)
Estazolam (ProSom)
Flurazepam (Dalmane)
Halazepam (Paxipam)
Lorazepam (Ativan)
Midazolam (Versed)
Oxazepam (Serax)
Prazepam (Centrax)
Quazepam (Doral)
Temazepam (Restoril)
Triazolam (Halcion)

The drug, zolpidem, marketed as Ambien, is used to promote sleep. It is not in the above list because it is chemically not a benzodiazepine. In fact, zolpidem is marketed as a *non*benzodiazepine sleeping pill. However, it acts biologically on one type of receptor for benzodiazepines to promote sleep. In contrast to other benzodiazepines, it has little antianxiety, anticonvulsant, or muscle relaxant effects.

Therapeutic Effects and Mechanism: As indicated above, the benzodiazepines can relieve anxiety and at higher doses promote sleep and induce muscle relaxation. The use of certain benzodiazepines to relieve anxiety and other benzodiazepines to promote sleep is basically a marketing decision by drug companies. Benzodiazepines are also used to treat seizure disorders and panic disorder. They are used to help physically dependent patients withdraw from alcohol because they are cross dependent with alcohol and, therefore, will inhibit the symptoms of alcohol withdrawal. Benzodiazepines produce their effects by acting in the central nervous system at many different sites to enhance the effect of the inhibitory neurotransmitter, GABA. Thus, benzodiazepines will inhibit neuronal activity.

Adverse effects: These drugs are safe when administered orally because they have relatively weak effects on the cardiovascular and respiratory systems. However, certain adverse effects are associated with benzodiazepine use which can be dangerous. Thus, these drugs can produce drowsiness, dizziness and impaired coordination, which many interfere with the performance of daytime activities. In addition, benzodiazepines can temporarily impair the ability of patients to learn new information (anterograde amnesia). Elderly patients are more sensitive to the sedative effect of benzodiazepine and may have relatively poor liver function, resulting in a decreased rate of metabolism of these drugs. Therefore, elderly patients who complain of memory impairment should be evaluated for the possibility that this impairment is caused by the use of benzodiazepines. Even though physical dependence frequently develops after chronic use, the abuse potential of benzodiazepines is considered to be low. The usual withdrawal symptoms are anxiety, restlessness, insomnia, and tremors. It should be noted that severe withdrawal symptoms could be avoided by discontinuing the drug slowly and gradually, over a period of several weeks. Under these circumstances, withdrawal discomfort is minimal and may not be detectable.

ANTIARRHYTHMIC DRUGS:

Therapeutic Effects and Mechanism: This class of drugs is used to treat abnormal rhythms of the heart. These drugs are thought to act by inhibiting the entry of charged metal ions into cardiac cells. Recently, some of the drugs in this class have been found effective in treating neuropathic pain. This has been shown for lidocaine (xylocaine), mexiletine (Mexitil), and flecainide (Tambocor). While lidocaine must be administered by injection, the other two drugs can be given orally.

BACLOFEN (LIORESAL):

Therapeutic Effects and Mechanism: Baclofen acts within the spinal cord and the brain to inhibit neuronal activity. Consequently, baclofen can inhibit hyperactive reflexes responsible for abnormal and excessive muscle tone. This effect of baclofen is due to its ability to bind to and activate a specific receptor for amino-butyric acid (GABA), called the GABA-B receptor. GABA is an amino acid and is the primary inhibitory neurotransmitter in the central nervous system (*see glossary*). A deficiency of this inhibitory transmitter at synapses in the central nervous system can produce sei-

zures, impaired coordination, and spasticity. Baclofen by activating receptors for GABA in the spinal cord and brain can counteract these neurological effects by producing muscle relaxation at a dose that produces minimal sedation.

Baclofen is used to relieve spasticity, which is characterized by hyperactive spinal cord reflexes in response to changes in position or movement. Spasticity is produced in a variety of conditions in which there is CNS injury, such as multiple sclerosis, spinal cord injury, stroke, and cerebral palsy.

Recent studies indicate that baclofen can be used to treat neuropathic pain, presumably by inhibiting pain transmission through the activation of GABA receptors.

Adverse effects: The most common adverse effects occur in the central nervous system, consisting of drowsiness, dizziness, muscle weakness and fatigue. These effects are most intense when the drug is first administered but then gradually subsides as tolerance develops. These effects can be reduced by starting treatment with a low dose of the drug and then gradually increasing the dose (e.g., after a 7 day interval). However, these adverse effects will be enhanced if the drug is taken together with alcohol or other drugs with CNS depressant activity (such as opioid analgesics, benzodiazepines, tricyclic antidepressants, antihistamines). After baclofen has been chronically administered, it should be discontinued slowly, since abrupt withdrawal after prolonged use can cause anxiety, hallucinations, seizures, and rebound spasticity.

Symptoms of overdose include vomiting, coma, seizures, and respiratory depression. There is no antidote and treatment is supportive.

DANTROLENE (DANTRIUM):

Therapeutic Effects and Mechanism: Dantrolene is also used to relieve spasticity. Drugs used for spasticity include diazepam (Valium), baclofen (Lioresal) and dantrolene (Dantrium). While diazepam and baclofen act at sites within the central nervous system, dantrolene acts directly in skeletal muscle. This drug inhibits the release of calcium ions from storage sites for calcium (called the sarcoplasmic reticulum). Since it is the release of calcium ion from these storage sites that trigger muscle contraction, dantrolene will inhibit muscle contractions and muscle spasms.

Adverse effects: Probably the main adverse effect of dantrolene is an extension of its therapeutic actions. By preventing the release of calcium ion from muscle stores, dantrolene inhibits muscle contraction. However, too much inhibition of calcium release can lead to muscle weakness and impaired rather than improved function. This weakness produced by dantrolene is an important reason why the drug is not used as frequently as other drugs (baclofen and diazepam) for spasticity. Dantrolene can also cause injury to the liver. Therefore, tests of liver function should be performed before and during therapy. Other adverse effects include diarrhea, loss of appetite, nausea, and rash. It can also cause drowsiness and, therefore, patients should not use CNS depressants, e.g., alcohol, when taking dantrolene.

OXYBUTYNIN (DITROPAN):

Therapeutic Use and Mechanism: This drug is used as a urinary antispasmodic. That is, it is used to treat urinary urgency, frequency, and incontinence. This drug has two actions important in producing these effects. First, it causes a direct relaxation of smooth muscles of the bladder. It also blocks receptors for the neurotransmitter, acetylcholine, which is released from nerve endings supplying the bladder and activates receptors on smooth muscles of the bladder causing contraction. By blocking the receptors for acetylcholine and directly relaxing bladder smooth muscle, oxybutynin prevents the bladder smooth muscle from contracting, increases bladder capacity, reduces spontaneous contractions of the bladder, and decreases urgency and frequency. If oxybutynin does not reverse urinary incontinence, other anticholinergic drugs, such as propantheline or dicylomine, are usually tried.

Adverse effects: Many of the adverse effects of Oxybutynin are related to its ability to block receptors for the neurotransmitter, acetylcholine, at sites in the body other than the bladder. Thus, by blocking these receptors in the eye, the gastrointestinal tract, the salivary glands, the sweat glands, and the heart, it can cause blurred vision and light sensitivity, constipation, dryness of the mouth, decreased sweating, and increased heart rate, respectively.

CLONIDINE (CATAPRES):

Therapeutic Effects and Mechanism: Clonidine hydrochloride is classified as a centrally acting antihypertensive agent which is an agonist and activates alpha-2 adrenergic receptors. The activation of these receptors in the cardiovascular regulatory centers in the brain and spinal cord produces a decrease in sympathetic tone, resulting in a decrease in blood pressure and heart rate. Clonidine is not usually recommended for first-line therapy for hypertension because there are severe symptoms (increased blood pressure, heart rate, tremor agitation, etc.) when the drug

is abruptly discontinued. These effects can be avoided if the drug is withdrawn gradually.

Clonidine has been used for the treatment of neuropathic pain. There are alpha-2 adrenergic receptors located in the dorsal horn of the spinal cord that regulate pain transmission. Activation of alpha-2-receptors have been shown to inhibit pain transmission at this site, thereby causing neuropathic pain relief.

Adverse Effects: Clonidine can produce a variety of unpleasant effects, such as constipation, dry mouth, dry eyes, skin problems, and sexual difficulties. Patients who experience constipation can control it by increasing the amount of high fiber intake and drinking plenty of water. Dry mouth can be relieved by sucking sugar-free candies. Dry eyes can be relieved by using artificial tear eye drops. Clonidine can also produce allergic reactions on the skin, and increased sensitivity to the sun light. Using sun screen can prevent skin damage. Sexual difficulties include difficulty achieving orgasm, decreased physical sensation and delayed ejaculation. It is important to remember not to stop clonidine therapy abruptly, since abrupt withdrawal from clonidine may cause severe symptoms that can be life-threatening.

Reactions With Other Drugs: The use of tricyclic depressants (e.g., amitriptyline) concurrently with clonidine can decrease the effect of clonidine. Clonidine can enhance the CNS-depressant effects of barbiturates, alcohol, or other sedatives.

PROCHLORPERAZINE (COMPAZINE):

Therapeutic Effects and Mechanism: This is a drug used to relieve nausea and vomiting. It produces this effect by inhibiting a site in the brain called the chemoreceptor trigger zone. When the chemoreceptor trigger zone is activated, it stimulates the vomiting center, causing nausea and vomiting. The chemoreceptor trigger zone contains receptors for the neurotransmitter, dopamine. Blockade of these receptors by prochlorperazine inhibits the activity of the chemoreceptor trigger zone, leading to a decrease in nausea and vomiting.

Adverse Effects: Prochlorperazine use is associated with drowsiness, dizziness, blurred vision, allergic skin rash, and hypotension. Prochlorperazine can induce seizures in patients at risk for seizures. The drug rarely produces serious side effects, such as jaundice, leukopenia, and agranulocytosis (*see glossary*).

GLOSSARY:

***Agonist*:** A drug that binds to a receptor and activates it, thereby producing a response.

***Agranulocytosis*:** This is a disorder in which there is a decrease in the number of white blood cells (neutrophils, eosinophils, and basophils) in the circulation. This is caused by damage to the bone marrow. Since these cells are an important part of the body's defense against infection by microorganisms, a decrease in these cells increases the vulnerability to infection. Patients with agranulocytosis may develop fever, sore throat, ulcerations and skin lesions. It is treated with antibiotics.

***Anticonvulsant*:** Drugs that block or prevent the involuntary muscle contractions associated with epilepsy. These drugs are thought to produce their effect in one of three ways: inhibition of sodium ion entry into the neuron, inhibition of calcium ion entry into the neuron, or enhancement of the effect of the neurotransmitter, GABA. Some anticonvulsant drugs are used to treat psychiatric disorders and neuropathic pain.

***Antidepressant*:** A drug that is used to treat depression but does not produce stimulant effects. It takes about two-four weeks for these drugs to be effective. Many of these drugs are also used to treat neuropathic pain, but their mechanism of action is unclear. Recent studies suggest that their ability to inhibit neuropathic pain may be due to the blockade of specific receptors on neurons of the spinal cord for the neurotransmitter, glutamic acid. This compound is thought to be important in pain transmission.

***Benzodiazepine*:** A class of chemically related drugs that have CNS depressant activity. These drugs can produce a spectrum of effects, including an antianxiety, sedative-hypnotic (sleeping pill), and muscle relaxant effects. These effects are due to an action of these drugs in different areas of the brain. Example of these drugs would be lorazepam (Ativan), diazepam (Valium) and chlordiazepoxide (Librium).

***GABA*:** This is the main inhibitory neurotransmitter in the brain. GABA is released from specific neuron in the brain and spinal cord into a synaptic cleft and activates specific receptors on another neuron, producing an inhibition of conduction. Thus, the message is one of inhibition. Some anticonvulsants are believed to exert their effect through enhancing GABA neurotransmission. There are different kinds of GABA receptors. Baclofen (Lioresal) is believed to produce its effects in the nervous system by directly activating one kind of receptor for the neurotransmitter, GABA.

***Liver injury*:** Some drugs may impair liver function. This effect is usually reversible when the drug is discontinued. Symptoms of impairment in liver function include loss of appetite, nausea, abdominal pain, and jaundice. The latter refers to the occurrence of a yellow color in the skin or in the whites of the eyes. It is due to the deposition of the compound, bilirubin, a breakdown product of hemoglobin, which is normally metabolized by the liver but which can accumulate in the blood and tissues when the liver is not functioning normally. Individuals experiencing these symptoms should notify their physicians immediately.

***Neuropathic pain*:** This refers to pain caused by a dysfunction in neurons of the central or peripheral nervous systems. This is a condition in which an abnormality in the neuron causes the conduction of pain nerve impulses.

Neurotransmitter: Neurons communicate through chemical messengers that are released from one neuron, cross a space (the synaptic cleft) and activate receptors on another neuron. The neurotransmitter can be removed from the synaptic cleft by a process, which transports the neurotransmitter back into the neuron that released it. This process, therefore, will remove the neurotransmitter from the synaptic cleft, thereby terminating its action. This means the neurotransmitter can no longer gain access to the receptor. Typical neurotransmitters are serotonin, norepinephrine, GABA, and acetylcholine. Many antidepressants (e.g., amitriptyline) *inhibit* the process which transports serotonin and/or norepinephrine back into the neuron from which they were released, thereby increasing the levels of these neurotransmitters in the synaptic cleft. This results in a greater activation of the next neuron. Such an action is associated with antidepression and possibly relief of neuropathic pain.

