❖The Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

I would like to relate an experience I have had in the past couple of months. I was engaged in the process of editing the "In Their Own Words" articles. My approach on these articles has been to edit with a very light hand. The purpose of the articles is to convey an experience that "belongs" to the teller; I try not to interfere too much with style or content. I had received some feedback from someone that I have a great deal of respect for and trust in that I might want to consider a slightly heavier hand in the editing process. We talked about issues of accuracy, sensitivity to personal matters, and good taste.

One of the "In Their Own Words" articles I was working on described the person's reaction to their severe pain and an attempted suicide. The words of my friend came to mind immediately; is this something I want to have communicated to the entire membership in such a public way? Is the description of his suicide attempt too personal for our newsletter? I also thought, with as prevalent as depression is among our TM members, do I want to be publicizing anything at all about suicide? I had considerable angst about the issue, and then finally decided to edit out the reference to the suicide attempt. I was not at all certain that I had made the right decision, but it seemed a safe decision.

Two nights after revising this article, I was reading my current batch of messages from the Transverse Myelitis Internet Club. There was a very short but very disturbing message entitled, "Suicide Attempt." One of our TMIC members, a young girl, had attempted suicide. She had been in counseling; it was suggested that she share her experience with others who have TM and might understand what she has been going through. There was a flurry of activity from the TMIC with many messages sent to her from people who shared their own experiences with depression, who shared thoughts about suicide, and who offered up a strong dose of good advice, empathy and compassion.

This experience rocked me to the core. I have known that depression is a critical issue for many people with TM. I have spoken to many people who are suffering from depression. I have taken phone calls from people in the middle of the night who need to talk through their dark thoughts and sense of hopelessness.

It was her youth, it was the matter of fact delivery of the message, it was her sense of despair. I was emotionally rocked…sad, angry, frustrated, frightened.

The next day, I sat back down at the keyboard, I opened up the "In Their Own Words" article I had been working on, and I typed the following words…

The pain had become so severe that I tried taking my life. How my wife got to the gun before I pulled the trigger, I'll never know.

Who was I going to protect by not sharing these words…certainly not this young girl. When we say, ***you are not alone***, we really have to mean that you are not alone. When you go out into public and have a concern that you might have gas because your sphincters do not work properly, or when you have an accident because you cannot get to a bathroom in time or can not even feel yourself urinate when you do, or cannot achieve an erection or no longer have the same pleasure sensations, or can no longer have an orgasm, or are concerned that you might fall while walking over an uneven crack in the sidewalk, or that you are so depressed that you are not sure you even want to see tomorrow, you need to be able to feel these feelings, you need to be able to have these thoughts, and you need to be able to share these thoughts and feelings with each other.

None of these issues are easy for anyone. For whatever cultural forces that are at work, and none of them are particularly healthy ones, we are not made to feel particularly comfortable talking about these issues. Well, if we can't talk about them, how can we get help for them? And if we are not made to feel comfortable talking about them, how can we feel normal while having these problems?

Well, you are not alone. And you are normal, whatever it is to be normal. Many of you in this TM family are afraid to fall and are

embarrassed when it happens. You are struggling with the sexual issues for yourself, and with the relationship concerns that exist for yourself and with your spouse or partner. You experience considerable grief, embarrassment and frustration about all of these bodily functions that just don't function like they used to function. You are anxious to do things alone and are angry about the loss of some or much of your independence. And many of you are very depressed. Really, you are not alone.

I have been reminded, again, what an awesome responsibility I have as the editor of this newsletter. Having TM means that you have very little information about how you got this condition. It means that if you have recently been diagnosed, you have very little information about how much recovery you are going to experience. You have very little information about treatments and you have no information about cures. There are a lot of educated guesses, but there is little definitive information. This newsletter has as a primary purpose to inform and to educate. And it has as a primary purpose to facilitate your seeing yourself as a member of a community that shares your concerns and supports you in the achievement of your physical, emotional and spiritual goals. Getting you the best and most accurate information, communicating the most useful information, offering you the greatest opportunities for networking and mutual support; that is what we are always trying to accomplish in this newsletter.

This job might be performed more effectively by someone with less emotional attachment to the readers. There are times when I cry while reading the surveys and entering the information; particularly the information about the children who have TM. I will try to make the best judgments about what is published in this newsletter. And as with everything I do, the decisions will be based on some amount of educated judgment, some discussion with and advice from the professionals, some exercise of common sense and a healthy dose of my emotional and spiritual self. Most of the time, hopefully, that will result in the correct judgments.

I have a 40-something year old and a 14-year-old to thank for getting me oriented in the "right" direction. Through their honesty, courage and willingness to share in their own very personal experiences, they remind us that we are not alone in our experiences. I hope and pray that today they find themselves without pain, with hope and comfort and with peace. I wish that for all of you. Please take good care of yourselves and each other.

From the President
Deanne Gilmur

Greetings to all members of the TMA. The glow of the First International Symposium is still with me and I hope in some small way, I can share that glow with those of you who were not able to attend. It was truly a life-changing experience and as so many attendees similarly commented, I felt as though I was enjoying a huge family reunion. Indeed, relationships and supports that will last a lifetime have now been developed for many of us.

The significance of the Symposium for the continued growth and development of the Association, as well as the increased awareness of transverse myelitis (TM) can not be overstated. The professional presentations focused on the three basic stages of the condition: 1) TM onset, 2) TM recovery/rehabilitation period, and 3) TM long-term living and care, increasing our knowledge and understanding of the many varied TM experiences. In addition, and of particular interest to me, were the uplifting presentations about the relevant research that is underway and the prognosis for viable "cures" that were discussed. I must share with you that my husband, Dick Gilmur, and I are believers in the expectation, and the accompanying exhilaration, that within 5 to 7 years nerve regeneration and remyelination research will generate positive results that will be applicable to and benefit individuals with TM.

As a result of the Symposium and the goals set by the Board of Directors, TMA will be strengthening its organizational support and advocacy for cure research. This is a logical addition to TMA's long established goals and objectives to provide support and education about TM, and the result of the natural evolution of TMA's growth and maturation as an Association. The continued development of critical partnerships will facilitate implementation of this vital outcome: a cure for TM and other spinal cord injuries and dysfunctions.

Speaking of partnerships, TMA's relationships with the medical community have been instrumental in advancing the awareness of TM and in developing some critical partnerships. Due to the publicity about the TMA through the Symposium, as well as the exposure from our Web site, the TMA is regularly receiving inquiries from physicians and other members of the medical community for information and referrals. In addition, some medical providers have started to refer their patients with TM to TMA as a source for information and support. One of the most noteworthy partnerships that developed over the past year is TMA's strong

relationship with the Johns Hopkins Transverse Myelopathy Center (JHTMC) in Baltimore, Maryland. The JHTMC was started this past June and Dr. Douglas Kerr, who is a member of our Medical Advisory Board, is also a Co-Director of the Center. This is the first clinic or center in the world developed and dedicated to transverse myelitis treatment and research. By seeing and tracking a large number of patients with TM, the JHTMC will contribute greatly to the increased understanding of TM, its diagnosis and treatment. The center is also dedicated to a comprehensive, multi-disciplinary treatment of TM. For more information about the JHTMC, you can link to its Web site from the TMA Web site. Dr. Kerr also has an article in this newsletter that provides a more detailed description of the services offered by the center, as well as the TM research opportunities that are being pursued by Dr. Kerr at Johns Hopkins Hospital.

Another outcome of TMA's partnership with JHTMC is the decision for both of us to jointly sponsor the Second International Symposium on Transverse Myelitis and to hold the event in Baltimore, Maryland. Our plan is to conduct the Symposium during the second or third week of July 2001 and to offer Continuing Medical Education (CME) credits to medical professionals. By providing CMEs, this event will be yet another milestone in TMA's continued march towards one of our goals, which is to increase TM awareness within the medical field. Planning and coordination activities have already begun. In fact, Dick went to the JHTMC in October and toured Johns Hopkins and accomplished some vital preliminary Symposium planning. The next Symposium is destined to exceed our expectations once again, so we hope you mark your calendars now and that we see you in July 2001 in Baltimore!

While at Johns Hopkins, Dick also participated in several media events about the JHTMC, TM and TMA, and the Cody Unser First Step Foundation (www.codysfirststep.org/). Cody is the daughter of Shelley Unser and race-car champion Al Unser Jr. She was diagnosed with TM in February 1999 at the age of 12. Cody's Foundation has been established to help raise research funds to fight paralysis and to build awareness of TM. Cody and her family have already done much to increase awareness of TM as many newspaper articles have been written about Cody and her condition and TM diagnosis. In addition, the November 29th issue of People magazine contained a four-page spread on Cody and news of her Foundation. The Foundation will be a powerful influence in helping to raise and direct funds for research, and to increase public awareness and improve the quality of life for those afflicted with all forms of spinal cord-related paralysis. The ongoing efforts of Cody, her mother, Shelley, Cody's family, and her Foundation are yet another voice that adds strength to the issues and causes for which we all advocate. Their efforts are very much recognized by me and my husband, and the TMA Board, and they are greatly appreciated as we all continue to work towards the same goals. The TMA goal to develop partnerships includes maintaining a strong relationship with Cody's Foundation. As TMA develops into an organization that is able to fund TM cure research (see, **Help Support TMA's Continued Growth And Development** article in this newsletter), we must look for opportunities to combine our research funds with other organizations and other funding sources to best support vital research efforts. We must also coordinate our research funding efforts with others to ensure coordination, cooperation, and collaboration occurs amongst the researchers being funded and the studies being proposed for funding. With all this said and the possibilities that increased TM awareness and research efforts can bring, I still find myself feeling that the future never looked brighter.

As we have gained many new members this year, I thought it appropriate to review TMA's past accomplishments. (The following information on accomplishments and past and future goals was discussed in the General Membership meeting during the Symposium and the full text of the minutes are available on our Web site.)

To date we have accomplished the following:

1. In November 1996 TMA became incorporated as a non-profit organization in the State of Washington.
2. In 1997 the Medical Advisory Board was created; our first Medical Advisory Board members included Dr. Charles Levy and Dr. Joanne Lynn.
3. The initial information packet for new members and interested persons was developed.
4. The TMA Membership Directory was developed and distributed to new members; this is consistently being updated.
5. The TMA Web site was created.
6. In September 1997 the TMA registered as a non-profit organization and received its 501 (c)(3) IRS status. This allows us to solicit donations as a tax-exempt charitable organization.
7. In 1997, TMA initiated publication of its newsletter with distribution as close to two times

annually as is possible.
8. A TMA research survey was developed to collect and record TM data.
9. In 1999 the New York State Legislature passed a Resolution naming June 6, 1999 as Transverse Myelitis Day.
10. In August 1999 the First International Symposium was held in Seattle, Washington.

As you can see, we have accomplished much. The interest, support, and ideas of so many TMA members have made these kinds of accomplishments and growth possible. The Symposium has served as a successful mechanism in helping us reach many of our annual goals. In review, those goals and their outcomes for 1998-99 were:

Disseminating educational information: Our membership has grown to almost 2000 members in 35 countries. These people have all received the initial information packet. Additionally, Board members receive anywhere from 15 to 30 individual contacts per week, requesting information or support from TMA.