Physical dependence*:** A condition in which the discontinuation of a drug that has been taken chronically produces withdrawal symptoms. The withdrawal symptoms can be inhibited or reversed by the administration of the drug or other drugs with a similar mechanism of action as the original drug. A condition in which one drug will inhibit the symptoms of withdrawal from another drug is called ***cross dependence.

***Receptor*:** A molecule located on cells to which a neurotransmitter or drug binds to produce its characteristic effect.

Part 2. Dealing With Change

"It is not possible to step twice into the same river."
Heraclitus. 540-480 B.C.

The Process Of Adaptation To Effects Of Severe Injury And Illness

James A. Arnett and Denise E. Rabold

This is the second installment in a series of articles written by James A. Arnett, Ph.D. and Denise S. Rabold, Ph.D. Drs. Arnett and Rabold are faculty members in the Division of Rehabilitation Psychology, Department of Physical Medicine and Rehabilitation at The Ohio State University. Rehabilitation Psychology is a specialty of psychology that serves individuals with disabilities as they adjust, adapt, and progress toward healthy and satisfying lifestyles. Psychologists working in rehabilitation use education, remediation, counseling, and advocacy to minimize effects of impairments due to disabling medical conditions and promote wellness through optimal psychological and social functioning. Dr. Arnett has a broad base of experience with a range of disabling conditions, and specializes in evaluation of mental performance and adjustment issues associated with impaired brain function. Dr. Rabold is licensed as both a psychologist and speech-language pathologist. She specializes in counseling and cognitive remediation for work, school, and community re-entry after acquired brain injury.

Change is part of life: it is inevitable and unavoidable. We cannot avoid the changes related to aging, work, illness, birth and death, nor can we avoid changes brought on by advances in science and technology. We cannot stop the river of change.

As functional, effective, and imaginative human beings, we must be able to deal with change. We might expect that, because we live with continuous change, we are equipped to deal with it – or at least a certain amount of it. We may even be expecting and planning for certain changes, such as a wedding, a graduation, a new job, a new baby, or

retirement. Although change is expected, it still causes stress. We feel anxiety about change whether or not the change is for the good or not. Anxiety goes with a need to react to and manage change. With a change, whether for better or worse; we must rely on our coping and problem solving strategies, and our defenses, until we have restored a sense of stability and understanding.

Is there a limit to how much change a person can deal with? More appropriately, is there a limit to the amount of change a person can deal with at a given time? There probably is such a limit; and this limit is probably different for each individual. The ability to deal with change is probably determined by several factors including age, education, experience, and family (environmental) support as noted in Part 1 of this article (The Transverse Myelitis Association Newsletter, Volume 2, Issue 1).

What happens when an individual is confronted with an overwhelming change? First we should note, as we did in Part 1, that each individual finds his or her own way to adapt to new situations and problems. If the process of adapting is unique, then we must look beyond the individual to make observations about how a person deals with a health crisis.

Following a health crisis – a serious disabling illness or injury -- there is probably a period of confusion and distress. There may be many different emotions experienced during this time. This time might be described as a period of disorganized thinking. The individual will be trying to understand what has happened, why it has happened, and what it means. Why did this happen to me? Did I do something that caused this to happen? Is someone responsible? If I cannot play tennis, can I still play golf? I don't know what it is, but I believe this happened for a reason. Will I get better? Will I get worse? Will I be able to make love? Will anyone love me? Will I be able to work again? Will I be able to drive? All of these and many similar questions are common during the early stage of dealing with effects of severe injury or illness. An individual may spend a lot of time thinking about the disease process, and trying to learn more about the disease. There may be problems of pain, which further limit concentration and the ability to think in organized and constructive ways. During this early period of adjustment, there is often considerable emotional distress and turmoil. This distress may be evident to others as anger, depression, anxiety, or guilt.

The period of confusion varies in length according to characteristics of the individual, characteristics of the illness and physical abilities, and features of their support system, family, and home environment. (Note, in Part 1, we described behavior as resulting from three complex factors: Physiology, Personality, and Environment.) With time, adequate care and support, the individual will move from the period of confused thinking to a period of organized thinking.

Movement from confused thinking to organized thinking means that after a period of confusion and distress, the individual begins to think in constructive and productive ways about their situation and problems. This is a time when old methods of problem solving and familiar ways of dealing with the world are expected to return. With this time of organized thinking come thoughts about the problems one faces and the beginning of planning for the future.

What can be said about the period of organized thinking? This is the time when a person, who is dealing with a crisis of change, begins to look more objectively at his or her situation, and begins to make attempts at problem solving and planning. A useful model of adjustment and adaptation has been developed by Rudolf Moos and Jeanne Schaefer. Drs. Moos and Schaefer suggest that regardless of individual and environmental differences, persons faced with a health crisis all have the same problems to solve. Called adaptive tasks, these are problems that all individuals must deal with after serious, disabling illness or injury.

Moos and Schaefer suggest there are seven common adaptive tasks that must be addressed in adjusting to the effects of serious illness. The seven adaptive tasks appear as follows:

Illness Related Tasks:

1. Dealing with pain, incapacitation, and other symptoms.
2. Dealing with the hospital environment and special treatment procedures.
3. Developing and maintaining adequate relationships with health care staff.

General Tasks:

4. Preserving a reasonable emotional balance.
5. Preserving a satisfactory self-image and maintaining a sense of competence and mastery.
6. Sustaining relationships with family and friends.
7. Planning for an uncertain future.

The first three adaptive tasks relate specifically to illness, hospitalization, and dealing with health care providers. The last four tasks are called general tasks because they apply not just to illness and injury

related problems, but to any sort of crisis (loss of home, loss of a job, or natural disaster, such as a flood or tornado).

In studying the adaptation model presented by Moos and Shaefer, it occurs to us that tasks 1, 2, and 3 (Illness related) might tend to be the focus of effort earlier in the adaptation process, while addressing the four general tasks would tend to come later. Of course, there are probably many exceptions to this. It would appear, however, that demands for dealing with pain, the hospital, medical procedures, and health care staff would occur early in an illness process. It would also appear that demands for dealing with these issues would occur at a time when the injured or ill person is most vulnerable, and most in need of assistance and support from family and health care workers. With the passage of time, the person will become more effective at using abilities and resources. The need for assistance and support is expected to decrease with time as functional skills are restored.

We have found this to be a useful model in guiding a person as they begin to deal with their problems following injury or illness. Much has been written about each of these issues; and because of limitations of space and time, we will not attempt to address the full list. Instead, we will focus on the General Tasks; because, as noted, these appear to describe best the long-term issues of living with disability. According to the Moos/ Shaefer model, the long-term adaptation to a functional impairment or disability would involve maintaining emotional stability, maintaining a positive self-image and sense of competency, maintaining relationships, and planning for the future. Adjustment can be described as the process of dealing with these adaptive tasks.

It should be noted that the adaptive tasks can be dealt with effectively, or they can be avoided or dealt with in destructive or negative ways. Probably the best example of destructive coping is the use of alcohol and drugs to ease depression and anxiety following a disruptive crisis. There is evidence that an injury that limits mobility and independence increases the risk of depression; and increased depression contributes to greater risk of abuse of alcohol and other drugs. As a simple example, more effective coping might involve finding a way to increase mobility, which in turn would lower the risk of depression.

Moving the focus of attention from the individual and placing it on the problems at hand leads to the interesting implication that all persons dealing with a crisis face common problems. Moos and Shaefer are suggesting that both the person with a disabling illness and the person who has lost a home through fire or natural disaster have much in common. Both must maintain an emotional balance. Both must maintain a positive self-image – one of self-worth, competence, and dignity. Both must attend to their relationships with family and friends. Both must make plans.

In the next installment of this article we will consider the adaptive task of planning for an uncertain future. We will address the issues surrounding planning for and returning to work.

Reference:
Moos, R.H. (Ed.). (1989). Coping With Physical Illness. (2nd ed.). New York: Plenum Medical Book Co.

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.

Children's Hopes and Dreams Foundation, Inc.

The TMA is attempting to collect information to create a children's directory for our members. In addition to assisting families with children with TM, the directory would also provide an opportunity for children with TM to find each other and develop support and relationships. The TMA children's directory is a work-in-progress (and I, again, implore you to participate and send me your information). Until we are able to compile this directory, we are on the constant lookout for resources that might assist you in helping your children share their experiences with others who might better understand their thoughts and feelings. Deanne has found such a resource, and we want to share it with you. It is the Children's Hopes and Dreams Foundation, Inc. The Foundation is a pen-pal program for children with any kind of major illness or chronic health condition. The children can be matched with a pen pal that has similar conditions and by gender and age. Please feel free to contact the Foundation, if you would be interested in their services.

Children's Hopes and Dreams Foundation, Inc.
280 US Highway 46
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Member Questions and Answers from Joanne Lynn, MD

Dr. Lynn is an Assistant Professor of Neurology at The Ohio State University. She is currently on the staff of The Ohio State University Multiple Sclerosis Center and has special interests in clinical research on the treatment of MS. Dr. Lynn serves on the Medical Advisory Board of The Transverse Myelitis Association.

Any decisions regarding diagnosis or treatment should be made in consultation with your physician who is best suited to make appropriate medical recommendations for you.

1. How do illnesses, such as colds, fever and flu impact TM?

There are two ways to interpret this question. The first possible relationship is that viral illnesses are well known precipitants of post-infectious TM. Somehow the viral infection sets off an autoimmune response directed at the spinal cord with resultant inflammation and injury within spinal cord tissue. Recurrent transverse myelitis has been reported; therefore, there is a very small theoretical risk that viral infection might set off a recurrence of post-infectious TM. However, this is very small and it is more likely that worsening of symptoms with a cold or fever would occur by the mechanism described in the next paragraph.

The other way to interpret this question is how do colds, fever and flu impact upon the patient with a past episode of TM who is now stable with residual neurologic problems from spinal cord injury. We know from studies of people with multiple sclerosis that fever may have profound effects on neurologic function in areas of the brain and spinal cord with demyelination (injury to the myelin or insulation material wrapped around nerve fibers). In normal myelinated nerves, small increases in temperature will speed up conduction of electrical nerve impulses. However, an increase in temperature such as a fever may cause failure (or block) of conduction of nerve impulses in demyelinated nerve fibers. In fact, decades ago before MRIs and other sophisticated tests, MS was often diagnosed with the aid of the "hot bath test". The patient was placed in a hot bath to raise body temperature and then reexamined to see if new neurologic problems developed. It is commonplace for a person with MS who is walking with a cane to become temporarily paralyzed in the legs if they develop a high fever. This phenomenon is not specific for MS but may occur in any injury to the central nervous system and especially when there is prominent demyelination as there often is in TM.

This means that a person with TM may experience a worsening of lower extremity weakness or numbness, etc. when they have a fever. People who have experienced this worsening with fever should try to bring fever down with Tylenol or aspirin if there are no contraindications to taking these agents and get with their physician to determine what is causing the fever. A worsening of neurologic function in the setting of a fever is usually not a new episode of transverse myelitis just the result of the stress of the fever on a neurologic system without the usual reserves to tolerate the stress.

2. For how long can the healing process continue and in what degrees?

Again, there are few good studies that report on the healing process and outcome in large numbers of people with TM. Berman et al reported that out of 59 patients with TM, 22 had good recovery, 20 had fair recovery and 14 had poor recovery. They observed that recovery usually began within 4 weeks to 3 months after the onset of symptoms. If no signs of improvement were seen within 3 months, significant recovery was unlikely to occur.

Reference:
Berman M, Feldman S, Alter M, et al. Acute transverse myelitis: incidence and etiological considerations. Neurology 1981;31:966.

3. Is there a way to prevent this (TM) from happening again, i.e., diet, stress reduction, vitamins, etc.?

For most people, the cause of TM is unknown or idiopathic. Therefore, there is no evidence available that diet, stress reduction or vitamins would decrease the risk of an exacerbation of TM. Of course, there is much that we do not know about the immune system. There are some studies that suggest that stress may have adverse effects on the immune system. However, it is virtually impossible to construct a stress-free life that is rich and fulfilling. For that reason, it would seem prudent for those with TM to follow the same recommendations for a healthy life-style that are given for all: adequate rest, regular exercise, a good diet, moderation in alcohol intake, no smoking, etc. There is no dietary or vitamin supplement that has been proven to heal nervous system injury so beware those who promote expensive regimens.

4. So many people who have TM

complain about fatigue. What possible explanations are there for this symptom?

Fatigue is one of the most common complaints in clinical medicine. The cause of abnormal fatigue is poorly understood in most clinical conditions. The only ways that we have to measure fatigue are through subjective rating scales in which the person reports how fatigued he or she is. There are several different types of fatigue, which include 1) a sense of low energy, 2) abnormal mental fatigue, 3) fatigability in physical activities, 4) delayed recovery after fatiguing exercise. There are very few studies on fatigue and TM, so we should look at what is known or hypothesized about fatigue in other diseases that injure the spinal cord such as MS, spinal cord trauma, and degenerative diseases of the spinal cord. The types of fatigue that would be most expected to occur in a person with TM would be the third and fourth types. With injury to the spinal cord, there is a breakdown in the pathway for nervous system activation of muscles. In order to move your right toe, upper motor neuron cells in the motor cortex on the left side of the brain must be activated and send a signal through nerve fibers along a pathway which crosses to the right side in the brainstem and then courses down through the spinal cord to the lower levels of the spinal cord. These fibers make connections with lower motor neurons in the spinal cord, which then send fibers to the muscle. These fibers spritz out chemicals that travel short distances to the muscle fibers and cause them to contract.

One theory about motor fatigue in spinal cord injury is that it is due to an increase in energy demands caused by the inefficiency that is caused by weakness. What this means is that if your legs are weak, you have to work harder than a person with normal strength to walk and this requires more oxygen consumption and more work for your heart and lungs. Some studies suggest that this increased inefficiency is especially present if you have significant spasticity (or abnormally increased muscle tone) which must be fought against to move a limb. Some studies have suggested that the muscles themselves function poorly after an upper motor neuron injury with weak muscle contraction and quick fatigue.

Another possible contribution to fatigue is the fact that nerve fibers within the spinal cord that have been injured do not transmit electrical signals as well as normal fibers. One type of injury is demyelination. Nerve fibers are normally surrounded by an insulation material known as myelin. In inflammatory conditions such as TM and MS, the myelin is injured. This may lead to a type of "short-circuiting" of electrical flow across channels which results in weakened nerve firing and thus fatigue.

Another contribution to fatigue may be that people with significant leg weakness may become deconditioned and have poor physical fitness. That part of fatigue might be lessened by physical training and physical therapy.

There is no cure for fatigue. Even though the mechanism of fatigue is not well understood, there are several measures that may be tried. Rest and conservation of energy for those times when it is most needed are important strategies. Fatiguing tasks should be performed in the morning before fatigue sets in for most people with TM. It is sometimes helpful to analyze daily routines to see if tasks are performed efficiently. Moderate physical exercise and condition will result in gradual benefits for most.

Several medications have been tried for fatigue in MS; they could also be tried for people with TM. Amantadine is an antiviral medication that has been shown to have some benefits for fatigue in MS. It is given in doses of 100 mg in the morning and the afternoon and is tolerated well by most people. Pemoline is another stimulant that has been used with some success for fatigue in MS. Of course, other illnesses that might cause fatigue should be considered such as hypothyroidism, sleep disturbances of various kinds, depression and others.

References:

Miller RG, Green AT, Moussavi RS et al. Excessive muscular fatigue in patients with spastic paraparesis. Neurology 40:1271, 1990.

Olgiati R, Jacquet J and Prampero PE. Energy cost of walking and exertional dyspnea in multiple sclerosis. Am. Rev. Respir. Dis. 134:1005,1986.

5. Are there eye problems or vision problems that can occur as a symptom of having TM?

No. By definition TM is a disorder of the spinal cord and cannot affect vision. Vision is affected by disorders of the eye, optic nerve, or optic pathways that radiate to the visual cortex that is located in the back of the brain (occipital lobe). However, there is a disorder that is related to TM named acute disseminated encephalomyelitis (ADEM). This is a monophasic inflammation of white matter in multiple areas of the central nervous system including brain, brainstem, optic nerves and spinal cord. It is triggered by the same things as post-infectious/post-vaccinal transverse myelitis. Some researchers propose that TM is just a form fruste

(a partial form in which not all of the elements of the syndrome are present) or isolated, limited form of ADEM. So it is possible that one might develop an acute problem with spinal cord, vision or eye movement abnormalities as part of the same process. Spinal cord and optic nerve demyelination may also occur simultaneously or in close temporal relationship in one form of multiple sclerosis known as Devic's syndrome.

There are many other nervous system disorders that might affect vision. If there is a disturbance of vision, obviously this should be evaluated by an ophthalmologist. It is difficult in this setting to review all of the possible problems with vision. Briefly, double vision or diplopia suggests a disorder of the brainstem that is directly above the spinal cord and links the spinal cord with the rest of the brain or with the nerves or muscles that move the eyes. One cause of loss of vision in one eye is inflammation of the optic nerve that brings messages from the retina of that eye back to the brain. If either of these things should occur, then this suggests an underlying process that is affecting several levels of the nervous system, not just the spinal cord. Some possibilities might be multiple sclerosis, sarcoidosis, systemic lupus erythematosis, infections, vitamin B12 deficiency, or less likely, cancer.

6. Should a person with TM be concerned about receiving a flu vaccination or any other type of vaccination?

This is a difficult question. The reason is that acute disseminated encephalomyelitis (ADEM) or TM may occur as an immune response to vaccination. ADEM is a monophasic inflammatory disease of white matter of the central nervous system (brain and spinal cord). Epidemiology of ADEM and, to some degree, TM is discussed in the chapter by Tselis and Lisak referenced below. ADEM and TM can occur after immunization with vaccines against measles, diphtheria/tetanus, rubella and pertussis. But when you consider the very large number of vaccinations given against these diseases and the small incidence of ADEM/TM that occurs, many would think that the incidence is rare enough to suggest a coincidence rather than causality. They discuss reports of ADEM after influenza shots.

Given these uncertainties, the only possible answer is that one must weigh the potential risks versus the benefits. One moderate view would be that vaccination should certainly be avoided during any phase of active worsening and in those in whom the initial episode of TM followed an influenza vaccination by a short period of time. Certainly, the benefits of influenza vaccination probably exceed the small risks in people who have significant risk factors for death or severe illness from the flu (e.g., severe emphysema or other lung disease, etc.).

Reference:

Acute Disseminated Encephalomyelitis. Tselis AC and Lisak RP in Antel J, Birnbaum G and Hartung H. Clinical Immunology. Malden MA: Blackwell Science, Inc., 1998. Pp118-119.

7. Should a person who has been diagnosed with TM who experiences recurring symptoms or an intensification of existing symptoms be tested for MS?

Recurrent idiopathic transverse myelitis has been reported (Tippett 1991) and does not necessarily mean that there is underlying MS. However, recurrent exacerbations of myelopathy or spinal cord dysfunction should prompt reevaluation. Myelitis due to an underlying autoimmune disease is more likely to recur than idiopathic transverse myelitis. This would include systemic lupus erythematosis, Sjogren's syndrome, or multiple sclerosis. Relentlessly progressive spinal cord dysfunction should prompt consideration of a spinal cord mass lesion such as tumor or abscess, MS, or a paraneoplastic disorder (immune attacks on the spinal cord related to an underlying cancer).

Other neurologic symptoms occurring after the initial spinal cord attack that might suggest multiple sclerosis or another underlying inflammatory central nervous system disease would include visual loss, double vision, trouble with speech or swallowing, vertigo or seizures.

In most follow-up studies of people who present with transverse myelitis, the majority do not develop MS. However, if there are abnormal lesions in the white matter of the brain, the risk of subsequently developing MS is increased. Those with myelitis who have total paralysis of both legs (complete TM) are more unlikely to develop MS than those who had incomplete TM (weakness or sensory loss without complete paralysis).

References:

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Ford B, Tampieri D, Francis G. Long-term follow-up of acute transverse myelopathy. Neurology. 1992;42:250-252.

Miller DH, Ormerod IEC, Rudge P, et al. The early risk of multiple sclerosis following isolated acute syndromes of the brainstem and spinal cord. Ann Neurol. 1989;26:635-639.

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.

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.*

REFLECTIONS
Roger (Doc) Livingston
Covington, Kentucky
November 11, 1998

Seventeen years and a few hours ago I was sitting at my desk at the University of Cincinnati. As I sat there, I noticed that both feet were tingling. I looked down and found that I had my feet wrapped around the base of my chair. I straightened my legs, finished my appointments with my students, walked to my car and went home. Since I was walking normally and did not feel anything unusual, I simply brushed it off. That evening, the numbness worked its way up my leg. When I went to bed, I noticed that the numbness was just below my knee. The next morning I felt some numbness in my rear end, a sore spot on my left shoulder blade and the numbness in my left leg continued but was now just above the left knee. It was Veteran's day so my youngest son was home. I took him with me to Louisville to do some business. We also ran a few errands and headed home. We were about ten minutes out of the town when I felt a rush which was warm but just an intensified buzzing and this tingling numbness moved from above my knee to just below my left breast (T4). My biggest concerns at that point were that I could not move my left leg, I was driving and I had an eleven year old with me. I considered going back to Louisville but then decided that it was only a momentary thing because I must have hurt my back with all the lifting I did over the weekend and it was going to stop. Also, I knew the doctors and hospitals better in Cincinnati. I said nothing to my son and continued. When I arrived home, I used a folding chair as a crutch and walked into the house. I rolled over the back of the couch and lay quietly. As I lay there, I could feel the tingling begin in my right foot and move up my right leg. I was only slightly frightened because I had been reading medical reports for years and I knew that I had simply pinched a nerve in my back. When dinnertime came, I could not walk to the kitchen, so my family helped me into a kitchen chair with wheels and wheeled me to the table. I still felt confident in my self-diagnosis. After dinner I called my family physician and related my symptoms. I told him what I had done over the weekend and that I thought I had injured a disc. His response was, "I don't think so" and he sent me to the hospital. The ER experience sucked. I had an obviously new physician who used the business end of a hypodermic syringe to scrape across my chest to see if I could feel it. By chance one of the better neurologists in town was on call that night. When he saw my chest he said it looked like a cat had slid down me with its claws extended <g>. He did a spinal tap and for some reason I didn't feel it (ha ha). He ordered a mylogram for the next day (that's all they had in the dark ages - 1981) and it revealed no tumors or other problems. I had a very bad experience with the mylogram because my muscles were so spastic. I couldn't lay flat or still because of the lower body spasticity and pain. Because I didn't keep my head motionless, I got one of those infamous

headaches due to the dye. It was the worst headache and pain that I ever had. As if my day weren't going badly enough already, my doctor gave me the diagnosis. Acute Transverse Myelitis. The next day I called my eldest son (14) and had him read the diagnosis, prognosis etc., from the MERCK manual. After hearing this and being able to move my feet ever so slightly, I knew that it was a passing thing. Interestingly, there was a major article in the "Journal of Neurology" on Transverse Myelitis (TM) earlier in 1981 and it discussed the use of steroids in the treatment of TM. Later that day he had them begin ACTH once each day for five days. During these early days, I was able to maintain a positive attitude and went as far as having my students come to the hospital and taught my classes from my hospital bed. DeNile aint just a river in Egypt.

After about a week, my neurologist wanted me to stop using my catheter. There were a few abortive attempts because I was just unable to go and then I asked him if I could have beer figuring I knew I'd have to go if I drank one. He said that he couldn't authorize it but if I were to have one, it would not hurt me. The next day when my students came for class and after a few hints, they brought a surprise in brown bottles and into the refrigerator they went. Three days later I could go. No more lugging the bag around. For my efforts I was rewarded by being sent to the Physical Torturist, I mean Physical Therapist. The first morning I stood. That afternoon I walked a little with parallel bars. Two days later he sent me home. During these days in the hospital I asked myself Why Me? But I never did answer myself and a little Elavil seemed to take care of the depression. In addition to my students, other faculty members, my former wife and one of my sons visited me. One son seemed to avoid visiting and if there was a reason I do not remember clearly what it was. I guess because of the reading I had done, the support I had received from everyone and what my neurologist had told me, I adopted the position of "what you see is what you get". In other words, I had to deal with my limitations but I always considered myself lucky because my disability and physical limitations could have been worse.

Three months later I started back to work on a part-time basis. I never did return to full time work. My body had told me that enough was enough. The stress had been too much. Working for someone who did not like me for 40+ hours per week, starting a private practice in Cincinnati and Lexington and Louisville, Kentucky and working constantly on a house that I could not really afford. I also started driving. I had no idea that you could drive a car without being able to feel the pedals. I wonder how many of us have done or are doing that. During the next 18 months I experienced some minor improvements but nothing of real significance. By my anniversary date in 1983, the medical establishment had acquired a CT scan machine in the City of Cincinnati. Like so many of us with TM, my results revealed no abnormalities. Also, in 1983 I tried additional physical therapy but found that the more active I was the more spastic I was and the more spastic I was the more pain I had. Enough was enough. By 1986 Cincinnati had a MRI. My neurologist showed me my MRI and one of someone who had MS. Even I could see the difference. Mine showed absolutely nothing and the MS patient had very clear white spots (plaque) on the cord and on the brain. For years after that I served as guinea pig for my neurologist's students. Not one student made the correct diagnosis. I have routinely asked general practitioners to make the diagnosis and they also failed. In 1996 I spent nearly three months in the hospital and it was a constant task to educate the nurses and physicians on transverse myelitis. The realization that TM is extremely rare, 1:1.2 million was really driven home.

As of today, I have had no exacerbation's. I still have marginal control of my bowels and bladder and I have a fair amount of spasticity. My most significant problem is a central pain syndrome at T4, the point of my compression/lesion. I have a band and the pain is constant. I take a lot of pain medication and have tried acupuncture, massage and magnets and none of them provided me with much relief. I do know others who got relief from all three. Until two years ago, I was walking with that awkward gate that TMers know all about. You know, the one where we have to look down at our feet to know where they are at and our locked knees so our legs won't fold. My neurologist said that the main reasons I did walk was because I wanted to. I encourage all of you who even think they can to try. Lock those knees and go at it one step at a time.