Expand the Medical Advisory Board and develop partnership opportunities between TMA and the medical community: In the process of planning the 1999 Symposium, many interested and supportive physicians were contacted and eventually some of those individuals became a part of the medical portion of the program. It has been our intention to add providers to the Medical Advisory Board (MAB) from representative and varied geographical areas and with a growing interest and expertise in TM. One of our newest MAB members includes Dr. James Bowen, Assistant Professor, Director of Neurology Services, Multiple Sclerosis Center at the University of Washington School of Medicine. Dr. Bowen is a MS specialist and researcher, and will contribute greatly to TMA through the application of his MS expertise to the TM arena. Our other newest MAB member is Dr. Douglas Kerr who hails from the Johns Hopkins Neurology Department. Dr. Kerr is an Assistant Professor of Neurology and Co-Director of the Transverse Myelopathy Center. (Additional information about our newest MAB members is found in an article in this newsletter).

Facilitate support and networking opportunities and increase awareness of TM, its impact and the need for additional research: In preparation for the 1999 Symposium, registration and information brochures were mailed to many physicians, clinics, and hospitals. We also advertised in the American Neurology Association's periodical. While these providers did not necessarily attend the Symposium, these advertising efforts served a vital public relations function and helped increase the awareness of the availability of the TMA as a resource to these doctors and their patients with TM. Also noteworthy with regards to the fulfillment of our 1998-99 goals for increasing awareness of TM, was the Transverse Myelitis Day in New York State initiated by the hard work of TMA member Pamela Schechter. This may become an annual event in New York and has developed into a support group that intends to regularly come together. The inaugural Transverse Myelitis Awareness Day in Australia was held on May 12, 1999. The Transverse Myelitis Support Group of Australia is planning their next Transverse Myelitis Awareness Day for May of 2000. Finally, the work of TMA's Web site director, Jim Lubin, has been tantamount in providing information about TM and the TMA to interested persons online. You may have already noticed pertinent information about the 1999 Symposium, as well as news articles on the site. This wonderful information has taken TMA a long way in meeting our networking goals.

As we come to the close of 1999, we are beginning to work on goals that were developed and discussed at the Symposium for the year 2000. They include:

1. Continue to expand the Medical Advisory Board.
2. Continue to develop partnerships with other medical providers and treatment/research centers.
3. Develop State and National representative activities in at least 6 states and 4 countries.
4. Continue ongoing update and expansion of educational materials and the initial information packets.
5. Develop enhancements to the Web site and information exchange via the Web site.
6. Increase charitable donations and financial support of the organization's programs and activities.

Work on some of these goals has already started. Jim Lubin has added links to important Web sites such as the JHTMC's as well as to other important information and resources. Work continues on the guidelines for State and National representative activities and an information packet of materials for education and support is being developed. I will be completing the task of putting this information together, getting input from other members, seeking approval from the Board of Directors, contacting those people who have voiced an interest in this role, and sending representative packets out in the early part of 2000. We are looking to add materials from the JHTMC to our initial information packet. We are also continuing dia-

logue with other facilities and organizations as we look for ways to combine our voice with existing efforts to promote funding for research that will benefit those with TM. Also, we are hopeful that our membership will help support the work of the TMA through charitable donations and gifts.

Surveying the accomplishments of the TMA, especially the success of the 1999 Symposium, is so rewarding and so humbling. This community that we all share a part of is strong, sensitive, and supportive. The Symposium was a magical experience that brought many members of our community closer together; together as a family. One participant commented that it was the first time that she had ever met anyone else with the TM diagnosis. Today, she has a TM family to draw strength from. Since the Symposium I have struggled for the words with which to share the impact and the power that this event had on the attendees, including myself. Suffice it to say, we worked hard, shed some tears, and had a lot of fun; just like most families do.

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.

I'd like to take this opportunity to introduce myself to the members of the TMA. My name is Dr. Douglas Kerr and I am a neurologist at Johns Hopkins Hospital. I have established through the department of neurology a center of excellence, the Johns Hopkins Transverse Myelopathy Center (JHTMC). The JHTMC has three explicit goals: 1) the treatment of patients with transverse myelitis, 2) determination of the causes of TM, and 3) establishment of better treatments (and potentially a cure!) for patients who have TM. We have gathered expert physicians and health care professionals from a variety of disciplines, including, neurology, urology, rheumatology, orthopedic surgery, neuroradiology, rehabilitation medicine and physical and occupational therapy, with the express goals of providing a comprehensive diagnostic evaluation and maximizing recovery and function. The JHTMC is the only such center for excellence in the entire world. As such, it provides a unique opportunity for patients and care givers to get questions answered, to understand more about their disease, and to ensure that appropriate steps are being taken to maximize function and independence. It also allows for research to be done in order to better understand the causes of this disease and to devise and evaluate more effective treatments.

Johns Hopkins Hospital Transverse Myelopathy Center

Douglas Kerr MD
Co-Director and Assistant Professor of Neurology

I became interested in TM through a variety of occurrences. While I was completing my neurology residency, I took care of two patients with TM and became determined to understand more about this mysterious disease. It seemed so dramatic a disease, with very little understanding of how it develops. Who gets it? Why do some patients recover, while others remain severely injured? How can we prevent TM? How can we develop treatments even for those people who have had their bout of TM long ago? It was then that I met Gunny (Richard Boyle). Many of you know this shy and reserved man. Gunny is a cousin of mine who developed TM in 1997. He contacted me and DEMANDED that I get involved with the TMA. I then spoke with Dick and Deanne Gilmur and became acutely aware of how difficult it is for patients with TM to get answers. Most physicians will see only one or two patients in an entire career, and therefore, are fairly uncomfortable with the presentation and management of patients with TM. As well, patients may get a few of their symptoms addressed by a physician, but then may have to "go shopping" for other doctors to address other concerns. This effort is time consuming and wasteful of energy. So, I decided to create a center in which a variety of care providers would attempt to give care "under one roof." Many of the physicians involved in the center have had expertise in TM even before we established the JHTMC. But I felt it was important to get everybody working together for a singular goal. By attracting a large number of patients, we learn more, and can utilize that knowledge to advance the understanding of this disease.

What do we offer at the JHTMC? A faculty neurologist with expertise in TM will be the primary director of your care while at Johns Hopkins. Drs. Kerr, McArthur, Irani, Royal and Pardo have extensive experience evaluating and treating patients with TM, and all have research interests

relevant to this disease. We will obtain a comprehensive history, perform a physical examination, and review all of your previous medical records. We may also wish to determine quantitatively your strength so that we can follow your progress. We will answer any questions you have at this point, and discuss possible treatments. We will then suggest additional studies to be performed in order to evaluate your case most completely. At the end of your visit, you will again have a brief visit with your neurologist to summarize the evaluations done while you were here and to coordinate further care.

A rehabilitation physician, as well as physical and occupational therapists will evaluate virtually all patients. Drs. de Lateur and Brown have extensive training in developing strategies to maximize patient's function following the onset of TM. They will evaluate strength, range of motion, bowel and bladder function, ability to carry out activities of daily living, skin care, and sexual function as indicated. Therapy evaluations will determine the major limitations of function, including ambulation, transferring from bed to chair, using the toilet, bathing, and eating. Assistance devices for each of these functions may be recommended. A series of exercises may also be suggested for maintenance of tone, strength and range of motion. Dr. de Lateur has been part of a team that designed a machine to quantitatively evaluate spasticity of the lower extremities. This is a state-of-the-art machine, and one of only a few in the entire world. For some patients, this may be an important tool to investigate how much spasticity is interfering with function.

Most patients with TM have spasticity, while a fair number of patients have pain due to their illness. Both symptoms interfere with recovery and quality of life. Spasticity often makes it harder to ambulate or to utilize the extremities in a coordinated fashion. A wide variety of medications are available for these problems, but for patients with TM, medications are occasionally prescribed in inadequate doses, or in suboptimal combinations. Some of these medicines have troubling side effects including fatigue. For some patients who experience these side effects, a novel approach employed at Johns Hopkins may be appropriate. Dr. Staats inserts a small catheter from a subcutaneous pump into the intrathecal space (directly into the fluid space that bathes the spinal cord). He can then administer medicines directly into this fluid either for pain control or for relief of spasticity. The medicines do not get distributed throughout the body, and so there are fewer side effects from this approach. Patients frequently report excellent results and often tell us that they wished they had not waited so long to do this.

There will be a psychologic evaluation performed; each of the physicians involved with the JHTMC realize that adjusting to the limitations imposed upon you by TM is a difficult task. Every patient reacts to this in a different way, and you will inevitably experience a wide range of emotions as you adapt. We will ask each patient to complete a questionnaire examining your own mental state. We will also ask about your sexual functioning and suggest possible strategies to improve this if necessary. In this way, we hope to find those patients who are depressed or severely anxious. It is our goal to help you work through the expected negative feelings and develop a positive attitude about your self and your future life. We may suggest that you initiate therapy with a psychiatrist (you could see one while at Hopkins), or we may suggest an antidepressant medication. Since a patient's mental outlook is a vital determinant of continued recovery, it is critical that we assess and treat depression related to TM.

The vast majority of patients with TM have impaired urinary function. Some have difficulty initiating urination, while others have difficulty controlling the urge to urinate. Some patients have features of both. As a result, we may recommend that you undergo urodynamic testing. This is a procedure where a small catheter is placed through the urethra and into the bladder. We then can monitor the activity of the muscles which control urination, including the detrusor muscle and the urinary sphincter. It is only when these muscles operate in a coordinated fashion that urination occurs normally. Through this simple test, which takes approximately thirty minutes to complete, we can determine the cause of many patients' urinary difficulties and suggest exercise or a specific medicine to maximize function.

We may suggest additional radiologic studies to be performed both for diagnostic and prognostic purposes. Drs. Kraut and Beauchamp are examining whether certain specialized radiologic studies, including magnetization transfer indices, magnetic resonance spectroscopy, or diffusion-weighted MRI, provide additional insights into this disease compared to standard MRI studies.

Studies that utilize electrical impulses to examine muscle and nerve function are important in the evaluation of TM patients. Electromyography has been shown to help clarify patient outcomes and may help us to determine the extent of neuronal injury. Somatosensory evoked potentials examine the neuronal circuitry from

the feet all the way to the brain. These studies help determine to what degree the neuronal impulses are "getting through" the damaged area, thereby clarifying the prognosis for continued recovery.

As part of our comprehensive evaluation, you may be asked to participate in a research study. Such an undertaking would be entirely voluntary on your part, and refusal to participate would not affect the care given to you at the JHTMC. These studies are designed to improve our ability to diagnose and treat patients with TM. Certain studies hope to elucidate why some patients recover significant function following TM, while others do not. There may be certain features of the immune response in some patients, specific cytokines or T cell subsets, for example, that result in increased damage to neurons within the spine. There may also be certain radiologic studies or electrical studies that enhance our ability to determine which patients will improve. Finally, novel therapies are rapidly being developed to enhance neuronal recovery of patients with spinal cord injury. Some of these developing therapies aim to diminish neuronal damage in the acute phase, while others hope to stimulate regeneration of neurons, potentially even years after the injury. Neural growth factors, neuronal stem cell transplantation, neuroprotective agents and many other strategies are being developed. There is both good news and bad news to report. First the bad: none of these therapies has yet been shown to work in humans, and none is routinely available at present. It will be, in all likelihood, 5-10 years before we can begin to restore function to patients with spinal injuries. And the good: virtually all physician-scientists in this field feel that a revolution in treatment will occur, allowing significant recovery of function to patients with TM. Until then, we need to assist patients in ensuring maximal function utilizing present medical technology, and to minimize the chance of recurrent injury either from TM itself, or from complications thereof.