For reasons other than TM, I lost both legs, one above and one below the knee in 1996. The medical procedures required twelve separate surgeries. They utilized a local anesthesia that allowed me to sleep through the operations with no complications. So like many of you with lupus, epilepsy and other ailments, I have the pleasure (yaga) of a secondary problem. But guess what?? People now recognize that I have a disability because they can see me in a wheelchair and my legs are missing. We don't need the reminder, but others do that just because one can't **SEE** the disability, it does not mean that a person is a malingerer.

I had better stop now or it will begin to start sounding like I'm having a pity party for myself. I can say that my experience has made me a stronger person. For the newbies, in particular, I would say, remember to rely on the strengths that have gotten you this far. Keep your faith in yourself, those around you and whatever higher being is yours. Keep a positive attitude and reach out to those around you and don't be proud -- everyone needs help, it is just a question of how much and what kind. Also, don't forget to do mind and body exercises. If you don't use it, you will loose it and I do mean ALL body parts both above and below the neck.

I have been with the group (tmic-list) on line since early 1997 and cherish the support and input from the group. I tried to keep a discussion group on TM going in the early 1990's on Prodigy but just couldn't keep people involved nor did I have the skills of our Jim Lubin. I wonder how many of them are now on the tmic-list or in TMA and we just don't know it? I have had my picture posted on the tmic home page and really wish more people would do it even if they are not part of the on line chatting. I'd be happy to scan any pictures for those who do not have the equipment to do it. My wheelchair and I will be in Seattle next August and I look forward to meeting you all.
Roger Livingston (Doc)
doc09@fuse.net
Transverse Myelitis is a rare disorder that strikes approximately one out of 1.3 million people. I am one of these people. This is my story.

I was born into the Wroblewski family in 1952 in Buffalo, New York. As the second daughter, and one of five children, I strove to be 'different' and unique among the voices of my noisy company. With a flare for the dramatic and musical talent, I enjoyed being the center of attention

Maureen Wroblewski
Rochester, New York

as often as I could grab it. I was gifted physically, and there wasn't much I couldn't do in this area. My friend Linda and I were the only girls in sixth grade who could climb the rope to the ceiling of the gymnasium :) I felt proud and confident because whatever I wanted my body to do, it could do. Then one morning, without warning, I was paralyzed from my waist down. This is how it happened. I was in high school and first period was the dreaded swim class. That morning I felt an unusual weariness and even stopped in the hall to lean against the lockers on my way to homeroom. Most of the time, people had a hard time keeping up with my long stride. I remember this detail only because it had bothered me enough that I wrote a note to my best pal, Jeanne, and I still have it in a shoebox somewhere. In the middle of pool time, I asked the teacher if I could sit out and she OK'd it. Then while trying to get dressed, I found I suddenly could not pick up my foot to put it in my shoe. My back hurt a lot and I started to cry. All I wanted was my Mother! They tried to put me in a wheelchair, but decided a stretcher was needed so the teacher just held and rocked me back and forth while they charged off for it. Then we rolled through the on-going gym classes to the nurse's office where the woman tried to calm me saying, muscles play funny tricks on us sometimes. I guess they called my Mom, and she came with the family station wagon and they rolled me in there. My sister came too. It was a strange ride, lying down in the back of the car, hair wet from the pool and my Mom and sister oddly silent. I learned I had caused quite a flurry of rumors in my high school class of 400.

When we arrived at Mom's hospital (she was a RN and worked at Park Ave. Hospital as Mrs. W), the Dr. examined me and struck my knees with his rubber hammer and they just sat there. I was admitted and sent to room 222. Hours later, Mom came to work at 3 PM. and I still hadn't seen a Doctor. They were waiting for the neurologist and couldn't even give me an aspirin until he arrived. I had a raging headache because I hadn't eaten since early morning and I hadn't urinated all day. I could just wiggle my big toe on my left foot. That was it. Evening fell and the flamboyant Dr. Fred Geib arrived and after an examination that included pins, he decided I needed a spinal tap. Mom couldn't watch. She left the room. X-rays revealed nothing. Probable diagnosis? Gullian-Barre Syndrome. Prognosis? Unknown. They didn't have MRI's (magnetic resonance imaging) available at the time and when technology eventually made this possible, my lesion on the spinal column at T-10 was no longer visible. I heard them say the spinal fluid showed an elevated white cell count, but no one ever stopped in to discuss any test results with me. I was only 15. Just a kid. That night I was moved into the intensive care unit in case the paralysis traveled up and affected my breathing. I was catheterized and had an IV put in for fluids, I think. I heard my Dad had come by to see me but I was sleeping and he didn't want to wake me. ICU is a strange place to be at night. Weird sounds. Once, when I was obviously distressed, a nurse asked me, "What's the matter, honey? Are you afraid you're never going to walk again?" What? What did she mean? The possibility had never even entered my mind! Mom told me they just put me in there because I was 'her daughter'.

So began my stay of three months...entered the day before Thanksgiving 1967 and didn't leave til the end of February. I hated hospital food and would often cross out the day's menu and ask for a ham sandwich. If I close my eyes, I can still remember the smell of the place when those trays would come along. I can't eat ham now. The walls of my room were covered with cards from relatives and friends. When I was released from ICU, I got to share a room with an elderly lady who had skin ulcers. I guess I was the only 'youngster' on the floor and so when I could sit up (whoa....stop the spinning world!) in a wheel chair, they would let me roll around to deliver the mail to all the other rooms. Once, my girlfriends came near Christmas and we sang carols around the wing just for the sheer joy of hearing our voices blend together once again. We had spent many an overnight singing Beatles songs till 4 AM and missed that shared experience. Then they left, and it was quiet again. Incredibly, I did not receive any treatment or medications while in the hospital. No physical therapy, no steroids, no vitamins. Too late, the damage was already done. There was no surgery to 'fix it'. I did come down with the flu TWICE during my stay.

Christmas was the hardest time. Mom bought me a purple velvet skirt and it fell off of me. Clothes felt uncomfortable and awkward. My brothers and sisters didn't know what to say or do there. I didn't either. I missed my little brother, who was very close to me. I think he couldn't come in because of his age. Later I learned he had broken down one night and cried for me to come home. Home. When I was finally scheduled to come home there were still no preparations made for 're-entry' into the world out there.

The ride in the car put butterflies in my stomach. It was snowy and I asked Dad to please slow down, I felt dizzy. When I got inside the house, I crawled around to refresh my memory of the place. I could only stand up if someone held on to me, and Dad was my main 'dancin partner.' Frighteningly, I nearly blacked out trying to pee on my own. (It's amazing to me now that no one ever addressed this issue or any other embarrassing, yet critical, concerns I had.) We borrowed a bedpan from one of our neighbors. There was no offer of counseling or any support groups. There was no support. We just made do.

I had tutors at home to help me catch up with school. I'm not sure when exactly I returned to school, but I was on crutches by then and yet I used the wheelchair to get around my expansive high school. Somewhere in the middle of all this, I had a physical therapist come to the house to assign me exercises. I hated these. I still don't like to do anything I can't do well. Someone had to help me or I just flopped around. I wasn't convinced they would do any good. I couldn't see any improvement. Discipline was not my strong point. I do remember the day I took more than three steps on my own. One, two, three and I'd usually lose my balance and tumble. This time I caught myself before the tumble and without holding on to anything, I walked clear across the kitchen, where Mom was holding her breath with her back to me. "Ta-dah!" Every time we would visit the neurologist, Mom would say, We want to know when is she going to run? He would smile indulgently and say, be glad she can walk. Running was not in my future.

So, little by little, improvements came. I was walking without aids, but it wasn't pretty. And so far as I knew, I was alone in the universe with this affliction. A little more stamina, a little more balance, a little more courage. Lots of falls. I was exhausted so easily. My body wasn't my own. I couldn't make it do what I wanted. It was out of my control. Like a child again, but no one expects a child to have these abilities. It's OK for a child. I wanted to tell everyone I met, " This is not the real me! This is not how I'm supposed to be!" I felt ashamed somehow. I was no longer graceful. People stared. Children pointed. I wet myself. Worse. I began to hide.

Years passed and I saw the Dr. less and less. There was nothing he could do. It was an isolated and lonely season. Still, I tried out for the school musical and got the lead role in Carnival. I was Lily and I had to set my crutches aside. I fell in love. There was a lot he never knew. I was good at pretending. I developed a habit of committing to social events with an initial enthusiasm and then canceling out at the last minute when fears or reality would stop me. My friends took me to a Young Life meeting and I met a real live Jesus I never knew growing up as a Catholic girl. And I loved to hear the stories of Jesus healing the blind, and the broken and the lame. I read the Old and New Testaments with a hunger for answers. I had a lot of questions for God. So I began my search for meaning in things unseen. Some of my sorrow lifted.

I graduated and went off to college at the University of Buffalo and then to grad school in Library Science. Walking across campus was difficult in Buffalo winters and I usually walked alone as it took me twice as long to get anywhere. I developed all sorts of coping mechanisms, some healthy, some not. I lost my Mom, my surest advocate. Then I began my career in the world of children's

library service. Surely, I discovered, I was born to be a storyteller :) in a long line of storytellers. And, finally, I began, on my own, to search for answers and possible help. This brought me to a neurologist who had other cases similar to mine. He corrected my diagnosis to Transverse Myelitis. He could tell me what had probably happened to me. No one else ever had. He got me into a study that allowed me to have a MRI. The pictures this produced showed only a textbook perfect image of brain and spinal cord. It had been too long. He explained that TM was a de-myelinating disease where quite probably a virus triggers a dramatic response from the body's immunolgical system. The body then actually fights against and mistakenly damages itself in an area of the spinal cord. The light of knowledge was beginning to shine. I had had a severe flu-like illness shortly before my episode and the Dr. thought it might have been mononucleosis, although the test had been negative. The myelin sheath surrounding the spinal cord enables the body to receive and send messages along the nerves from the brain and back to the muscles. Once damaged, scaring results leaving a lesion that is sometimes visible with a MRI. All body functions are affected from that point on the spinal cord on down. Nowadays, people are treated immediately with steroids to reduce inflammation. Sometimes during our visits my neurologist would tell me about another person he admitted with a diagnosis of TM. I was hungry for details but little could be shared. He also helped by sending me to a Dr. who eventually taught me to manage my bladder through self-catheterization. That was one liberating step for me. He also encouraged me to try physical therapy once again, and that resulted in the use of an orthotic brace and a cane that has made a world of difference in my gait and endurance. Why this idea had never occurred to us before is a wonder to me. I had just gone from crutches to nothing and I suppose they thought if I wasn't complaining, everything was OK. Well, it was OK, but it wasn't good. And now it was getting better.

My story takes a dramatic turn when I purchase a computer and acquire Internet access. One day, it dawned on me that I could do a search on this critical issue in my life, *Transverse Myelitis*. I typed it in. I waited. The hair on my head literally stood on end when the screen filled with a message that would change my life. There were others. And they wanted to talk with me! As I read their individual stories, the tears would stream down my face. "Dad, Dad" I would call. "You've got to read this! It sounds just like me!" They understood my fears about the future. They hungered for the facts of just what had happened to them and were willing to work to get the answers. We could all get our voices together and be heard! There were hundreds of us. Some were in wheelchairs, some even on respirators. I began to realize how blessed I really was. They had married, and even had children. They had endured the darkness of the unknown as I had. The mother of one child diagnosed with TM started The Transverse Myelitis Association. Her name is Deanne, she lives in Seattle and she is my friend. When the opportunity came to meet her and a few people from this group in Columbus Ohio, I knew I had to go. There was no question. Whatever the cost, I knew I had been waiting all my life for this answer to prayer. I flew to Ohio and got myself to the convention center. I was lost. This place was huge and I carried a heavy backpack. At long last I walked into the room where a circle of people were introducing themselves. I sat down next to a lady in a wheelchair and everyone looked at me. Hello, I said, my name is Maureen and I've come from Rochester, New York. I was paralyzed from the waist down at the age of 15 by Transverse Myelitis and I have never met another person on this planet with TM. Sandy Siegel walked across the circle and put his arms around me and I fought not to cry in front of everyone.

On the morning of 3rd May 1990, I was busy working at home. I had a business designing and making bridal wear. I went to take a break and get changed to take my daughter to the doctor's, and as I raised my arms to change my sweater, I got the most awful searing pain in my groin area. I could not sit down and even standing was almost unbearable. I have a recollection of having slight lower backache earlier in the day. Also, about a week earlier, I had backache, but put this down to gardening.

A neighbor helped me to get to my doctor who was unable to examine me as I was in so much pain. She thought that I had slipped a disc. She gave me a morphine injection in the thigh and told me to go home and lay on a hard surface and that she would come and examine me after her surgery time. I did this. I lay down on the floor, and after a short time, felt that my feet were very cold. I asked my daughter to bring me a cover. Then I fell asleep for approximately one hour from the injection and when I awoke, I found that I could not move at all. So when the doctor did arrive, she was flabbergasted, and could not understand what had happened. I found out later that she had never come across TM before.

My Encounter with Transverse Myelitis
Ann Moran
Ireland September, 1998

I was taken by ambulance to our local hospital. The hospital was eleven miles away. This was at 6 PM in the evening. They also did not know what was wrong and I was very cross that I had been left in the casualty department for six hours and did not see a consultant, only a trainee doctor. Well, eventually they decided I had to be transferred to another hospital, which would have better equipment to do tests. So, at 12:30 AM I was transported by ambulance to Galway and a hospital, which is approximately fifty miles from my home.