For more information on the JHTMC, please visit our website at www.med.jhu.edu/jhtmc. If you wish to be evaluated at the JHTMC, please call (410) 614-1522. Please be advised that it may take weeks to months to be evaluated. Why? We need to obtain referrals from your primary doctor to allow you to be seen here. Each evaluation (rehabilitation doctor, MRI, electrical study, etc.) requires a separate referral, a process that must be initiated by you and your doctor. Some insurance companies do not even allow patients to be seen out of network. In addition, we need to coordinate your care as best we can, which takes a lot of planning. Each of the doctors has a full schedule, and at times we may be "swamped." I, for example, only see patients on certain days, and then on other days I am in the laboratory trying to create new ways to restore function to patients with TM.

I hope that our center is of service to patients with TM, and remember I am available for questions and concerns through the e-mail contact on the JHTMC webpage. I believe there is a brighter future for patients with TM!

James Bowen, MD and Douglas Kerr, MD PhD to serve on TMA Medical Advisory Board

The TMA is very pleased to announce that Drs. James Bowen and Douglas Kerr are joining Drs. Joanne Lynn and Charles Levy on the TMA Medical Advisory Board. The addition of Dr. Bowen and Dr. Kerr enhances the stature of The Transverse Myelitis Association and serves to facilitate the achievement of our goals. We greatly appreciate their willingness to contribute their expertise to our Association and our members. We were very fortunate to have all of the physicians on our Medical Advisory Board attend and make presentations at The Transverse Myelitis Association International Symposium in August, 1999.

James Bowen, MD
Assistant Professor, Neurology
University of Washington

Dr. James Bowen was born in Vicksburg, Mississippi and grew up in New Mexico. He received his undergraduate training at Eastern New Mexico University. He went on to complete his Medical Degree at Johns Hopkins University in 1982. He served two years of residence in internal medicine (1982-84) and three years in neurology at the University of Washington (1984-87). He was the Chief of the Neurology Division at Pacific Medical Center in Seattle from 1987 to 1998. He also attended the Multiple Sclerosis Center at the University of Washington Medical Center during that time and served as Co-Director of the Center from 1989 to 1998. In 1998 he was recruited to join the faculty at the University of Washington. Dr. Bowen is currently an Assistant Professor of Neurology and Assistant Professor of Rehabilitation (adjunct). He is also the Director of Neurology Services for the Multiple Sclerosis Center at the University of Washington Medical Center and Director of the Multiple Sclerosis Research Center at the University of Washington.

Dr. Bowen has research interests and numerous publications in both multiple sclerosis and Alzheimer's disease. Current research involves

treatment of multiple sclerosis, rehabilitation issues in multiple sclerosis, and the epidemiology of dementia. Dr. Bowen and the Center are currently conducting seven studies of treatments for multiple sclerosis, including medications, stem cell transplantation and cooling. The Center is the recipient of the Department of Education Research and Training Grant for Multiple Sclerosis Rehabilitation. With this grant, the Center is studying issues of aging in multiple sclerosis, employment, wellness promotion, depression, exercise, cognition, and medical needs analysis in patients with multiple sclerosis.

Douglas A. Kerr, MD PhD
The Johns Hopkins Hospital
Department of Neurology

Dr. Kerr was born in Bloomington, Indiana. He received his undergraduate degree in Biology from Princeton University in 1988. He received his Medical Degree in 1995 from Jefferson Medical College, Thomas Jefferson University, Philadelphia, Pennsylvania and his Ph.D. in 1995 in Biochemistry and Molecular Biology from the College of Graduate Studies, Thomas Jefferson University. He served as a resident in the Department of Internal Medicine, The Graduate Hospital, Philadelphia, Pennsylvania in 1995-1996. Dr. Kerr served as a Resident (1996-1998) and the Chief Resident (1998-1999) of the Department of Neurology, The Johns Hopkins Hospital, Baltimore, Maryland. In 1999 Dr. Kerr became an Assistant Professor in the Departments of Neurology and Molecular Microbiology and Immunology, The Johns Hopkins Hospital.

Dr. Kerr obtained his research training under Dr. Kamel Khalili examining molecular factors relating to virus reactivation during immunosuppression (for example in AIDs patients). He determined the involvement of several cellular factors that cause certain viruses (JC Virus) to reactivate in AIDs patients, resulting in the universally fatal disease Progressive Multifocal Leukoencephalopathy. He also determined that several hemotherapeutic agents have potent antiviral activity against HIV-1 and JC virus, a finding that has been extended and is now being evaluated at Johns Hopkins Hospital in patients with HIV-dementia.

It was during his residency that Dr. Kerr became interested in transverse myelitis, and initiated experiments to define mechanisms underlying neuronal death in spinal cord injury. The laboratories of Drs. Marie Hardwick and Diane Griffin have successfully investigated mechanisms of neuronal apoptosis and have revealed fascinating insights about critical modulators of neuronal death. Utilizing the expertise of these laboratories in neurovirology, neuroimmunology and neuronal apoptosis (a fancy term for programmed cell suicide, which is what happens in many patients with TM leading to permanent disability), Dr. Kerr employed a novel viral model system to reveal for the first time that the Survival of Motor Neuron (SMN) protein functions in the protection of neurons from apoptotic death; and that mutant SMN protein found in patients with the neurodegenerative disorder spinal muscular atrophy (SMA) accelerates neuronal apoptosis. He has elucidated several potentially important mechanisms that govern this function, and is in the process of submitting a manuscript detailing his findings. It is hoped that this knowledge will allow the development of strategies designed to protect neurons from death following an injurious event, such as transverse myelitis. He has also generated exciting data regarding the potential role for neuronal stem cells in restoration of function in spinal cord injury. By combining his expertise in neuronal death and stem cell transplantation, Dr. Kerr hopes to advance the field of transplantation into the central nervous system and to ultimately consider the use of this technology in patients with transverse myelitis.

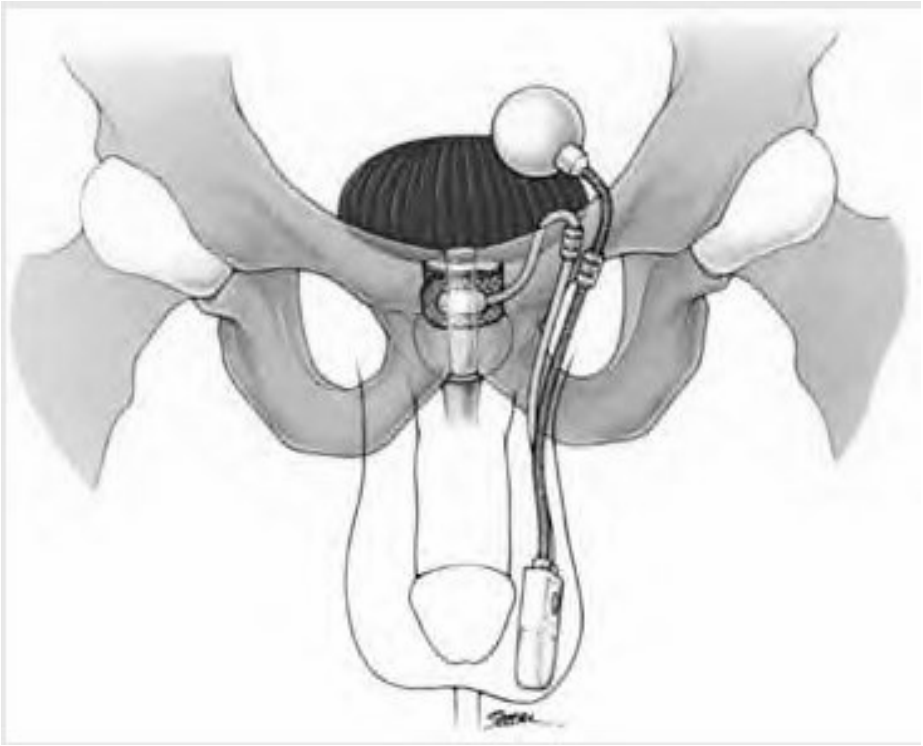
Dr. Kerr has numerous publications involving neurotropic viruses in the central nervous system. He has also published an article regarding the determination of a critical prognostic marker found in the cerebrospinal fluid of patients with acute transverse myelitis.

Discussion of the Artificial Urinary Sphincter (AUS)

Dr. Charles Jennings

Dr. Charles Jennings is a Diplomat with the American Board of Urology; a Member of the American Urologic Association; a Fellow of the American College of Surgeons; and a Member of the Society of Urologic Engineering. Dr. Jennings practices in Lima, Ohio. He performed the surgical procedure discussed in this article on Victoria Frohna who, in the following article, describes her experience.

The AUS is an implantable prosthetic device that provides an increased pressure resistance to a lower urethral pressure resistance, thus, resulting in urinary continence. The device consists of three connected components (figure). First, there is an inflatable pressure cuff that surrounds the urethra or the bladder neck providing increased resistance against urinary leakage. Second, the cuff is connected to a fluid-filled pressure regulating balloon reservoir



AMS Sphincter 800 ™ Urinary Prothesis, Courtesy of American Medical Systems, Inc., Minnetonka, Minnesota

that provides the required hydraulic pressure to the cuff. Lastly, a resistor-valve pump is connected to both the reservoir and cuff, and regulates the exchange of fluid between the two depending on whether the cuff is inflated or deflated. The device functions by providing a constant pressure resistance to the bladder outlet from the inflated cuff, thus, providing continence. When this increased resistance is not needed during voiding, fluid is then transferred from the inflated cuff into the reservoir by manipulating the pump, located in the scrotum or labia majora. The cuff remains deflated between two and a half to three minutes, allowing unobstructed voiding. The cuff automatically reinflates through transference of fluid to it from the reservoir via the pump's resistor valve. This process of deflation and reinflation of the cuff is referred to as "cycling."

When bladder pressures attain those greater than urethral resistance pressures, urinary incontinence results. Increased bladder pressures may originate from either its own layered-wall properties or from transmitted abdominal pressures to it due to coughing or straining. Incontinence represents an abnormal relationship existing between the bladder and urethra, either bladder pressure is too high or urethral pressure is too low. As mentioned above, the AUS is generally implanted in patients suffering from urinary incontinence due mainly to this low urethral pressure resistance, provided that they have normal resting bladder pressures. This particular type of incontinence, categorized as Type III, stress variant, may occur after previous surgery involving the bladder neck or urethra resulting in the body's own intrinsic sphincter being incompetent. Another situation where an incompetent intrinsic sphincter may arise is from disorders or injuries of either the spinal cord or its peripheral nerves supplying the bladder neck and urethra. The AUS has its best utility in the setting of an incompetent intrinsic sphincter associated with normal bladder functioning. The candidate for the AUS must be able to completely empty the bladder spontaneously and must not have a resting bladder pressure that is too high. Simple urodynamic testing will identify those patients who either are in urinary retention or carry high resting bladder pressures, both of which threaten the health of the upper urinary tracts and kidneys.

Patients who undergo implantation of the AUS for appropriate indications generally fare well as reported in most hospital series. Continence as defined by wearing no protection, such as pads, ranges from 91-92%. Mechanical failure rates for the device in two large series has been reported as 0% and 21%, respectively, with a follow-up range from 2.5-8.9 years. Other less common complications include erosion of the device through the bladder neck/urethra or through the skin, device-related or urinary tract-related infections or, more seriously, upper tract and kidney damage.

The implantation of the device, while not technically difficult to perform, requires proper pre-operative preparation including a dexterous, motivated and thoroughly informed patient who has met the appropriate indications for this procedure. The immediate preoperative preparations of the patient include broad-spectrum prophylactic antibiotics along with proper skin and bowel preparations. There should be no deviations from proper surgical technique and the device should be handled very carefully by the OR team. Post-operatively, a foley catheter should be left in overnight. The device should be left in the de-activated mode (cuff deflated) for two to six weeks depending on whether this was a first time insertion or a revision. Revisions

usually do not require the longer de-activated time period. All wounds should be kept as clean and dry as possible. Broad-spectrum oral antibiotics should be continued for a few days post-operatively. Anti-spasmodic medications should be provided for bladder spasms that usually occur up to several weeks post-operatively. Light work or recreational activities may be resumed in two to three weeks with return of normal activities, including even intercourse, usually by six to eight weeks. Patients should plan for follow-up visits with their health care providers for as long as they have the device. The visits focus on signs of erosion or malfunctioning of the device, upper urinary tract deterioration, and patient satisfaction. Most insurance carriers will cover the, roughly, $3000 device provided that proper indications for the procedure are documented.

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My Experiences with Transverse Myelitis and Artificial Urinary Sphincter Surgery
Victoria A. Frohna
March 18, 1999

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October of 1997 changed my life dramatically. I had been divorced for a long time, and had raised my two sons alone. Also, I kept very busy with my life as a Licensed Practical Nurse (LPN) at our local community hospital where I had worked 15 years.

I recall the last day I had worked, which was October 2, 1997. I also recall the "backache" pain I felt that evening after a 12-hour shift. I felt lucky to have a four-day "off" period, and just relaxed for that period of time anticipating my return to work on October 7, 1997.

The morning of October 7, however, it was very clear to me that work was out of the question. I vividly recall awakening at 5:05AM that day, due to the severe pain in my lower back. The pain was very different than previous back pain had been for me. The excruciating pain seemed to start in my low back, but it also literally wrapped around my thighs like a tight band. Due to the difference and severity of that pain, I seriously thought I had ruptured a disc or two in my lumbar spine. That thought was pretty certain in my own mind when I tried to roll over in bed and could hardly move my legs. Somehow, I managed to sit up on the side of the bed and then realized my bladder was very distended or full "up to my earlobes." Holding onto furniture to manage the short trip to the bathroom, I was able to void at the time – for the last time. My attempt to return to bed unsuccessful because of the pain, I screamed for my son who assisted me back to my bedroom just as my legs crumpled beneath me, and I fell to the floor.

That morning I did go to work – in an ambulance. My normally low blood pressure was 170/90, due to the pain and also fear regarding my symptoms. I was immediately given Demerol 100 mg, Phenergan 50 mg IM, followed by Valium 10 mg orally. But as I laid on a gurney in ER, even the narcotic medication did little to relieve the pain. My feet and legs were like ice to touch, and the ability to move my feet and ankles was lost. Of course, I was admitted, and a CT scan was done. I received pain meds every four hours, and when I attempted to void again, that was also unsuccessful. At that time I was catheterized.

The next day, October 8, 1997, it was decided that I would be transferred to Dayton, Ohio, to be seen by a neurosurgeon there. At a later date, I was told that I was thought to be a "neurosurgical emergency." At the Dayton hospital a MRI was ordered STAT, and done soon after my arrival there. The next morning, another MRI was done, followed by a spinal tap. (I was told that Transverse Myelitis doesn't show up on a CT scan – only on the MRI. Also, my CSF from the spinal tap showed an elevated serum protein – an indication of TM). After the lumbar puncture was completed, my neurologist came to my bedside to tell me the diagnosis: Acute Transverse Myelitis.

Never have been so ill in my life. The first week in the acute care facility was difficult for me. After all, I was used to being the "caregiver," and not the patient. The emotional toll felt almost as bad as the physical toll this syndrome had dealt me.

From October 8 until October 15, I was given high doses of steroids to help decrease and eliminate the swelling and inflammation around my spinal cord. My urinary catheter was removed and then replaced, after it was determined I had no bladder control. Bowel function was also adversely affected, of course, since my TM injury occurred at the level of L-1. This same week, I did spend some hours sitting up in the hospital room chair – after my caregivers pivoted me into it. At the time, I was unable to bear any weight on my legs. Tearfully, I asked my doctor if "I'll be

a paraplegic?" He replied that I would probably be "functional."

It was on October 15, 1997 that I was again transferred to a third acute care hospital for "long term rehabilitation." I was told I'd probably be there about six weeks.

October 16 was my first full day in rehab. I was actually able to stand between the two parallel bars for the first time. On October 17, I remember my family arriving to visit just after I had walked 36 feet between the parallel bars for the first time! I cried tears of joy, because it was really the first indication that I may actually walk again. Although my right leg was extremely uncontrollable and my left leg was only slightly more controllable, my physical therapists and occupational therapists were also very pleased with my progress. It was necessary to literally tape up my right foot and toes so that I wouldn't trip over my own foot. My right side was more adversely affected because the majority of the swelling was on the right side of my spinal cord – however, the left side was also affected. Initially, I was unable to abduct my right leg at all due to the injury, and standing and keeping my own pelvis beneath me was virtually impossible.

By the time I was discharged home on November 7, 1997, (three weeks later), I was elated to be able to stand at a counter for over 16 minutes, and I was **walking** with the use of a walker a total of 170 feet. My physical therapists asked me if I've always been so stubborn? My answer was, "sure." And I feel that that factor, and especially G-d and the support of family, friends, and co-workers have helped me to cope with this illness so far.

It was early in spring of 1998 that I received a call from a nurse/friend of mine who had only recently heard of my illness. My friend told me of a new surgical procedure to eliminate urinary incontinence. The procedure is the implantation of a device known as an "artificial bladder sphincter," and luckily for me there is a local Urologist/Surgeon who is doing the procedure. After examinations, some testing and much discussion, I decided to have the surgical procedure done on April 27, 1998.

The artificial sphincter surgery is one of the best things I have done since my onset of TM. The device is relatively simple, with a "balloon" filled with sterile water placed beneath the abdominal muscle near the bladder. The device also has a "cuff" which fits around the bladder neck or urethra, and resembles a very small blood pressure cuff. Then the "pump" of the device is implanted within the labia of a woman or the scrotum of a male. All parts of the mechanism are implanted, and nothing is visible on the body surface, and so only the pump itself can be felt when manipulation is necessary to void. It is very easy and painless to use, and I went literally from 100% urinary incontinence to 100% urinary continence (control) after my surgery, and after healing had occurred. Of course, there is some surgical discomfort after the procedure is done. But the surgical discomfort, at least for me, was minimal as compared to the initial acute pain of myelitis. The sphincter is appropriate for patients like myself, in that I had **no** bladder control because of the TM. However, I am told that the device is **contraindicated** in a patient with urinary retention. The best option, of course, is to discuss it with your physician.

As I complete this article in early April 1999, my physical therapy is completed. I can walk short distances without my cane (if no obstacles are in my path), but I will need my cane 90% of the time. I also wear an AFO (ankle-foot orthotic/brace) on my right foot and ankle. Balance continues to be a real problem and I fall frequently. Bowel control is also limited as most TM patients are aware, but my bladder is controlled 100% by me.

I am hopeful that as time passes, I will regain my balance (and not fall anymore!). I am also hopeful that I can complete my goal of becoming a Registered Nurse – perhaps even working with neurological patients at some later date. Meanwhile, I hope my experience and description of the surgical procedure will help others in similar situations.

We only become stronger persons after the adversity we ourselves endure.

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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.

Pregnancy and Delivery Issues with Transverse Myelitis

I have received at least one or two questions a month about pregnancy and delivery issues from couples who are considering having a child. There is a paucity of information on the subject, which makes it very difficult for persons with TM to make these very important decisions about whether they should become pregnant and have a child. Often times I refer these people to Paula; she is able to present her own experiences about pregnancy, delivery, and child-rearing issues. Dr. Lynn graciously responded to my request to present some information that might assist persons with TM in making these decisions. I also asked Paula to prepare an article, which enumerates the information she has been sharing with persons who she talks to about these issues regularly. We recognize that there is not enough information presented here upon which you are going to base these decisions. It is our hope that there is sufficient information presented by Dr. Lynn and Paula to stimulate your thinking about the issues and to help you frame the questions that you would like to ask your own physicians in making your decisions.

The following information is offered as a general response to questions related to 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 detailed history or an examination. Any decisions regarding diagnosis or treatment should be made in consultation with your personal physician who is best suited to make appropriate medical recommendations for you.

Dr. Lynn, could there be an exacerbation of TM symptoms from pregnancy or a reoccurrence of TM symptoms from pregnancy? What are the potential risks to the mother with TM or the child during pregnancy? What variables should a couple consider, when the woman has TM, when deciding whether to become pregnant? Are there any general guidelines that would help couples make these decisions?

There does not appear to be much information in the literature specific to Transverse Myelitis that would assist couples in making decisions about pregnancy. However, I am aware of MS research that has tracked women during and after their pregnancies; thus, it is possible to offer some recommendations to women with MS based on the results of these studies. What happens with MS is that there is a significant decrease in attacks of MS during the second and third trimesters of pregnancy, but then in the six months after delivery, there is an increase in MS attacks. The results of a small study suggest that women who had a child were not any worse off then women who did not five years after the delivery. This type of information is not available about TM.

An important issue for the individual to consider is whether there is any sign of an underlying autoimmune disease such as SLE or MS, as pregnancy can affect disease activity in these illnesses (although not predictably). It is difficult to assess how a monophasic illness (one occurrence), such as typical Acute Transverse Myelitis, would affect a woman during pregnancy and delivery.

The following is a summary of a journal article (Berghella, V., Spector, T., Trauffer, P, Johnson, A.; Department of Obstetrics and Gynecology, Thomas Jefferson University Hospital, Philadelphia, Pennsylvania. "Pregnancy in patients with preexisting transverse myelitis," In Obstetrics and Gynecology. Vol. 87, no. 5, Pt 2 (May 1996): 809-12.) describing two cases of women with Transverse Myelitis.

Background: Although several cases of pregnancies of traumatic spinal cord injury patients have been reported, to our knowledge, only one case has been reported detailing the perinatal outcome in a patient with preexisting transverse myelitis. **Case**: The prenatal course and pregnancy outcome in two patients with preexisting transverse myelitis is presented. The major complications encountered were urinary tract infections and mobility problems. **Conclusion**: Patients with preexisting transverse myelitis can have successful pregnancies with term vaginal deliveries. Prevention of potential complications, such as anemia, preterm labor and delivery, decubitus ulcers, and autonomic dysreflexia can be achieved with coordinated multidisciplinary management.

Finally, a chapter in the following book (Norwitz, ER, Repke, JT. "Obstetric Issues in Women with Neurologic Diseases" in Neurologic Disease in Women, Kaplan, PW (ed.), Demos Medical Publishing, Inc., New York, New York, 1998; pp. 122.) offers a brief discussion of pregnancy in patients with paraplegia due to spinal cord trauma, although there is no significant mention of TM. For women with paraplegia due to spinal cord trauma, they mention several things:

1) Urinary tract infections may complicate pregnancy. These are common in women without neurologic problems, but more so in

those with spinal disorders. Antibiotic therapy to suppress urinary tract infections should be considered.