Here I was given a mylogram, and they sighted some small clots of blood on the lower back area from waist upwards. So they operated straight away to remove them, but found that this was not the cause of my paralysis. They were only on the surface. There had not been any pressure on my spinal cord from the clots. I never heard the word "paralysis" used once until the next stage of my journey with TM.

The next stage of my journey, DAY 2, I was taken by helicopter to Dublin, almost 200 miles away from my home. On being admitted, this is where I first heard the word "paralysis" mentioned, and it scared me to death. I just could not believe it. I thought what was wrong was something like pins and needles and would go away after a while. I had never heard of anything like TM before.

Little did I know what a long journey I had to face and all of the difficulties I would encounter. I had several tests done in Dublin, which included MRI and CAT scan, and a brain scan, lumbar puncture – which I will never forget until the day I die! Unfortunately for me, I had a trainee doctor doing the lumbar puncture. Several blood tests were also done. MS was mentioned, but ruled out. Nothing could be found in the way of cancer. So, the final diagnosis was TM.

I was put on steroids as from day 3 in the Dublin hospital. I think that I continued to take these for three months. I have requested my records but have not received them yet to check on this. I also started Physiotherapy and was put on a tilt table each day starting for five minutes and building up to 20-30 minutes. I had completely lost my balance and could not sit myself up in bed or turn over. I had to be turned every two hours, day and night. After two months, I was transferred to the rehabilitation hospital also in Dublin. Here I had to stay for six months and learn to live without my legs. I had no movement at all in my lower region. It was very frustrating. Then one Saturday evening, after being put to bed, (we had no choice, we were put into bed after teatime and that was that) -- I always tried to move my feet or legs, which only happened in my brain. But one Saturday, I managed to move my big toe, very slightly. This caused great excitement on the ward, and I had everyone, including the nurses, coming to look at "my toe."

Each day we did Occupational Therapy in the morning and Physiotherapy in the afternoon. Learning to transfer from my wheelchair onto a bench, and as I had lost my balance, I was terrified of making this move. Many times I cried at these therapy classes from fear and from the loss of the use of my legs. It was a long ordeal, but gradually I did get stronger and learned to transfer. But even up until the day I returned home, I could not do this by myself. I had to have help. I can't say that I had any severe pain in my legs. It was more like a severe burning sensation. At first I could not bare to brush crumbs off my lap. This hypersensitivity is still there. I find that I am "switched off" to it most of the time, but it has eased a great deal. I only have these feelings around my feet and ankle area now.

Toileting was a huge burden for me. I had had a catheter fitted the evening of the first day while in the hospital in Castlebar, and when I started to get sensation back, which was about three months after the onset, I could not bare the catheter and had to have it removed. From there I had to learn to use the intermittent self-catheterization, which I did for several months. Eventually, I was able to use the toilet normally. By the time I was going home, in December 1990, I was fine, but had to make sure that I visited the toilet about every two hours, or regulate it as to what drinks I had. Up until today, my bladder problem is the worst part of my TM. For me, everything else I can cope with and, of course, the more sensation and normal feelings I am getting back, the more problems with my bladder. They tell me that my bladder shrunk with the paralysis and so the capacity is not so great. There's talk of doing surgery for a by pass, but I am not really keen to have this done, so I am battling on and coping with it. I never had any real trouble with my bowels, except in the first two or three months. Then they returned to normal.

The position I am in today is that I am making progress even though it is very slow. I have normal feelings from my waist to my knees, and sensitive to touch from my knees to my toes. I do some standing every day and I am able to walk a few steps with a rollator walking frame. I do make an effort to do these things every day to try to strengthen my legs.

It is my knees that give me trouble. It's as if they have not "thawed out" yet. After standing a while, my knees collapse. I rely on my wheelchair to get around the house and to go shopping, etc. In addition to all of this, I have had to face having a partial mastectomy for breast cancer in December 1996. Thankfully, to date, I seem to be keeping well.

I note from other people's letters that they use leg braces. I must enquire about these to see if they would help me. I did purchase some "legs" called a "walk about." I heard about it on a program called Beyond 2000. It was a man in Australia that invented it. But because my legs and feet, in particular, are still very hypersensitive, I have been unable to use these "legs" as when I try them on, they cause my feet and ankles to go into spasms. I am working along with a personal assistant that does my physio and we are using massage and aromatherapy on my feet and legs and I find that this is helping. My legs are not so sensitive at the moment.

Through all of the years I have been unable to walk, I have kept busy being involved in several things. I found that this has helped me "stay sane." I learned to drive using hand controls. This was a big stepping stone as it means that I am not confined to the house, and as I live in a rural area, it is essential that I am able to get out and about independently.

I have been Chairperson of our local branch of Irish Wheelchair Association. And I am currently Secretary. I am also involved in a group called The Centre for Independent Living which was started up with the help of a lady from Berkeley, California, in Dublin back in 1991 and 1992 and came to the West of Ireland in 1995. My job was Leader Coordinator, which meant visiting all the people with disabilities in the Mayo region who were involved with CIL. This does not mean that all the people with disabilities in Mayo were able to have the PA service. CIL helps people to find Personal Assistants for the disabled and gives guidance on how to work with a PA and also on living independently. But because CIL relies on the government community employment schemes to fund the PA's, there are certain criteria, one of which I came under this year. I had been on the scheme for three years and so had to take a six-month break. My time is almost up now, only to find that the numbers that are allowed on the scheme are covered. So, I may have to wait until next year to get back on the scheme. In the meantime, we will continue to lobby government for permanent funding for the Personal Assistant service.

Maybe the fact that I will not be working with CIL is a good thing. I could concentrate on TMA, and try setting up a support group with your guidance here in Ireland. I have not done anything like this before, but would be very interested in doing so. I know how I have felt all these years. Feeling so isolated, not knowing anyone else with the same problem. I did meet three other people when I was in the rehabilitation centre that were diagnosed with TM. I will try to get in touch with them through the disability magazines here and maybe if I write to the rehabilitation hospital, they would pass my name on to patients past and present.

I will look forward to hearing from you.

Regards, Very sincerely,
Ann Moran
Derrygorman Westport
Co. Mayo Ireland
098-26469

Doris Ballou
Melbourne Beach, FL
November 6, 1998

My bout with Transverse Myelitis began on May 5th, 1998 as I was flying home from Rome, Italy. My roommate on the trip through Italy had caught a bad cold about three days before we left Italy. Soon after we were airborne on our way from Italy to Florida, where we live, I began to feel ill.

I thought I was catching my room-mate's cold so I tried to relax and drink plenty of fluids. Before long, my chest felt like someone was squeezing it and my head was splitting with pain. I took two Tylenol tablets, but they made me nauseated. I asked the steward for ice for my head. I never have a headache, so I thought the cold germs hit me full force. The steward took one look at me and said, "you need a doctor. Can you believe there are 54 doctors on this flight going to a convention?" I told him not to bother the doctors, that I would be all right. In no time, four doctors were around me questioning me about my aches and pains. They asked the steward to clear a middle aisle row of seats so I could lie down. When I was stretched out, the stewardess brought a tank of oxygen and the doctors checked my vital signs. They evidently thought I was having a heart attack, because one of the doctors would check my blood pressure every few minutes. One of them had the airline captain order an ambulance to meet our plane in Philadelphia. I was transferred to the hospital there, given antibiotics, many tests and kept for four days until my fever broke and I was able to head for home.

When I landed in Orlando, Florida, I

tried to stand to walk to the door of the plane where a wheelchair was waiting, but my legs were completely numb. I told the stewardess my legs were asleep and I couldn't move them. She helped me to the door and to the wheelchair.

My son met me and drove me to my home in Melbourne Beach. I saw my pulmonary specialist the next day to check on what was diagnosed in Philadelphia as bronchitis. I was wheeled into his office in a wheelchair. When I told him my legs were numb, he checked the circulation and thought my leg pains were from the trauma of my illness. He gave me more antibiotics and sent me home.

After another day of misery, not being able to even stand on my legs, I called the doctor, went back to his office, and he put me in the hospital to undergo tests from the vascular specialist, the cardiologist and the neurologist. The second neurologist who saw me diagnosed my problem as Transverse Myelitis, after he ordered a MRI and a spinal tap. I was given prednisone by IV and kept in the hospital for a week, then sent to a rehabilitation hospital.

A physiatrist directed my care at the rehabilitation hospital. I continued the prednisone orally until I was weaned off of it. I had four hours of therapy for my legs each day for ten days. I was able to go home and have visiting nurse and physical therapist care three days each week for six weeks.

I now exercise on my own and see the neurologist and physiatrist from time to time. I am taking neurontin twice a day. I go to an aquarobics class two or three times a week. I was doing this before I contracted Transverse Myelitis.

My progress the first two months was outstanding. I went from totally immobile legs, to getting around in a wheelchair, to a walker, then to a cane. The last four months I can not see any progress, although the doctor says that the damaged nerves in my legs are healing. He says that I may take eighteen months to recover but encourages me with the hopes that my legs will be fine again.

I had MRI's two days this week. The doctor says that they show my condition is stable. The lesion that has been affected in my spinal cord is T10 and it has not changed.

I continue to work toward the goal of overcoming this Transverse Myelitis or developing the strength to live with it and keep doing the pursuits that I enjoy – serving the Lord through his Church in teaching and serving others. I am a retired Director of Christian Education, a teacher and a short-term missionary. I enjoy gardening, painting and other hobbies. I am a widow and I enjoy my family, four sons and their families, including six grandchildren. Many faithful friends are a blessing, too.

I am grateful to find the Transverse Myelitis Association on the Internet and thankful for Deanne Gilmur, Sandy Siegel and all of the officers. I appreciate communication with other TM patients and the encouragement from case histories in the periodical.
I was inflicted with TM at T-12 in June 1991 at age 59. I was admitted to an ER as a paraplegic and remained so for about six weeks while being medicated and treated through physical therapy (PT). After eight weeks I was discharged from the rehab center as a wheelchair outpatient with minimal ambulatory skills. I remained an outpatient for two years while undergoing PT at home and at the center. My ambulatory skills were reacquired through the following stages: physical therapy on the mat, acquiring transfer

Anonymous
Arizona

skills from bed to wheelchair, halting steps on the parallel bars, practice with a walker, graduation to walking with two canes, then one cane, and then no canes. I still utilize a cane for safety purposes, and to assist me over curbs and up flights of stairs.

Initially, the whole process was painless, but pain increased gradually as I reacquired mobility. In short, now if I were to walk ten miles per week, you would need to administer morphine about once an hour to relieve the pain. My pain (leg and groin pain) is minimal if I walk exactly one-half of a mile per week in three separate days, and I do not overdo sitting and standing.

It is my experience that acute TM is a very manageable disorder if one experimentally develops a strict regimen tailored to one's own case. I think it is a good idea to keep a detailed diary as to PT, medication, pain levels and character, and general notes. Presently, my own regimen is as follows:

1. Exercise Monday, Wednesday, and Friday including stretching, walking (on grass or on a treadmill) 1.5 miles per week, and lifting weights on a fitness machine which covers all major muscle groups.
2. Hot tub therapy every evening for my legs.
3. Daily medication including Darvocet and Baclofen for pain, and aspirin for blood thinner.
4. Vitamins C and E.
5. Lots of sleep including about seven hours per night and a two-hour siesta.

I have found that my most therapeutic

position while resting is lying on my left side in a prenatal position, and on a firm mattress, I might add.
6. I work with my computer lying on my back on a bed.
7. My diet consists of fruits, cereals, some soups, and mainly fish and chicken with rice every evening. I utilize prune juice and light doses of Correctol to maintain regularity.
8. I do not use caffeine or alcohol, or much sugar.
9. My only vice is puffing on a good cigar or two every day.

I cannot travel by air very conveniently, because I have a continence problem. Accordingly, I travel by car and never stray too far from a restroom. I also carry a urine bottle, which I rarely need to use. For safety, I carry a cell phone in the car because I sometimes travel in remote areas or in large, unfamiliar cities. In accord with my exercise and diet program, my bowel movements are very regular but require digital stimulation for initiation. I still lack some sensitivity in that area. My social life is near normal. However, I cannot sit and talk for more than about an hour because of excessive pain accrual.

My occupational therapy consists primarily of working with the computer, including professional writing and personal financial management. After coming to terms with TM on the basis of a strict regimen, which had to be developed experimentally with the help of my doctors, my life in retirement might be called "normal".

However, in 1996 I was diagnosed with having incipient Parkinson's Disease (PD), another neurological ailment. I am currently being medicated for PD with Permax and Carbodopa that seem to be working to offset the advancement of shaking of my right arm. I have been told that my longevity should be normal and that the PD will not be fatal. There are a number of drugs being developed for PD, and I expect the disease will be mitigated in my case. Unfortunately, PD is often accompanied with growing depression. I am now experimenting with low doses of Prozac to offset this effect.

I hope that this information will be of use for the TMA and its members. You all need to be convinced that there are intelligent means to handle TM. I know it requires a comprehensive approach and a regimen tailored to each case.

Very truly yours,
"Anonymous in Arizona"

While reading the newsletter, I noticed that my situation differed from almost all of the others. I would like to share with you my story.