2) People with high thoracic or cervical spinal cord injury may have decreased pulmonary function. Because of the size and position of the developing fetus, the diaphragm may be displaced upward and lung volumes reduced. This causes discomfort in women with healthy neurologic systems; in women with paraparesis, it might cause inability to take in enough oxygen. Some women might even require respiratory support by a mechanical ventilator during the later stages of pregnancy. Because of this problem, pulmonary function tests should be performed on such women to assess respiratory status.

3) Most women with paraparesis can deliver vaginally. They note that women with complete cord transection above T10 segment (level of the navel) will have painless labor. However, often TM is incomplete or recovers partially so this is not reliable for patients with only partial sensory loss below T10. It is noted that women with significant sensory loss may not appreciate labor contraction pains and, therefore, those with significant sensory loss are recommended to have more frequent cervical checks after 28 weeks gestation to look for premature labor.

4) The chapter also talks about a condition called autonomic dysreflexia. This is a condition of uncontrolled discharges of the autonomic nervous system which is an uncommon but life-threatening problem in patients with traumatic spinal cord injury. **I am not certain if this ever occurs in a person who has had inflammatory transverse myelitis.** However, in a severe myelitis, it is conceivable. In this problem, the person develops severe headache, severe high blood pressure, reflex bradycardia, sweating, flushing, and occasionally problems with breathing or heart rhythm. It results from loss of brain (hypothalamic) control of spinal cord reflexes controlling the sympathetic nervous system functions (which control vegetative functions such as blood vessel size, bladder function and others). Stimulation such as an overdistended bladder or uterine contractions can cause autonomic dysreflexia. This chapter describes steps to reduce the risk of autonomic dysreflexia and to manage this complication.

It is important that you consult your neurologist and your obstetrician to discuss your specific case, particularly since there is very little research in the literature to guide a decision. Also, if you have a significant paraplegia you should consult an obstetrician who specializes in high-risk obstetrics.

My Life As "Mama Zoom"
Paula Lazzeri

I've heard people say that parenthood is one of the toughest jobs they ever took on. I can say, that's very true and, for many reasons, it's also one of the most rewarding. Life after TM can be very frustrating and challenging. I grew up in a family of seven siblings with strong, loving parents. What that did was convince me that I definitely wanted children someday.

I contracted TM at the age of 12, just two months into the 7th grade. At the onset I could not move my arms and legs and had trouble breathing. Twenty years later, I am still a C6-7 incomplete paraplegic with majority use of my arms and hands. My left hand is very numb yet it is stronger than my right. I have difficulty writing, using scissors, opening jars, working with small items (i.e., paper clips, typing, and keys). Thankfully, I can weight bear on my legs and am able to do pivot transfers from wheelchair to van, toilet, and couch. I cannot feel temperature and pain from my chest C6 level down but do feel that tingly sensation and have many spasms. After the onset of TM, my doctors noticed I had a slight curve to my spine (scoliosis). By my 3rd TM anniversary, the scoliosis had progressed so far that I only had an inch of space between my breast and backbone. Since there was danger to my heart, the decision was made to fully fuse my spine using metal compression rods.

After being married for six years, my husband and I started thinking about having a baby. We went to a high-risk OB doctor to be evaluated. My primary issues about getting pregnant were would carrying a baby full term effect my spinal fusion; would my baby be at any higher risk to get TM; with the paralysis, would I know I was in labor; with weak abdominal muscles, how would I deliver a baby; and would I have trouble breathing since I already struggled with less than the normal lung capacity? We discussed each of these topics after a full physical. She was able to answer most of my questions. My spine was very strong ten years after the fusion, and I could expect nothing to happen to my back. There were no studies on TM and pregnancy so as to whether Jesse would be at any higher risk was not answered. For that matter, there were no studies, "period," on anything having to do with TM, so we had to proceed blindly with this. The weak abdominal muscles were fine, because your body takes over and medical staff are able to help push if needed. She did find that premature labor is common in paraplegics. So, I saw my OB more frequently than other women and was monitored very closely near the end of my pregnancy. As far as

the breathing, that would most likely be a problem, but it was a "wait and see" kind of thing. Most women, at some point late in their pregnancy, have trouble catching a deep breath. We received the green light to get pregnant.

It didn't take long and I was back in her office a few months later. I quickly discovered that certain aspects of this pregnancy would be perfectly normal. The first four months I spent doing taxes in the restroom at work (I am a tax accountant), while I experienced the thing called "morning sickness". My body underwent the normal amount of abdominal swelling and I soon found myself with the equivalent of a basketball in my lap.

There were some things that were uncertain and gave us some concern. Myk completely worried about the delivery, especially when we found out there was no way I could have an epidural. We feared I would have premature labor and be rushed in for an emergency C-section. Because I suffered from frequent urinary tract infections (UTI), my doctor put me on antibiotics and prenatal vitamins, along with my normal doses of baclofen and ditropan. Since there were no studies on the effects of these drugs on women during pregnancy, we had no concrete evidence on which to base which and how much I should take. I took baclofen, ditropan, antibiotic (to prevent bladder infection) and prenatal vitamins throughout my pregnancy. When deciding whether to take the baclofen and ditropan, my OB did go to her risk database. The only information she found was that it did cause some complications (which ones I cannot recall) in rats (no human studies were available) at a very high dose. Knowing I was not on high doses, that the study had only been done on rats, and that the symptoms I experience without the medications were unbearable, the decision was made to continue taking them. My history of bladder infections was also quite large so she did not want to risk me getting an infection; she put me on antibiotics. When we weighed the alternatives, it was clear the spasms and symptoms without the meds would be far worse than any side effect that might appear with the meds.

As a C6-7 quad, I have only 75% of the lung capacity of a normal person. So, near the end of my term I developed some serious breathing problems. When I saw my doctor, she made some final decisions that were important for the baby's and my welfare. Because of the trouble breathing properly and because premature labor is common in paraplegics, we decided that she would do a C-section at least three weeks early, using a general anesthetic. In order to avoid autonomic dysreflexia, a condition adversely affecting one's blood pressure, the usual procedure is an epidural anesthetic, but because I have a complete spinal fusion, this was impossible.

The doctor discovered how much she had underestimated the strength of my spasms when she tried to do an amniocentesis and the spasms kept pushing the needle back out as quickly as they inserted it. For the same reason, they were forced to use a blood pressure cuff instead of the IV generally used to monitor. The delivery, at that point, went as planned and our baby boy was born sleepy but completely normal and healthy. One week after the C-section, the suture came loose, again because of the spasms, and the doctor restored the incision successfully using a metallic thread.

I did not worry much, until afterwards, how I was actually going to get around with Jesse. I did not think much about how I was going to hold him and push my chair, get him in and out of the crib, in and out of the car, and generally have the energy to take care of Jesse and myself. Myk and I did not talk much about the after care until Jesse was born. I just did not realize how difficult caring for an infant was going to be. It was very tough until he was able to walk!! Myk, being the wonderful, patient and understanding person he is, just filled in where needed. You have to realize you need help and have to ask for it. I was not used to asking for help. I did not take Jesse outside my home without Myk or someone else to help until he was more self-sufficient (walking and talking and able to take direction from me). Being able to walk with a child in your arms is a gift and one that I have never experienced. Jesse grew to know what kind of comforts I could give him and does not expect anymore. He knows no different.

Keep in mind that, while most mothers develop special abilities once baby arrives, the physically challenged mother needs to develop the dexterity of an octopus. Once I was healed and able to take on some of the responsibility of being a mother, I had to devise original means of accomplishing that feat. Obviously, I couldn't carry Jesse and push my chair at the same time; I used a pillow crosswise on my lap, and balanced him diagonally on it, facing me, with his feet tucked under the armrest of my wheelchair. Some things my husband, Myk, had to do, such as lifting Jesse in and out of the bathtub, crib or car. For the first couple years, I didn't go out alone with Jesse. I needed help getting him to and from and in and out of the car, buildings, and elevators and pushing a grocery cart around the store. Myk was most always there, but when he

couldn't be, someone from our family helped.

Jesse will be seven years old in three months and is in the first grade. When we look back at those first six years, we can honestly say they were hard, at times frustrating and exhausting, but they have been the most fulfilling. This will be the third year in a row I have gone to Jesse's class to share with the children about who his mama is and all about being in a wheelchair. It wasn't until recently that we realized Jesse had given little thought to the fact that I am in this chair, when he asked me where all the other mama's wheelchairs were. He's very proud of his mom and loves it when I come to his class. In turn, Myk and I are extremely proud of our son, especially when we see how easily he interacts with anyone who is different in any way. He is a constant reminder of what a good decision we made seven years ago.

Member Questions and Answers from Joanne Lynn, MD

Joanne Lynn, MD 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. If you have questions for Dr. Lynn regarding the Transverse Myelitis condition, please send those to Sandy Siegel; we will attempt to have your questions addressed in the next newsletter.

The following information is offered as a general response to questions related to Transverse Myelitis and is not to be construed as a specific medical recommendation for any individual. This information is based on the information provided in a brief question and is without the benefit of a complete history or an examination. Any decisions regarding diagnosis or treatment should be made in consultation with your personal physician who is best suited to make appropriate medical recommendations for you.

What is a lesion? What are doctors describing when they explain that they have identified a lesion or lesions at particular levels of the spinal cord in regard to TM? Why are people effected in one place on the spinal cord and others over larger areas of their spinal cord, and still yet others in non-contiguous areas - is that possible? Why do some people with TM have lesions and others do not?

The dictionary definition of the word *lesion* is an abnormal change in the structure of an organ or tissue due to injury or disease. Most patients with TM undergo examination of the spinal cord by MRI (magnetic resonance imaging). Often this type of imaging will display an area of abnormal signal within the cord, which is circumscribed and well defined; this is a detectable lesion. Lesion is a very nonspecific word meaning any abnormality of structure. In TM, the abnormality may be the result of inflammation, swelling or destruction of cord tissue.

Sometimes there is tissue damage that does not show up on a MRI of the cord. In this case, a microscopic lesion or area of inflammation or tissue injury is presumed to have occurred at a certain level of the cord based on findings on neurologic examination, but the MRI was not able to pick it up. One would assume that if a biopsy was done of the injured area of the cord, abnormalities such as inflammation would show up on microscopic examination of the tissue.

It is true that the lesion may be small, limited to one level of the cord, and well localized. Other people with TM have a lesion that spans many inches of the spinal cord. And yet others can have multiple lesions at different levels of the cord. We do not know the reasons for this variation at this time. However, if one assumes that TM is caused by inflammation of the cord caused by the immune system reaction to various infections, etc., then it is understandable that the white cells of the immune system can come to any level of the cord through the bloodstream.

People are told they can resume all of their physical activities, but sometimes when they have completed these activities (running, walking, weight lifting, swimming, aerobic exercise, golf), their symptoms are intensified for a while afterward. Are these people hurting themselves from a healing standpoint? Are they causing any damage to the nerves that have been injured? How should a person evaluate the type and amount of exercise they are doing? What factors need to be considered?