I have had Crohn's Disease for many years. I also have several other autoimmune diseases, Rheumatoid Arthritis, Iritis and Meniere's disease. I cannot accurately pinpoint the onset of my TM, because at the time, some of the symptoms were attributed to my other problems. In late '94 and early '95 I had a very

Hinda Lee Sheffer
Los Angeles, CA

severe flare up of my arthritis. When I had trouble walking in mid '95, I thought it was the after-effects of the flare up or even the beginning of another flare up. Later in the year, I had severe pain in my spine in a previously injured area for which I had a cortisone shot. In July my Mother was in the hospital for major surgery and my legs felt very heavy, but I attributed that to the many miles of hospital corridors I was covering.

At the beginning of August, I had difficulty urinating and consulted a urologist. The results were negative and no cause was found. When I asked him what to do he said, "wait and see." In hindsight, I can see that was the time I should have had a MRI and possibly detected the TM at that time.

As my walking became progressively worse, my neurologist sent me for the first set of MRI's. They did studies of the thoracic, lumbar, and brain. I was put on a decreasing course of Decadron and then no further medication.

I feel that the onset and subsequent diagnoses was clouded by my pre-existing conditions. It was so easy to think that the problems were related to the rheumatoid arthritis. In July I fell off of my neighbor's porch, but we all thought that it was due to a crack in the step. The signs for TM were there. They were just misinterpreted.

In November of 1995 I went to see a consultant about my TM. He felt that in six months to a year I should regain 90-100% function. That did not happen.

In June 1998 I heard a lecture about electrical stimulation. My neurologist told me that a similar treatment was used in our area and proved to be ineffective. At the same time, a Resident in rheumatology asked if I'd heard of the Gamma Globulin Infusion Treatment.

On October 15, 1998 I went for a consultation at the Rancho Los Amigos Medical Center in Downey, California. I was told that the Gamma Globulin is only used in the first three months of TM. It is not approved in the United States for myelitis. There is a worldwide shortage of the medication.

The bowel and bladder dysfunctions are the most devastating aspects of this disease to me. If anyone has similar problems and has found a way to reverse the situation, I would like to hear from them.

Thank you for allowing me the opportunity to share my story and my feelings. After three years it is a big relief to know that others are in the same position that I'm in. I thought I was all alone.

Hinda Lee Sheffer

John Bryant
United Kingdom

My name is John Bryant and I am a 48-year-old man married to a wonderful girl whose name is Pat. We have a delightful 4-year-old daughter, Charlotte. Firstly, may I thank you for all the information you have sent me. It is comforting to know that one is not alone in suffering with Transverse Myelitis. I used to think that I was a "medical enigma" as no one could explain to me its cause or my prognosis. But having now established contact with the TMA, I've found that there are other people "out there" who have similar conditions and experiences as mine.

Around the end of January 1996, I started experiencing dizziness and difficulty in coming downstairs. I was having to look for every step. I found that I was walking unsteadily. My GP prescribed medication for vertigo and made a further appointment. In between time, I started losing feeling in my torso and legs. I couldn't tell when I was going to the toilet and I started experiencing partial impotency.

On February 20 I was admitted into the hospital where I underwent three lumbar punctures (spinal taps), CAT scan, three MRI's, blood tests and various evoked potential tests. My neurological consultant then put me on a five-day course of steroids (methyl prednisone) but this did not help. The only thing it did was bring on Diabetes! The spinal fluid indicated an abnormal cell and my condition was classed as Non-Compressive Myelopathy. I was sent home still walking but somewhat unsteadily and with a walking frame. The numbness had reached my navel, but two weeks later it had progressed to chest level! I was re-admitted for a second course of steroids and a week later a third course. All to no effect! I still had had no specific diagnosis and no indication of whether this condition would continue, worsen or improve! All I was given was non-committal answers, such as "we fully expect this or that to happen, to get your feeling back or to walk again." All negative, gray responses. They had ruled out spinal tumors, blood clots, spinal stroke and Multiple Sclerosis. This was the time I felt as though I was a "medical enigma."

More evoked potentials, blood tests and possibly another MRI. Vitamin B12 and Folic acid were checked. Finally, TM was mentioned and it was explained that an unknown virus had attacked my spinal cord and stripped the myelin sheath from the nerves. Nobody that I spoke to had even heard of it. It seemed to be similar to MS, only it affected me a lot quicker.

I spent six months (wasted time, in my opinion) in rehabilitation having Physiotherapy having been told that intensive physio may "kick start" my recovery. Some hope! By this time I was seeing a clinical psychologist and on Prozac to help me accept the trauma of this debilitating condition. I was sent home to begin my new life with my condition. We had a ramp fitted, a lift installed for access upstairs, the bathroom altered so I could use the shower and toilet. I purchased a lightweight wheelchair and I've recently started driving again using hand controls. So, things are looking up. My condition has not improved any. I am now wheelchair dependant, a paraplegic, numb from the chest down (level T5). My hands are now totally numb affecting my sense of touch. This condition affects the sphincter that controls bladder and bowel movements and, obviously, needs careful management and can be embarrassing, as my daughter sometimes perceives of me as a baby. I still get depressed when I consider my life now to what it was before TM. But with a brilliant and supportive wife and strong family ties, this is helping me from dwelling too much on the negative. But it's not easy and not over by a long way, but I'll get "there."

Thank you for patiently reading this elongated report and allowing me to tell you of my experience with TM. I have found it most beneficial putting it all down on paper. God Bless those that empathize with me.

John Bryant
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What lies behind us and
what lies before us
are tiny little matters compared to
what lies within us.
-Oliver Wendell Holmes

For years, I actually had no idea what I *really* had until I looked up Transverse Myelitis on the web. I'm probably one of the longer survivors of Transverse Myelitis and want to share my life experiences with all of you hoping that my story will help cast a light of hope on many and inspire others at the same time.

Anonymous
Toronto, Ontario
Canada

I am a 24-year-old woman who on December 27, 1986 was diagnosed as having Transverse Myelitis. I was a healthy and active 12-year-old girl at the time. On Christmas Day of 1986, I had gone to church with my family and I remember that the church was so crowded that there were not enough seats for everyone and so I remained standing throughout the one-hour mass. I remember complaining to my parents of lower back pain and sore legs throughout the mass, but did not think much of it at the time. After all, it is quite normal to complain of sore legs after standing for about an hour. When I got home on Christmas Day, I felt fine. It was not until the 27th of December that things changed. On the 27th, I woke up fine and went to the washroom. Before I entered the washroom, I got this *excruciating sharp* pain in my back. The pain was so strong (as if someone had just stabbed a knife through my spine) that the minute I felt it, I leaned with one hand against the wall, because I thought I was going to fall. The sharp pain lasted only seconds and I felt completely fine afterwards. I did my morning care and then went to the living room to watch some television. When I sat down on the sofa my legs began to hurt. I remember the pain in my legs was strong, but this pain was different from the sharp pain I had experienced a couple of minutes before in my spine. This pain was not sharp, but it was more like a *sore* type of pain. I was scared and confused.

I did not know what was happening so I got up to go tell my mother who was downstairs in the laundry room. As I walked through the house, my legs were sore and they also felt very weak and numb. I thought I was going to fall. I managed to get to the basement by holding onto the walls. When I reached the bottom of the steps, I took about three steps and then my legs completely gave out on me and I fell. My mother thought I had bumped into a table and she came to help me up, but I then realized that I could not stand up. The slippers I had on had fallen off and I now could not put them back on because, at that instant, I could only feel my legs and feet but was not able to move them. Seconds later, I began to get a tingly sensation (similar to what one feels when their foot is sleepy) that started at the tips of my toes and was rising up my legs. As this tingly sensation was rising up my legs, I was losing movement and sensation. The tingly sensation reached below my chest and there it stopped. When the ambulance came, I was still fully conscious of everything and I no longer experienced any other pain.
At the hospital, my parents were first told that I had some type of a rare virus that is more common in males. However, when I was admitted at the Hospital for Sick Children, the diagnosis changed. Here they first performed some type of X-ray on my spine (I do not remember its name) where they injected some kind of *dye* in my spine in order to see it. I then had a CAT Scan which was followed by a Magnetic Resonance Scan a couple of days later. Meanwhile, in the hospital, I was given steroids for about two weeks. The steroids had no affect on my situation. After undergoing various tests, (some that I do not even remember) the doctors diagnosed me with *Transverse Myelitis.* At the time I had no idea what Transverse Myelitis was. The truth is that I do not think the doctors really knew what it was either. None of the medical staff ever really explained the diagnosis. All I was told was that I had suffered some type of inflammation in my spine and that I was never going to walk again. The shock at the time was unimaginable. It was a devastating experience, but today I know that I survived.
I underwent more tests in the hospital. A week after my diagnosis, I underwent *plasmapherisis* for six days. This type of test was, of course, not fully explained to my family either. We were told that perhaps I had some *white blood cells around my spine that were causing this paralysis.* The plasmapherisis did not worsen or better my situation. Before I left the hospital, I had regained my sensation up to my waist. I still could not move my legs or feel them. After a month of being in the hospital, I was transferred to a rehabilitation center where I remained for about seven months. Here I began occupational and physiotherapy. I began to slowly improve. Eventually, I regained some movement and sensation up to my knees but it varies. Today, I still use a wheelchair 100% of the time.

I finished university and graduated last year with a Bachelor of Commerce. I now work full time as an investment accountant. My life is pretty much like any other person's. I see my situation not as a disability but as a *challenge.* Surviving Transverse Myelitis has been a learning experience. It has not only made me a better person, but I have learned to never take things for granted and to make the best of everything. I will admit that the road to recovery was not easy. However, today I know that **anything is possible with a positive attitude.** I can still do almost everything but in a different way. Nothing is impossible, everything is possible and life is what you make of it. **Dreams can still come true** after TM.

Sincerely,

I was stricken by TM on December 12, 1995. I was 35 years old. Prior to

this date, I had been on total bed rest for high blood pressure. I was 8 months pregnant when I was bedridden. I don't remember having flu-like symptoms, but by this time in pregnancy, tiredness and weakness seemed normal. I was only allowed out of bed to use the bathroom. The time period for bed rest was Halloween until the morning of December 11, 1995.

Monday December 11, 1995
This is how December 11, 1995 went. It was the day I had my first baby by way of C-section. I went into the hospital for induction of labor. I was going to have my baby (natural childbirth). They induced me at 9:00

MY TM STORY
Leslie Hoffmire
Bowie, MD

AM and I was in labor until 6:00 PM. At that time I asked for an epidural. This was placed in my lumbar 4 and I pushed for another 3 hours. At that time the baby was stuck. So, the doctor decided on a C-section so we wouldn't hurt the baby. Up until surgery I was controlling my legs. I remember feeling the incision. It was like a tingling sensation. I also remember hearing the baby cry. After that I was knocked out. I came out of anesthesia and was taken to recovery, and then taken to my room. That was about 11:30 PM. At that time the doctor asked me how I was? Tired and weakened. I had become anemic from pushing and surgery. I had a bladder catheter and an IV already attached to me because of surgery. I think I couldn't move my legs at that time. I think they told me it was still the epidural and by morning it would be worn off.

Tuesday December 12,1995
The next morning I still could not move my legs. My left leg was worse than the right leg. I could hardly flex my ankles or point my toes. I couldn't lift my legs off the bed without using my hands. I was paralyzed from the hips down to my toes. My doctor came in and did some little tests. He scraped the bottom of my feet to see if I had reaction - none. He took a pin and poked my feet to see if I had reaction - none. Needless to say, the doctors checked and rechecked their notes to make sure they didn't screw-up. It was a routine C-section. At that time they called in a neurologist. Just by hearing the symptoms, he had two diagnoses: 1) viral infection of the spine or 2) Guillian-Barre syndrome.

Guillian-Barre syndrome (Mosby Medical Encyclopedia definition) - a disorder with inflammation of many nerves. It begins between 1 and 3 weeks after a mild fever linked to a viral infection or with immunization. Pain and weakness affect the arms and legs. Paralysis may develop. The condition may spread and involve the face and chest muscles. There is no treatment other than supportive care.

Needless to say, when they told me about this disease, I was very scared. I had just had a baby and looked forward to living a normal life. They also told me Guillian-Barre was treated with steroids. They told me if it was viral, then it would go away by itself and physical therapy would be used to strengthen my muscles and I could live a normal life to raise my baby. So, I was hoping for a virus. More tests were to be performed the next day.

Wednesday December 13, 1995
The neurologist did nerve tests on my legs. This machine measured the nerves with electrical shocks. It felt like someone taping your knee with the little hammer. He concluded my nerves were working but just asleep. This was a good sign; meaning nothing was damaged. After this test was completed, they sent me for a MRI. The films came back showing an inflamed lumbar 4. I was also very bruised where the epidural had been. I still have my MRI pictures.

Thursday December 14, 1995
My IV was taken out because I was not weak anymore. They did a spinal tap of the fluid around lumbar 4. The fluid was tested. They were looking for Guillian-Barre; the count would have been very high. If it was viral, the count would have been low. The test came back low and I had a viral infection. At that time I was told no medications will cure this, it must work itself out of me like a cold. If it had been Guillian-Barre they were sending me to John Hopkins Hospital in Baltimore, Maryland. I was in Anne Arundel Hospital in Annapolis, Maryland, the birth hospital. It was not Guillian-Barre so that night they sent me to downtown Annapolis to the main hospital. I was put in pediatrics because I was breastfeeding my new-born baby girl and they had cribs.