There is more information about exercise in multiple sclerosis than in transverse myelitis. However, the basic principles regarding exercise in MS also apply to TM and other spinal cord injuries. An interesting phenomenon can occur when a person with MS experiences an increase in body temperature either by exercise, hot external temperatures or fever. Weakness or other neurologic symptoms may worsen. This is attributed to the fact that electrical

nerve signals do not travel through demyelinated nerve tracts as well as through normal nerves at hot temperatures. (Myelin is the insulation around nerve fibers; it is destroyed in MS). Some people with TM also have demyelination of parts of their spinal cord and may also experience worsening of neurologic symptoms such as weakness, numbness, tingling or other abnormal sensations when they exercise and raise their core body temperature. This transient worsening does not mean that another attack of multiple sclerosis or transverse myelitis will occur with exercise.

Because of this worsening of function with elevated temperature, neurologists used to warn against exercise in MS. However, there is more understanding now of this phenomenon and most neurologists would recommend exercise for people with MS and TM if certain principles are observed. A proper exercise program designed for a particular individual should include type of exercise, duration, frequency, and intensity of exercise.

Stretching is an important part of any exercise workout but is especially important for people with spinal cord injury who may have abnormally increased muscle tone (called spasticity). Muscles and tendons should be stretched gently before starting on an exercise routine. It takes more energy to exercise when there is significant spasticity.

For those who have significant weakness in the legs, it is best to start with gentle aerobic exercises such as walking if possible, propelling a wheelchair, swimming, water aerobics, bicycling. The goal should be to gradually increase endurance and stamina. As Randall Schapiro, MD has written, the "no pain, no gain" approach to exercise is exactly wrong for people with MS and other spinal disorders. If there is partial weakness, trying exercises that require too much resistance or doing too many fatiguing repetitions may lead to injuries such as sprained ankles, etc. Exercise programs must be individualized according to the person's level of training and type of underlying neurologic problems. However, exercise is strongly recommended for people with MS and should be for people with TM also.

In fact, a recent study of 46 patients with mild to moderate disability from MS who could all walk, some showed that an aerobic exercise program of three supervised training sessions per week for 15 weeks had significant benefits including improved fitness and strength and reduced body fat. A 5-minute warm-up period was included and care was taken to control the air temperature and to prevent overheating by fans. In addition to the obvious benefits, the exercise group also showed some benefits in bowel and bladder function, fatigue and depression. This study was reported in the April 1996 issue of Annals of Neurology.

You may find it useful to read about the stretching exercises described in Dr. Schapiro's book or to ask your physician for a referral to see a physical therapist to help design an individual exercise program. Obviously, you should consult with your personal physician for recommendations regarding exercise. However, I would say that people with TM should not be scared away from exercise by worsening of tingling in the legs, etc. It is unwise to exercise to the point of significant pain as your body is probably trying to tell you that you are injuring it. The guide here is "start slow, and go slow."

Could you speculate as to why TM impacts one particular area of the spine and not another? Is it a random process? Could there be any influence from a physical episode such as a strain or a blow to that area?

I don't think that I can speculate in any meaningful way about why one area of the spine is affected in TM and not another. It has been noted that the thoracic spine is most frequently affected, followed by the cervical and then lower levels. There have been attempts to link many neurologic illnesses to trauma including multiple sclerosis, amyotrophic lateral sclerosis (Lou Gherig's disease), Parkinson's disease, etc. However, there has never been good evidence to back up these proposals and trauma would seem to be an unlikely cause for most episodes of TM. It should be noted that the spinal cord can suffer injury from trauma with resultant high signal lesion in the cord which could mimick TM. Preexisting canal stenosis (not enough room in the canal for the spinal cord) could also predispose to spinal injury with trauma.

Is there a causal relationship between TM and seizures - any relationship?

By definition, TM normally affects only the spinal cord. Seizures are caused by abnormal discharges in the brain. Therefore, TM should not be a cause of seizures. However, there are processes of inflammation that may affect both the brain and the spinal cord at the same time. In those cases, the TM would be caused by inflammation of the spinal cord and the seizures by inflammation or injury to the cerebrum (part of the brain).

Reference: Randall T. Schapiro, MD. Symptom Management in Multiple Sclerosis. New York: Demos Medical Publishing Co., Inc., 1998.

Member Questions and Answers from Norman J. Uretsky, PhD

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. If you have questions for Dr. Uretsky regarding medications, please send those to Sandy Siegel; we will attempt to have your questions addressed in the next newsletter.

The following information is offered as a general response to questions related to Transverse Myelitis and is not to be construed as a specific medical recommendation for any individual. This information is based on the information provided in a brief question and is without the benefit of a complete history or an examination. Any decisions regarding medications or treatment should be made in consultation with your physician who is best suited to make appropriate medical recommendations for you.

Do antidepressants interfere with libido and ability to achieve orgasm? If so, why do antidepressants have this effect? Are there classes of antidepressants that have less effect on libido and orgasm than others?

There are several antidepressant drugs that are used clinically. These drugs can relieve depression in a majority of patients, but are associated with certain unpleasant side effects. One side effect produced by most antidepressant drugs currently in use is impairment in sexual functioning. This effect not only leads to a reduced quality of life but has been known to cause patients to become noncompliant and refuse to take their medication.

In order to determine whether an antidepressant drug interferes with sexual function, it is necessary to distinguish between the effects of a drug and those produced by depression itself. This is because both depression, as well as antidepressant drugs, can produce sexual dysfunction and, in particular, a loss of sexual desire. In fact, depressed patients, taking antidepressant drugs, often do not complain about sexual dysfunction simply because their sex drive is reduced by the disease. In addition, patients who experience drug-induced sexual dysfunction usually don't spontaneously complain about this impairment and will only mention this problem if they are directly questioned. It has been suggested that this is the reason why the incidence of sexual impairment associated with antidepressant drugs is reported to be lower in the Physicians' Desk Reference than in the results of clinical studies, where questions about sexual dysfunction are usually asked of the subjects.

Data from several studies indicate that most antidepressant drugs are associated with sexual dysfunction. Thus, tricyclic antidepressants (e.g., imipramine -Tofranil, amitriptyline – Elavil, etc.), monoamine-oxidase inhibitors (e.g., phenelzine-Nardil), selective serotonin reuptake inhibitors (e.g., fluoxetine - Prozac, sertraline - Zoloft, etc.), and selective norepinephrine and serotonin reuptake inhibitors (e.g., venlafaxine -Effexor) are reported to produce a decreased sex drive, erectile dysfunction, delayed orgasm, inability to achieve orgasm, impaired or painful ejaculation, and/ or penile or clitoral anesthesia. The antidepressant drug, trazodone (Desyrel), has been associated with the condition called priapism (prolonged painful erection requiring immediate medical attention) although the incidence of this adverse effect is rare (1 in 6000).

A variety of strategies have been developed to deal with the problem of sexual dysfunction caused by antidepressant drugs. One approach has been for the patient to take a "drug holiday." That is, the patient discontinues taking the drug for 2-3 days before the anticipated sexual activity. Such an approach has been useful in treating sexual dysfunction caused by the selective serotonin reuptake inhibitors, sertraline (Zoloft) and paroxetine (Paxil). However, it has not been successful in patients taking fluoxetine (Prozac) because the active metabolite of the drug remains in the blood for long periods of time and is present even after the drug holiday. Another problem with this procedure is that the temporary discontinuation of paroxetine (Paxil) and sertraline (Zoloft) can produce a transient withdrawal reaction. An approach, recommended from case studies, is adding drugs to the antidepressant regimen. Thus, cyproheptadine (which blocks serotonin receptors), yohimbine (which blocks noradrenergic receptors), or amantadine (Symmetrel) or methylphenidate (Ritalin) (which activates brain dopamine receptors) have all been reported to be effective in reducing sexual dysfunction induced by the selective serotonin reuptake inhibitors. However, one problem with this approach is that these adjunct drugs, like all drugs, can, themselves, produce unpleasant side effects. Probably a better strategy is to change antidepressant drugs to one that is less commonly associated with impairment in sexual function. In general, three antidepressants currently available are associated with a relatively low incidence of sexual dysfunction (although they produce other side effects). These are bupropion (Wellbutrin, Zyban),

nefazodone (Serzone), and mirtazapine (Remeron). Studies have shown that switching to one of these antidepressant drugs can produce a marked improvement in sexual functioning.

The mechanism by which antidepressant drugs produce impairments in sexual functioning is unclear. Certain inferences, however, can be made. In general, drugs that increase serotonin transmission in the brain produce dysfunctional symptoms (described above), suggesting that activation of central serotonin receptors may mediate sexual dysfunction. Since antidepressant drugs that both increase serotonin transmission and block specific serotonin-2 receptors (nefazodone & mirtazapine) are less commonly associated with sexual dysfunction, the activation of these particular receptors may mediate the dysfunctional effects. This concept is supported by the low incidence of sexual dysfunction associated with bupropion, which increases dopamine and norepinephrine but *not* serotonin transmission in the brain.

Is aspartame a neurotoxin and is it possible that aspartame can cause MS type symptoms?

Aspartame is an artificial sweetener and it is also found in some diet soft drinks. There have been many reports published on aspartame and I am not aware of any documented problems. There have been a number of diseases that have been attributed to aspartame, including epilepsy, multiple sclerosis, brain cancer, Alzheimer's disease and diabetes. The evidence, however, does not support any relationship. The FDA reports that the product is safe, and the Multiple Sclerosis Foundation and the Canadian Diabetes Association also report that the product is safe. Methanol, which can be toxic, is one of the metabolites of aspartame, but it is toxic only at a certain dose. There is no evidence that the quantity of methanol produced from taking aspartame is sufficient to be toxic.

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.*

TM and HIV Disease
Will Carter
San Francisco, CA

The following message was posted to the Transverse Myelitis Internet Club on Monday, June 14, 1999. Will was the first person to contact the Association who developed TM with HIV as an underlying condition. Through Will's willingness to share his story, we are hoping that we are better able to reach out to people who have HIV and Transverse Myelitis.

Dear People:

For the last year or so I have been a voyeur to your site. From what I see, there aren't any other people that fall into my particular niche. I am a gay African-American man in his forties living with HIV disease in San Francisco. Last year I came down with Transverse Myelitis, a disease I hadn't heard about until its onset. I wanted to write something about my experience because there may be more people out there like me and maybe they will not find it as difficult or as isolating having these two diseases. I suspect that there are at least a few people with TM and HIV. That said, here is my story.

I remember the exact moment I felt the effects of Transverse Myelitis. It happened a week before last Labor Day. I was on my way from my office on Monday afternoon. The day before I did the laundry and ate something during the day. That night, after returning from the laundromat, I took a rest on my couch and woke up in the evening, went to the bathroom and vomited. I noticed that everything I had eaten that day including breakfast went out of me. It was like I hadn't digested anything during the day.

The next day, Monday, I had an appointment with my therapist at one o'clock. As I left my job, I remember feeling a small pain in my lower back. I was carrying my briefcase and thought that it had caused a muscle spasm. By the time I got to my car across the parking lot, a pain was emanating down the front of my left leg, then my right leg. By the time I got across town, I could hardly stand the pain. I kept my appointment and told my therapist about the pain I was having. He said it sounded like a touch of sciatica. When I left an hour later, I could barely walk because of the pain. For the rest of that week, my condition worsened daily. I made an appointment with my doctor to see her after the holiday, but by the weekend I couldn't walk. I was on

some painkillers and thought it would all go away if I could just rest a little. There were other problems as well. I hadn't had a bowel movement or urinated for about three days. I didn't have a fever or anything, body aches, but I sure felt bad. Finally, that Thursday or Friday, I called my doctor and she said I should go to the emergency room immediately.

I waited for my partner to get home from work. I am a gay person and have been in a stable relationship for much of the past eighteen years now. I could barely walk down the stairs from my house. When we got to the hospital, I was placed on a gurney. I remember the intern said that it seemed like I had an extreme case of back pain and that I was probably going to need an immediate operation on my spine. My partner dismissed his diagnosis as guesswork. In any case, the first thing they did was to put a catheter in my penis and drain my bladder. That caused me a great deal of relief. After waiting about a half an hour, they took me in for a MRI. They scanned every thing from the top of my head to halfway down my spine. Just when I thought I was finished, they took me in again. They had found something on my spine about half way down. They didn't know exactly what it was, but when I told them I was HIV positive, they immediately started talking about CMV or PML. Now, I'm not only a person living with HIV, but I am also a long-term survivor. I was diagnosed as HIV positive in 1987 and have gone through years of problems with HIV. Unfortunately, it has been my experience that medical people tend to over estimate the effects of HIV and do a lot of guessing when they find out you are HIV positive, even here in San Francisco. Anyway, when the doctor wanted to immediately put me on anti-CMV drugs, I asked her what the "B" answer was. I told her and the other docs that until they came up with a more definitive diagnosis based on the results of some kind of tests, I didn't want to take a battery of drugs that may do me more harm than good.

So they ordered a spinal tap. That was the first one I had. First, they had problems finding a gap in my spine. They tried several times before the needle would go in. When it did, I felt the most excruciating pain I have felt in my life for about two minutes. I could feel the nerve from the middle of my back to the top of my big toe on my right leg. It felt like a toothache only in my leg. The results of this ordeal were that they found only slightly elevated proteins in my cerebral spinal fluid.

I spent the next three days in the hospital. The first day I was just about paralyzed from my waist down. The second day, I could actually stand up, which amazed just about everybody, me included. By the third day I could walk, although with some effort. The forth day, the day after Labor Day, they sent me home. I talked with my doctor who had returned from Holiday. I asked her what her diagnosis was, and she told me she believed that I had a case of Transverse Myelitis. I had never heard of TM before that day. I asked her if it was an HIV OI (Opportunistic Infection, like PCP, CMV, PML or KS). She said no, that the HIV could have contributed to it, but that it is just one of those diseases that can happen to people in their forties. I had just turned 45 in June.

Over the past year, I have slowly recuperated. At first I had to be particularly careful of incontinence. For two weeks I had to catheterize myself. Then I had to get pills to stop me from urinating five times a night. Unfortunately, I had a couple of bouts of incontinence at inconvenient times and places. My legs hurt all the time. The bottoms of my feet felt numb, then like they were on fire. The back of my legs and my buttocks were both numb most of the time. This took months to get over.

Sexually, I was completely impotent and even though that has faded with time, sex just isn't what it used to be. In the beginning I couldn't feel anything in the top of my penis. Even though that has faded, sex still is not as gratifying as it used to be. One of the most difficult things for me with TM is how to deal with it and HIV. I found your board while surfing for information. As I read through some of the letters, I didn't see any from people like myself, people with TM and HIV. One of my complications is that people with HIV disease must take a regiment of drugs, many of which are experimental. At the time I was on the first version of what we call the cocktail, 3TC, d4T and Crixivan, a protease inhibitor. Now my doctor wants to switch to another cocktail including Combivir, Sustiva, DDI and Norvil. Since Sustiva crosses the Blood Brain Barrier and is known to have psychiatric side effects, I'm wondering how it will react with TM?

So that's my story. I wish all of you well even though I don't know you. I will try to update you from time to time and would appreciate any other person with HIV disease or African-Americans to get in touch with me.

Will provided some additional information for the newsletter that we thought might be important to include with his story posted to the TMIC.

My name is Will Carter and I live here in San Francisco. I'm what they call a long term-survivor with HIV, having tested positive in 1987. Since then only a few days have passed here and

there when I haven't taken powerful HIV drugs at least once a day. Many of these drugs were experimental and still are. We really don't have any ideas of the side-effect profiles of long-term use of HIV drugs.

Although I am the first to contact your organization with TM and HIV, I cannot believe I am the only person with this type of dual-diagnosis. Indeed, I think there may be quite a few people with HIV and TM, and it may be that TM is misdiagnosed in people living with HIV. I say this because it has been my experience with friends of mine with HIV that doctors often become stymied with the plethora of maladies that can strike PWA's. Only a few, like KS, PCP or CMV are recognizable. But, over the years, I have seen different neurological manifestations of HIV in friends where the doctors have been left scratching their heads.

When I got TM I was very fortunate in that I was diagnosed and treated in a world-class hospital by capable medical professionals. Still, when they found out I was HIV-Positive, they wanted to treat me presumptively for CMV. I refused, as was my right. I wanted some kind of empirical evidence before I started taking gancyclovir for something I may or may not have. It was only after the MRI that they saw evidence of TM, a disease I hadn't heard of until then.

I don't know if there is a direct connection between HIV and TM. Both are viral diseases and both can affect the nervous system. There may be an autoimmune dysfunction associated with each, but whether there is a causal relationship remains to be seen.

One interesting thing occurred recently. My doctor switched my HIV drugs from Crixivan, d4t and 3tc to Combivir, DDI, Saquinivir, Norvir and Sustiva. These drugs are from three different classes of HIV medications; Nucleoside Analogues, Protease Inihibitors and Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI's). For much of the past year, I have had sensations in my legs and feet ranging from burning and numbness to coldness, and sometimes I have had difficulty walking. Anyway, these symptoms subsided while I was on the five-drug combination. Unfortunately, I wasn't able to continue the regimen past two weeks due to the side effects of one of the drugs, Sustiva, which crosses the blood-brain barrier in sufficient amounts to disrupt HIV activity. As I said, during those days, I was almost symptom free of TM. I will be going back to combination therapy in the next week or so, having given my body a rest. I will be switching from Sustiva to another NNRTI, delavradine. I mention this because there may also be a connection between anti-HIV drugs and TM. It certainly was noticeable by me.

Tim LaPlant
Manchester, CT

When I first spoke with Ms. Deanne Gilmur she asked me to write my story. I wanted to, but never knew how to say it. I am glad I waited, because no one has been able to relate to my circumstances until now. Everyone in the forum who has shared a piece of their past could not have spoken any better or clearer. Thank you for giving us a forum to release the ghosts from our past.

It was Thanksgiving 1971 and we had a blizzard. I was 13 years old with about a week before my 14th birthday. One of my brothers worked for a snowplowing business and I had a chance to make money. I talked them into letting me work with them for the day. It was a very wet and heavy snow, and we worked for the whole day.

I was getting tired as the day progressed. About an hour or so before we were to quit for the day, I had a sharp pain that started in my upper back and it traveled all the way around to my chest. I could not straighten up from a hunched-over position. I was being paid so I continued to shovel snow with the pain. It continued the rest of the evening. I took a hot bath that seemed to help. I woke up the next morning back to normal.

On December 12, 1971 I was walking home from the store with friends when the sharp pain came back. It seemed more severe then the first time. Two of my friends had to carry me home because I had a hard time walking with the pain.

I do not remember my parent's reaction when I arrived home, but I do remember that I went to bed with the pain having a hard time sleeping. I finally went to sleep waking up later on with the pain. Again, it took awhile to get back to sleep. My father woke me up to do my paper route at 5:30 A.M. When I went to get out of bed, I fell out, not being able to walk. I crawled down the stairs trying my hardest to get up. I slept most of the day.

My parents finally took me to the local hospital over 24 hours after the pain began, around 7:00 P.M. I no longer had any control over my bladder or bowel. It would just happen without me feeling a thing.

After being in the hospital for over five hours, the emergency room doctor told my parents there was nothing wrong with me. As someone else mentioned in the forum, they believed all of the symptoms were

"all in the patient's head." Let me tell you how qualified this doctor was. He stuck my legs with pins and I did not have any feelings. An hour later, he comes back in to see me and asks me why my legs were bleeding. I had to tell him it is where he stuck me with the pin.

My parents carried me into the hospital and then carried me out without a diagnosis. No medication, no therapy, no wheel chair. Just go home. My parents were not fighters. They did not ask where to go from there; they just took me home.

I had to crawl around the house to get from one room to the other. After about a month of doing that my mother finally called my pediatrician. He recommended a neurologist. I went to him a month later. By this time I had regained the ability to stand and walk again. I walked on my toes, not on my whole foot. I did not have feeling from my lower chest/ upper back to my feet.

I taught myself how to walk again. I took control of the spasms of my legs and used them to my advantage. I would stand holding onto something and as my legs began to spasm, I would move in any way the spasm took me. At the beginning, it was mostly falling to the ground, but eventually it was forward and sometimes backward. I would walk sideways like crabs, sometimes straight, sometimes slow, but mostly fast before falling many times.

Friends and family could not understand and most of the time were cruel with their comments. As one person stated in the forum, we had to try to overcome adversity. To me that was an understatement. I felt alone and had no one who understood or who wanted to help.

The neurologist finally classified me as having Transverse Myelitis. He put me into the hospital for tests. I had also developed headaches. He stated that headaches were not part of the symptoms of Myelitis, which does not seem to be the case since others in the forum have stated that they have experienced them also. I never had the opportunity to get any form of therapy; instead I was given Codeine for my back and Darvon for my headaches which never really worked. Since Tylenol has been on the market, I have consumed many.

He did several spinal taps, EKG, EEG, and put dye into my arm to check out my bladder, bowel, etc. Never heard of a MRI or CatScan back then. I was 14 at the time, so I did not understand what was going on and no one was willing to explain. My parents did not ask a lot of questions, so they did not know either. I was in the hospital for three days the first time in February 1972 and five days the second time in September 1972.

Unfortunately, my neurologist trashed my file so I no longer have the records. He seemed to be a good neurologist, but if it was out of the realm of the norm, like TM, he did not seem to know. It might have been the time frame since it was the early 1970's.

I was out of school with tutors for the end of my freshman year and the beginning of my sophomore year. I went back to school against the will of my neurologist. He wanted me to stay home (he told me if I went back to school, he would no longer be my doctor). I wish I had stayed home. I could not adjust to the fast pace of high school. I felt like I did not belong. At times, I could not make it to the bathroom in time. I was so embarrassed. I missed out on many things growing up, because I could not be far from a bathroom. I never knew how quickly it would happen. I would agree to go places and then cancel at the last minute with some bad excuse. As I have gotten older, control has come back. I now might have an accident or two a year.

It took about 18 months or so to get the feeling back in my legs. I still do not have the full feeling in my lower back, but my upper back is oversensitive. In 1982, I had an operation, which allowed me to have my daughter in 1994. In 1996, I had a heart attack because of extremely low potassium, which caused my artery to spasm, and then shut down. I now take a daily prescription of potassium.

As for today, like the others, I still have a list of symptoms, which I wish would go away. But I thank G-d for my health and allowing me to have a child. Lately, with the fatigue, I have been experiencing short-term memory loss. I was told it would never happen to me again, but it now scares me to hear of others getting it more than once and others experiencing Multiple Sclerosis after having TM. I wish to go to a Physiatrist but do not see any listed in my area. I would like to find a great neurologist and have a MRI and CatScan done just to see what is going on.

As for me, I am a natural gas trader in the energy business and have a beautiful wife and daughter who are very understanding. We are in the process of adopting a second child.

Thanks for letting me share my experience with you.