Friday December 15, 1995 - Tuesday December 19, 1995
These days in pediatrics were used to prepare me to go home. Some time on Friday my catheter was taken out. It was a few hours before my first bladder movement. I was glad I could control that. The nurses were trying to figure out how they could teach me to self catheterize myself at home, not being able to pull my legs up. But they didn't have to worry about it anymore, because my system took over. It wasn't until Saturday, December 16th that I had my first bowel movement, with a little help from a suppository. After that I was pretty regular.

Tuesday December 19, 1995 - Present
I live in a two-story house. I had to have a hospital bed and trapeze, wheelchair with removable sides and

a portable commode with removable sides set up in my living room on the bottom floor of my house. In the hospital they started physical therapy. They taught me how to bump-stairs (that is go up the stairs on your rear-end). They taught me how to slide off the bed and get on the potty and wheelchair. The hospital set up a home physical therapist to come. My arms were very strong so this helped me to do a lot of transferring by myself. My parents and my husband's parents took turns staying with us so I had help while my husband was off at work. I needed help with the baby and the cooking and cleaning. I had physical therapy 3 times a week at my house. Each time the therapist came, I was able to do more and more. I had to relearn how to climb stairs. Everyday I had exercises I had to do. This all involved leg weights. Every couple of days I had to increase the weights because I could tell I was getting stronger. It was amazing if I couldn't perform a certain task one day, the therapist would tell me by the next session I'd be able to do it, and he was right. I was amazed at the human body. I now know what it's like to be a baby, because you have to crawl before you walk. Each day I could feel myself getting better. My legs would tingle like when a limb falls asleep. I remember one morning waking up and pulling my right leg over my left without using my hands. I was so happy, I called for my family. On December 28th, 1995 I walked behind my wheelchair for the first time with the therapist. We took movies. It was like dancing. This progress continued. I then went to a walker, then a cane, then no assistance. My biggest fear about walking without assistance was would my legs give out and I fall. The therapists told me it could happen, but as long as I kept improving it probably won't. I do remember that hard-soled shoes were the best for the support. This was all in a time frame of about 2 months. On February 6, 1996 was my last visit to the neurologist. I walked in. At that time I was released from his care and I didn't need to come back unless I felt I wasn't making progress. After that I still did weight exercises and took long strong walks. The neurologist told me walking was very good exercise. My recovery was painless except for muscle fatigue. Through all of this, I was recovering from a C-section, anemia and breastfeeding. I did not suffer any bowel or bladder problems.

It's been almost 3 years from getting TM and I still feel the effects. I have coldness in my feet and legs that comes and goes. Sometimes when I stretch my legs, my thigh muscle will tighten up and my knee will not bend. But I am able to force it to relax back to its normal state without using my hands. I can feel every muscle working, which if you are normal, you don't feel it. My left leg is a lazy leg. When I'm tired I don't pick it up like normal, so I sometimes trip on things. Once in a great while, I have fallen but not gotten hurt. I can't run anything like I used to, and there are times when it's hard getting off the floor without using my hands for help. Especially when I'm holding something heavy. I can still do my favorite sport of snow skiing, boy I'm glad I didn't lose that. I love the snow. My weakness is in the hips. I feel very lucky to have come as far as I did. I continue to walk as much as possible. I had another baby in March 1998 and no complications (natural childbirth). Having two babies keeps me going.

Also, forgot to mention that I do get the leg tremors. I feel it mostly in my knee joints. It happens at night when I'm tired. The way I stop it is to relax and stretch and massage my back. If it's really bothering me, I take an Advil or two and this helps me get to sleep.

Well, that's my story. I hope it helps the study and others to keep going. My doctors didn't know too much about TM, but due to this technology of the Internet, I think I may know more then them. I'm glad I found your website. I thought this was an odd case, but now I know it wasn't. Thanks for the information, member listing and newsletter. I've already contacted a member that lives near my parents in New Jersey. If I get there soon, I'm going to visit him. Can you tell me if any others may have been paralyzed after giving birth? I look forward to hearing from the Association. Feel Free to call me, I'd love to talk to others about this disease. I feel lucky to have come through this as well as I did.

Fellow TM sufferer,
Leslie Hoffmire
3101 Twin CT
Bowie, MD 20715
(301)464-4508
I had been working for a construction company for just a couple of months. I was eighteen and it was my first really good job. We were building a power plant in southeastern Oklahoma. They were behind schedule and had us working seven days a week, twelve hours a day. I was young, healthy and making good money. I thought I had nothing to worry about.

It had been a wet rainy summer and everyone on the crew had been fighting a summer flu. I was just beginning to feel the aches and pains on Friday morning when I went to work (Hmmm). On Saturday I just felt terrible. My head was pounding, I had no energy and I was perspiring profusely. I went on to work but shortly after lunch I had a fainting spell. My boss sent me home. I went

Twenty-four Years Ago Today
Larry Throne
Oklahoma

to bed at 2:00 PM and slept straight through to Sunday afternoon when my father came in to check on me. It was after 5:00 PM. When I awoke, I couldn't urinate, my bladder was distended and I had a fever. Dad took me to the ER and I was catheterized. The ER doctor sent me home and told me to return the next day for testing. The next morning our family doctor was calling, he had talked with the ER doc and was concerned. He wanted me there at the hospital ASAP. Over the next 24 hours, everyone at the hospital in Ada, Oklahoma had poked, prodded and examined me. I think the janitor even had his turn. They did a spinal tap (those sure are nice, aren't they)! When I woke up the second day, I was paralyzed from the waist down.

I was transferred to St. Anthony Hospital in Oklahoma City. In the next four weeks, I went from being a strapping 190lb construction worker to a 130lb paraplegic. The first week or two, I was really sick. My fever got so high they packed me in ice to attempt to break it. I remember coming in and out of a coma and the pain was unbearable. It felt as though a spike was being shoved up my spine. Luckily, I don't remember everything from that period. Everything was getting dark and I remember telling my brother something was sitting on my chest. I just couldn't breath. I vaguely remember having the respirator placed on me. I remember the fear I had of not knowing what was happening, and not being able to see or speak.

Late that night, an overwhelming feeling of comfort and reassurance came over me. It was God telling me to trust in him and everything would be okay. I was totally blind and on a respirator for the next 10 - 12 days. Then one day there was a flicker of light! For the next four days, as if a large hand were drawing back a curtain, I was getting my sight back. I remember focussing on my mother. She was so happy and worried at the same time. The paralysis started moving back down my chest. They took me off the respirator and eventually the paralysis stopped at T-5. I had been in the hospital for almost four weeks before I heard anything about TM. A doctor from Mayo clinic was visiting St. Anthony and he diagnosed the TM. I never did get his name, nor do I remember seeing him.

The next year was filled with endless hours in PT with little spurts of progress like the time I first moved my big toe. You would have thought I'd jumped up and danced a jig the way we were acting. That was the start. In the next year (year two), I went from walking with leg braces up to my chest to walking with a single cane. I still have the leg spasms, lack of complete sensation and the back pain some of you have. Also my bladder control could be better. But hey, I'll take anything I can get! Ten years after I was diagnosed with TM, I was in an airplane crash (whole nuther story by itself). I cracked my pelvis and broke some other bones. That has really slowed me down. While in the hospital over that episode, my doc showed me x-rays of my knees. I was wearing them out by locking them back to walk. He told me if I want to keep walking, I had better start riding in my chair, at least for when I go for long distance walks.

A couple of years ago I fell down and almost ripped the cartilage in one of my knees. Once again, my doc told me to take it easier on my knees. Today, I use my chair more than I ever have. Only walking around the house and keeping a real close eye on how I do things. I also suffer from the fatigue some of you have complained about. It makes life hard when you feel like you're running on empty all the time. Today, I'm married to a wonderful girl and we have two children and two grand children. I manage a mental health clinic specializing in working with children and families with emotional problems. I am working on a second masters degree in social work at the University of Oklahoma.

In the past 24 years, I have traveled over most of this country and to many different countries around the world. Sailing has been my release valve. I have sailed at most of the locations I have traveled to. I have taught sailing to over 100 people, including 29 emotionally disturbed kids I taught last summer. It was great! I have had plenty of bad times and good times. I've been able to go on with life. TM has slowed me down a little, but I'm probably a richer person because of it. I've learned to enjoy and appreciate what is in front of me. I see the beauty of the smallest flowers as I've struggled past them, when most never notice. I've smelled the fragrance of the spring days, the warmth of the summer sun, and the sting of a winter's breeze and understood the significance of it all.

It's been a long lonely trail in the past 24 years. I have only met, conversed with or heard of about 10 or 11 people with TM. Finding this group (the tmic) has given me a sense of belonging. I feel as though I've found my family. Only you guys can fully understand the fears, frustrations, and yes, the fortunes of having this disorder. It is great to have found my home.

Larry Throne

I am in receipt of your newsletters and must commend all those involved in this very informative publication. In just a short two year period your association has become international...what a wonderful effort. Belonging to a support group and receiving information concerning your rare disorder is the beginning of feeling better about yourself. You are not alone. I have Gullian-Barre Syndrome and not TM. However, these two or many rare diseases are difficult to differentiate. I am writing now so that you will know that you have a lot of company in your pain, discomfort and frustration.

At the age of sixty, I had just completed my third New York City 26-mile marathon in November 1994. A flu shot and a chest cold in December .... then completely paralyzed from the neck down on January 18, 1995. I have been there and done

Eileen Prevatel
Wappingers Falls, NY
September 16, 1998

that, from full failure of bodily functions to the entire scale of tests and treatment. The first few weeks were the worst, the depression unexplainable as well as the pain of even a sheet on my legs and feet. Still unable to stand on May 12, 1995, I went home with a wheelchair/slide board/ tub-chair and a commode. Needless to say, my husband became my nurse and full-time caregiver. My son moved home for two months and took charge of my rehab, by August I was walking with braces on both legs and a cane. In September I started Aqua-jogging at the YMCA and continue that course of exercise to the present time.

After three and one-half years my hands are still numb, as well as my legs from the knees to my toes. Walking in ski boots; not feeling if my feet are hot/cold or wet and the balance problem all continues to be a problem. Most of all the depression and frustration of not being the person I use to be is the hardest .... But we all know that there are so many others worse than we and must make the most of what we have. With a positive attitude, we can hope to have a full recovery.

Swimming seems to help me the most. I am in constant pain and discomfort with leg spasms but have discontinued all medications in fear of side-effects. I do take vitamins and with bone-thinning, 1200 mg of calcium daily. I plan to start acupuncture therapy. I encourage suffers of any disease to seek second and third medical opinions and treatments.

My AFOs/braces are restrictive; uncomfortable; inconvenient, but necessary for longer walks. Will be helping at the finish line of the NYC marathon for the fourth year in November, aiding the disabled runners of the Achilles Track Club of NYC. Our son runs with blind and/or wheelchair athletes and expects me to join him in the next race. So-0-0 watch for me .... I just may make it. Thank you for allowing me to share with all of you.

Eileen Prevatel

Jim Lubin is *New Mobility Magazine*'s 1998 Person of the Year. To really comprehend the magnitude of the honor bestowed on Jim, you have to be aware of the other people who were nominated for this award. The nominees represent an incredible display of talent, creativity, conviction, energy, commitment, intellect – impressive, lofty company. *As noted by Barry Corbet, the Editor of* New Mobility Magazine:

This year, once again, our quest to name our Person of the Year award drew a bumper crop of nominations (New Mobility, Vol. 10, Issue 64, Jan. 1999: 6).

Where does the Internet get its boundless promise? From people like Jim Lubin. Sipping and puffing his Morse code, he is the author and sustainer of

New Mobility Magazine's 1998 Person of the Year: Jim Lubin

several virtual communities that support the unsupported and connect the disconnected. And for people who have transverse myelitis or use a ventilator, he offers sanctuary and fellowship they can't find anywhere else. For his steadfast commitment to service, Jim Lubin is New Mobility's 1998 Person of the Year (New Mobility, Vol. 10, Issue 64, Jan. 1999: 5).

Our winner embodies what is perhaps the highest and best of the qualities we look for – direct service to people with disabilities (31).

In addition to recognizing Jim's efforts and contributions, the article represents a wonderful opportunity to educate the public about Transverse Myelitis and about the Association. In fact, if you look closely at the monitor behind Jim on the first page of the article, you will notice The Transverse Myelitis Association Home Page.

The article, written by Jean Dobbs, Executive Editor of New Mobility Magazine, describes the service Jim has performed for the TM community and for the community of people with disabilities.

Jim Lubin is sipping and puffing. Playing and programming. Learning, sharing, living. He's building virtual communities, and he's doing it one breath at a time with Morse code. Fleshing out those stingy dots and dashes to create a full life for himself and a smorgasbord of resources for others.

[Jim] presides over four Web sites he started to help people with disabilities. The sites are home to three "listgroups" where the common bonds are transverse myelitis, quadriplegia or ventilator use, and the MO is support, connection and information (31).

Jim has accepted the honor with his usual graciousness and humility.

Many people have told me I am such an inspiration to them, but I don't really know why, and it makes me a little uncomfortable. I'm just an ordinary person who got sick and found a way that works for me to handle my situation (36).

Maybe you are just an ordinary person, Jim. But you had decisions to make about **how** you were going to "deal with" your sickness. The **how** has been anything but ordinary. Your contributions to those who have TM and their families, your contributions to the tmic, and your contributions to The Transverse Myelitis Association are **extraordinary**. We are all so proud of your well-deserved recognition and award and are so grateful for the creativity, energy and enthusiasm you bring to your work in the TM community. We are all truly blessed to have you for a friend!

If you are interested in ordering a copy of the January 1999 New Mobility Magazine, with Jim's beautiful picture on the cover, you may do so by calling (888) 850-0344, ext. 108 or by Fax at (215)675-9376.

Help TMA by Shopping on the Internet: iGive

Jim Lubin

One of the ways to support The Transverse Myelitis Association is through a new website called iGive. Just by browsing the iGive member page or buying online through iGive's merchant partners, money goes to The Transverse Myelitis Association, at no cost to you. In fact, The Transverse Myelitis Association now has 78 supporters who use iGive, and we have generated nearly $300 for our cause. iGive calls this new form of giving 'Technogiving,' because it lets us donate our time to support our cause while online.

iGive has become quite a success story. The service was launched in 1997. It is growing at 20-30% per year, and now has over 36,600 members who use iGive to support over 3,662 worthy causes, such as The Transverse Myelitis Association. I have established a link to iGive from the bottom of our web site (www.myelitis.org). If you click on the link, you will be taken to iGive where you can register to become a member. Every new member who signs up for iGive creates an instant donation to The Transverse Myelitis Association of $2.00.

It is free to join. The average 'active' member is now raising over $40 a year, at no cost to them or the Association. You can raise money in various ways. Just by joining, a $2 donation goes to The Transverse Myelitis Association. Each time you visit the site, you raise additional cents. Finally, and most importantly, each time you make a purchase from merchants in the iGive mall, up to 12.5% of the product price is donated to the TMA. Your visits only count when you click on one of the ads or on the buttons on the iGive control panel, up to the current maximum of 5 per day per person. That way, the sponsors know that you actually saw their ad and they're happy to donate money to the TMA.

It is a fast and easy way to earn money for the TMA. It does not cost you anything extra nor do you pay more when you shop iGive. If you try iGive and do not like it, they will cancel your membership at your request without questions. The iGive merchants offer great deals at competitive prices. It takes very little time, and shopping online may actually save you time and money. Each time you buy through iGive's Web site, you raise needed funds for The Transverse Myelitis Association. It is private and confidential, and it is convenient from your home. iGive has office supplies, sporting goods, gifts, software, special auction items, books, CDs, videos, toys, flowers, nutritional products, gardening supplies, cooking items and more. If you are not already an online shopper (and 20 million Americans are) you will be pleasantly surprised at the convenience, great prices, and selection. I hope that you will consider giving iGive a try and by doing so, help out your Association.

Deanne, Dick and Paula are in the process of finalizing arrangements for the first TMA Symposium, August 12-15, 1999 in Seattle, Washington. It is very exciting, because we know what is going to happen when you have the opportunity to be in a room together and begin to share your stories, your concerns, your fears, your hopes, your support, your lives.... This is a very important and exciting time for the TMA and for all of you, the members of your Association.

The Association has been involved in a fund-raising effort in order to

acquire sufficient funds to put on the symposium. The finances are required to cover such expenses as the rental fee for the conference rooms, the travel expenses for a few of our speakers, printing and mailing costs, and registration materials. There are many things the Association could do, if funds were available. The Association could pay for the banquet, for instance, if enough money were raised. The Association has not been able to raise anywhere

Fundraising: What You Might Do to Help the TMA
Sandy Siegel

near this kind of money from our inception to the present. So, this effort is a daunting task.

This brings me to you. Each of you and all of you. Deanne, Paula, Debbie, Jim and I have been involved in the fund-raising efforts. We have sent letters to the pharmaceutical companies; we went through all of the surveys, identified the medications that our members are taking and Drema's daughter, Heather, did an awesome job of matching all of the medications with the companies. Dick and Deanne have been searching for funding and submitting applications to both private foundations and government agencies. But there is not a single guarantee that any of this effort is going to result in a single penny of financial support. And there is no way we (the Association officers) are going to be able to do much more than we are currently doing to raise the funds that are needed. We have jobs, we have families, we have TM, we are caregivers, and we have the regular work of the Association that takes a great deal of time and effort from our lives. And we are in the process of planning and arranging a symposium.

We can't do this alone. We need your help. We are asking you to help us raise the funds so that this symposium is everything we want it to be for you. Some of you may know people who work for associations or foundations and may know some sources of funding. Some of you may work for companies who sponsor these types of things, and may be able to ask for support from them. Some of you may work for companies who will match funds that you raise on your own. Some of you may be like me, and don't know anyone with more than this month's mortgage payment, and will have to find smaller ways to raise money -- smaller, but no less ambitious. We have had people raise money for the Association with car washes, volley ball tournaments, all sorts of things. Your churches, synagogues, mosques, sweat lodges, temples (have I left anyone out) may be interested in supporting you and the Association's efforts by sponsoring a pancake breakfast, a pinochle party, bingo, or some other type of fund raising event.

We are asking you to do everything you can (that is legal and ethical) to help us raise the money for this symposium. If 40 people each raise $1000 -- we're there. If 80 people each raise $500 we're there. We received a check from a middle school in Illinois last year. A student from their school was diagnosed with Transverse Myelitis and the school had a volley ball tournament fundraiser -- those kids raised almost $500. Really boggles the mind.

Be resourceful and creative. Think about everyone you know who can help. Consider all of your contacts. And remind everyone that his or her contributions to the Association are completely tax deductible.

We are committed to putting on this symposium. It is going to happen if we do not raise a dollar. The Association will find a way to pay for the facility and then we will make do with what we can afford to do. We will still get people together, we will still offer the educational opportunities, and many good things will come out of it. But, there would be fewer people who would be able to attend, because the personal cost of the symposium would be much higher, and we would not be able to do as much for everyone as we would like to do.

It is implicit in our Association that there are some people who are unable to pay and there are others who are able to pay more. It is always our hope that those who are able to pay more will do so and help out those who are elderly and live on fixed incomes, or those who are on disability and also live on fixed incomes, or those who have medical expenses which force them to make decisions about heating their homes, feeding their families or buying their medications. We do have every conceivable situation among our members. What we share is a neurological condition -- our life circumstances are as different as you might imagine -- or not imagine. But what the Association offers in the way of support and education needs to be available to everyone. That is the reason why we have avoided using membership dues to cover our expenses. And what the symposium is going to offer should be available to everyone. The hard reality, however, is that it will cost people considerable sums of money to make the trip to Seattle from all over the country and all over the world.

We are asking you to help each other get to this symposium and help make

it everything we would like it to be for you. We also have some suggestions for personal fundraising to help some of you think about ideas for raising the funds to travel to Seattle and to pay for your flights, rooms and meals. One of our members is engaged in this type of fund-raising with her family and in her community, and she will offer you some suggestions along these lines in the following article. These funds are not tax deductible, but there are lots of wonderful people in our families and communities who would help those of us who are in need of help get to a symposium, if they understood its significance for you -- and without Uncle Sam's tax deduction.

The more you raise, the more we can do for you, the less it will cost per person, the more people who will be able to attend. It is a fairly simple equation. I don't think that asking people for money is easy. It is hard for me. But I'm engaged in the process of doing just that because the good I see coming out of this symposium for me and for Pauline and for all of you is greater than my discomfort about asking people for money to support our effort. I am hoping that many...most of you will be able to find that same motivation.

I wish the Association had the money to do this without asking any of you to do anything. I wish we had enough foundation grant money, government grant money, whatever, to do this without asking for your help. Maybe some day we will be there. For now, we represent almost 1400 members. To most foundations and to the government, that is going to look pretty small. We have a lot of work to do to make 1400 people look large enough to support in every way -- and believe me, that is exactly what the Association intends to do -- if there were 125 of us, we would be worth all of the research, treatment, rehabilitation and social services our society can afford -- and we can afford about all that we need. But for now, we are small, we are very young, and we are very big plans, very little money. I wish the Association had enough money to subsidize the trip for individuals or families who cannot afford to attend. We don't have it. But we will try to help you find ways to do it.

We (Deanne, Sandy, Paula, Debbie, and Jim) will do what we can to raise money. But that may not be enough -- and I'm being totally straight with you -- it may not amount to anything. There are no guarantees from our fundraising efforts -- only that we will attempt to carry out our efforts with all of the energy and enthusiasm we can muster. We need to depend on you. All of you. Please take some responsibility. Someone out there may be able to find $10,000 or $20,000 -- stranger things have happened. And allow me to share a perspective. This isn't likely to happen by sending e-mail messages to Bill Gates asking for help. This is more likely going to happen by talking to people we know in our families, among our friends, with co-workers and employers...people we know in our communities ... in our lives. The e-mail messages are so easy to ignore. This is going to happen by approaching people who know us and care about us. It may be that those are the people we are most uncomfortable with approaching -- but that is where it is most likely going to happen.

Ask for help if you need it from us. Please also keep in mind that as you raise money for the Association, you represent the Association. So, if you plan to knock off the corner grocery store as your fundraising technique, please don't leave them a copy of our brochure. Really -- what I would ask you to keep in mind as a good rule of thumb about fundraising, when you ask for support, you should do so in a manner that would allow you or someone else from the Association to approach the same person for support in the future and have that person "feel good" about the Association, even if they tell you, "no, I'm not going to help you, go away." That's not easy to pull off, but I am asking you to do that for the Association. Thanks -- we appreciate it.

I am excited about meeting all of you in person. I am more excited about being in the room when all of you meet each other. Please own the task of raising the money to support this symposium. Please make it your personal responsibility to help yourself and to help your friends. Please help your Association make all of this possible for you.

I greatly appreciate your patience in getting through this message. Take care. I look forward to hearing from you. Paula Lazzeri looks forward to receiving all of your contributions. Please keep us posted. Good luck!

Hello, my name is Drema. I live in Virginia and have had TM in my life since 1989. I want to be in Seattle next year along with my very supportive daughter, Heather. Since I have been on medical leave of absence for the past seven months, it will take a financial miracle to do it. And I do believe in miracles. Especially if a person is willing to step out on faith that they will be able to accomplish their goal. Then their faith is rewarded by doing more than they could possibly have expected to do. I just finished making 162 pounds of fudge and sold it to raise my Christmas shopping money. I did it!

In thinking about how I am going to get to Seattle, I have come up with

some ideas that will work for me in my part of the country. I hope you will find some you can use and this in turn will spark some new ideas from you that will further my efforts also.

Last summer my daughter held a car wash at Wal-Mart on the weekend of the fourth of July. Wal-Mart gave her

Fundraising: What You Might Do to Help Yourself (Attend the TMA Symposium in Seattle)
Drema O'Dell

matching funds for TMA. You can request matching funds for many things from many companies. Sending people to a non-profit organization's symposium may be a matching funds request that many companies would approve. I think if there are several of you TM'ers in a geographical area, you could work together on this. They would be more likely to approve matching funds if it were going to benefit several people directly in that store's local area.

Many home party companies, such as Tupperware, allow you to do fundraisers where you are given a percentage of gross sales. The more people that you would have participating, the more money you would make.

My church has also used the matching funds program in fundraisers with Wal-Mart, selling Krispy Kreme doughnuts. They buy doughnuts from the distributor for $1.25 per dozen (300 units usually) and are sold in the lobby for $3.00 per dozen!!! Pick a busy Saturday before a holiday and this is an easy sell-out. On a smaller scale there are traditional bake sales.

Southern gospel singings are big in my local area. You may be able to use your church or a school auditorium. Getting free advertising on radio and in the newspapers plus the true support of church members will help greatly. Probably a free-will offering is what you will garner from this approach.

I plan to have a choir festival soon after Easter. Church choirs will have spent the holidays working on church programs and Easter will be the end of the difficult and time-consuming season for them. They will have loads of well-rehearsed music and, hopefully, will love the chance to present it to an audience outside of their own church setting. I may go with free tickets to be given out by each choir in their own church with a prize (yet to be determined) going to the directors of the choirs that give out the most tickets. I think free-will offerings will be the only way to go on this, as well.

If you or your family is involved in high school band then you may try having a band festival. This would involve an entry fee per band and trophies being donated for the winners.

Does all of this work make you too fatigued? You need to get family, friends, church members and pastors behind you. Make them see how much you want and need to go to Seattle. I know that Sandy Siegel can provide us with letters to send to all of our relatives, friends, and co-workers asking them to make a personal donation to help us to finance our trips. My daughter used this method to raise funds to go on a mission trip to Alaska her senior year of school and it was great to see the response from relatives and neighbors and church members.

We may also be able to obtain sponsorships or grants from local service clubs with a copy of the letters from TMA about the purpose of the trip and exhibiting a financial need for their support.

Your church or religious group may be willing to sponsor you financially or assist you in raising money. You may need to come up with the ideas, but you will be able to find people who will understand that you are not able to do all of the physical work involved and they will help you. Retail businesses love to get their names and pictures in the paper for helping humanity. Some grocery and restaurant chains provide coupon books for organizations to sell to raise funds. A club or class could sponsor this for you. Raffles can raise large funds

quickly once you have obtained the items to raffle and checked on the state and local laws concerning such programs.

Good luck and let's get started in the New Year raising money to get to Seattle and even a little extra to send to the TMA to help defray the cost of the conference. Please share your ideas with each other on the Transverse Myelitis Internet Club or through letters to each other in the mail. If you live near others with TM (check your directory), then get in touch with each other and work together on your fund-raising efforts.

Hope to see you all in Seattle!

Drema
levi@i-plus.net

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An updated Transverse Myelitis Association Membership Directory will be published and mailed in the Fall, 1999.

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