It has taken me quite a few weeks, and lots of soul searching, before I have reached the point where I feel comfortable about submitting my story. This is because I was only mildly affected by TM. Compared to the majority of fellow sufferers, I feel

Stuart Newton
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London
August 25, 1999

as though I am some kind of fraud, especially as they are generally much worse off than me. However, after much encouragement, I have decided to write it anyway, in the hope that there may be someone else with a similar story or that it may provide comfort to someone.

I was a 25 year old, healthy young man living in London with a career in the money markets, when I went on holiday with a group of friends to Cyprus in September 1995. After a heavy week of late nights and partying, I started to feel unwell on the last day of our holiday. It wasn't until I arrived back in the UK that I developed a fever and an excruciating headache. I was taken to the hospital and given medication to combat the dehydration. I was then released some 12 hours later after being told that I'd just had a nasty viral infection. My instructions were to take it easy and rest. After a couple of weeks, I still felt very weak and noticed that I kept losing my balance and having dizzy spells. I requested a second opinion and after an initial consultation was immediately hospitalized for further investigations. During this period I became steadily weaker, my balance deteriorated and when the consultant stuck pins in me, I realized that I had a loss of sensation from my nipples downwards.

After numerous tests centered on my liver and blood count that were slightly abnormal, I eventually saw a neurologist. Then followed three further weeks of tests including three lumbar punctures, two MRI scans (all of which proved inconclusive), evoked potential and nerve conduction tests. Eventually, most well known neurological diseases were ruled out, including MS. Unfortunately, over this period my symptoms became worse to the extent that I was so weak that I could hardly get out of bed unaided. My balance was so poor that I had difficulty standing up. The loss of sensation from my nipples down had become worse.

It was at this point that my neurologist told me that he thought that I had a mild case of TM, a condition that I had never heard of. I was eventually transferred to yet another specialist neurological hospital. Thankfully, my condition bottomed out after I was given what I believe to be some sort of steroid medication. However, at no point can I remember feeling a sharp pain in my back or a tight feeling around my waist, nor did I lose control of my bowel movements, although I had very bad constipation. I stayed in the hospital for another month, where I received intensive physiotherapy focusing on building up my strength and learning how to walk properly again.

When I left the hospital, my symptoms included weakness in my limbs, I became easily fatigued, I had poor balance, I had some loss of sensitivity from my nipples downwards, and my left side was weaker than my right, together with some hypersensitivity. At this point my neurologist told me that my symptoms would improve with time and physiotherapy, and that there was a good chance that I would make a full recovery. Unfortunately, after some three years of rehabilitation, during which time I managed to relapse quite badly on three occasions, usually through over exertion, I found myself being admitted to the hospital, once again, for a course of intensive physiotherapy. At the same time, my neurologist carried out further tests to ascertain the extent of damage still found within my nervous system. He concluded that as the healing process had not worked by now then it was unlikely that I would make any further significant progress. He surmised that the best that I could hope for in the long-term was to regain 60% of my previous function. My diagnosis has now changed to "neurological condition affecting mobility secondary to TM." I have been given this diagnosis because even though I have much the same symptoms as I had three years ago, physical fatigue and weakness in my limbs remain my main problems. This usually occurs after any sort of sustained physical or mental activity. I have become stronger to some extent, and can walk some 200 yards. Just before I become overtired, my balance starts to give me problems.

I am receiving physiotherapy twice a week and it helps. But I am unable to drive because my reactions slow considerably when I get tired. I am unable to work because I am just not physically strong enough to travel and to complete even a half-day of work.

Therefore, you can see how my story and my symptoms differ from most of the others found on this website. That's not to say that I can't relate to most of your circumstances, and I have still found reading your messages truly inspirational. Until I discovered the TMA, I really was at a loss as how to find people with either similar experiences or people who had even heard of TM within the UK. This condition is so rare. I now feel as though I have found such people.

I would like to know if anyone else in the TMA can relate to any of my symptoms, especially the fatigue and limb weakness, which really trouble me, or if anyone has contracted TM through similar circumstances. The

other thing I'd like to ask, is how everyone deals with coming to terms with something like this. I know that I am not as badly affected as some of you out there. But ever since the day three months ago that I was told that I wouldn't make a full recovery and the best I could hope for is just over half of my previous "self," I'm finding it very difficult to come to terms with it. I'm very lucky in that I have a wonderful set of supportive friends. But I still don't think that even they realize what a devastating effect something like this can have on your life. I think the thing that I have most difficulty with is coming to terms with the fact that it is unlikely that I'm going to achieve the goals and aspirations that I had set for myself in the future, especially in terms of things like work and social activities. I hear people saying that you have to go through a grieving process to mourn the loss of the old "you," but no one seems to know how long something like this takes. I guess everyone is different.

Anyway, I'm really glad to have found a group of people who I can finally relate to; at least in part, if not completely. Although my tone throughout this story seems to indicate that I'm resigned to my neurologist's prognosis for the future, believe me, that in keeping with nearly all the messages I read, there's no way that I'm going to just accept it without a fight. God bless you all and remember, it's just too easy to give in.

Michelle Stevens
Pasadena, CA
April 1999

My name is Michelle Stevens, and here is my encounter with TM…. In February of 1995 I was 34 years old. I had just moved to Northern Virginia to try to start a fresh beginning for myself after a non-progressing 6-year relationship. And I had had about enough of the traffic and the people of Southern California. I had been doing well with my new job and I was spending almost all my free time working out. I was a fanatic about my workouts. I worked out at the gym every other day for at least three hours and twice a week I went to a kickboxing class, then would run, and on the weekends would either roller-skate or bike ride. This, I believe, was the key to my recovery.

I am a Corporate Travel Agent. I work on site at particular accounts. This is a very high paced and high stress job. October 1995, on a weekend, I started getting this strange tingling in both my feet. It was sorta just irritating, but then kinda hurt. I figured I must have pinched a nerve, and also was having some lower back pain. But having thrown my back out numerous times, thought nothing really about it. After talking to a few friends about a pinched nerve, I found it odd that this was happening on both feet and now both legs, when a pinched nerve normally only affects one side. Then by Monday night my feet were completely numb. I actually continued to work out! The treadmills at the gym were set up in front of mirrors, and I was just sorta staring at my legs with each step. I was amazed that I truly could not feel them. Still that week I had a lot to do. I was to meet my girlfriend in Miami on Thursday and we were going to the Cayman Islands for the week. So, I really didn't think about my numbness till I went to bed. I would pray to G-d, "come on, just give me my feet back…." Then after a few days of this, I started to get scared. I called my normal GP from work and demanded for him to see me that day. He really didn't seem to have a clue. Did the usual, "can you feel this? How about this…? And he took lots and lots and lots of blood…and said that I had a generous thyroid? (Who knew?) But I still think of him as a great doctor and a good friend. So, I went back to work and finished my day.

The next day was the creepiest. Now I had all sorts of new numb spots around my lower body and felt that tight band feeling around my diaphragm and waist. I went to work as normal and waited for my doctor to return my frantic call. He said he still was not sure what was happening and that the next step would be to schedule a MRI, possibly some time next week. I said, "Nooooo! Not next week, but today!!!!" He was a bit shocked, but after I told him the thing had now moved up to my chest, he quickly jumped into action. He thought that this "Thing?" could inhibit my breathing. He said that he would call me right back. Well, within 20 minutes, I received a call from a neurologist, and they had made room for me immediately. So, I went there and got right in. My doctor is wonderful, a very nice and caring person, very real and personable with a sense of humor, thank G-d. He did some test with a sharp pin. He poked all over my back, neck, legs, etc… then he did some reflex tests and some strength tests. Then he did this small little exercise that really scared me. He moved his finger very slowly across my face and all I had to do was touch my nose then his finger. And then a small hand exercise touching my thumb to my pinky then ring finger, etc…. This I could hardly do at all. He had me stand up, close my eyes and keep balance on one foot at a time. I could not. He started to show lines of deep concern in his caring face. He would stare at me for a minute and not say anything. Then he said that we need to do a spinal tap and a MRI right away. I would have

to go to another place to get the MRI done, but he would do the spinal tap. So, I said, well, since I am here, go for the spinal tap. This was not a great experience for any of us involved. He had such a hard time trying to get the needle in. We tried many different positions and the one that worked was most uncomfortable and it seemed to take forever. He broke three or four needles and we somehow knocked over all of the iodine on the middle of the floor, which is still stained today. Finally, he got enough fluid and sent the nurse in to get some blood, still reeling from the tap. The poor nurse missed my vein and could not seem to get it in. By this time I had had enough poking and started to fall apart and cry. But just for a little bit till the concerned doctor came back in and looked at me again with concern and said there is a lot of protein in the fluid. But still, it could be a number of things. That's when he started saying MS, Lupus…all sorts of other creepy stuff. But none of this was really sinking in. After all, I still had to get packed for my trip.

So, then he had called me a cab to take me to get the MRI. So, I went and they drew some circles and lines on my back and did the MRI. Now, it's about 6:30 PM and my sweet doctor stayed at his office until the MRI guy gave him the results. Then he said that they still did not find anything, and that I was to report to his office at 9:00 AM the next day and that I should be prepared to maybe go to the hospital. Now, I was beginning to think that I would not be going to the Cayman Islands. My actual diagnosis was not really even in my mind, but I was upset because I have always been absolutely terrified of hospitals! So, I called my best friend in California, my one true love, Leonard. And told him that I may have to go to "The Hospital." He said that if that were the case, he would drop everything and get on a plane.

The next day I got a ride to the doctor's office where he did a quick exam and said that he was going to admit me to the Alexandria Hospital and set up some more tests. This was the day I was supposed to meet my friend in Miami. So, she called my doctor during the exam to make sure he was not bluffing, and he reiterated that I was not going anywhere. So, I checked in to the hospital, then got wheeled down to the MRI for two more long scary tests. They put my head in some sort of weird basket and then did some other MRI, took lots of blood, etc.

OK, so finally my doctor comes in my room around 4:30 PM and throws himself in a heap on the chair and says, OK, you have Acute Transverse Myelitis. He seemed relieved that it was not MS or Lupus. I said, Transverse what? He seemed exhausted and tried to explain as best he could. He had knowledge of this from his earlier days at the University. He said that there is no infection and that there is swelling of the spinal sheath at the base of my neck (C2). And that he was putting me on steroids. I never really had any bladder or bowel problems, but since then my bladder feels as if it has shrunk.

My best friend, Lenny, flew out on the next red eye to be with me, and stayed for a week to help me get back on my feet. This event, for some reason, seemed to really scare him and brought him to the realization that he still really had feelings for me. And this, I must say, is the one truly good thing that came from this terror called TM. Because later that year, he came back to ask me to be his wife. So, I spent four days in the hospital on heavy steroids, then continued with the Prednisone. On the third day, I was able to feel my feet again, and was able to walk without scaring my doctor that I might fall. I went home and never had any physical therapy. After being home for around three days, more and more feeling came back. Then I woke up in the middle of the night with excruciating pain in both of my knees. But I did not want to go back to the hospital, so I waited until the doctor got in and I got a very mild pain pill. I must have hyperextended my knees while continuing to work out with numb legs. I had also done some nerve damage to my arms and had to wear some elbow pads so I wouldn't whack them. I could not take a bath for a long time and sometimes if I stood in a hot shower too long, I would lose my air and my upper body strength and hyperventilate. But it would pass. I was never able to return to my full work out and I feel much weaker now. I get fatigued easily. Since it has been almost four years, a lot of the strangeness seems to become a part of you. Now my biggest fear is heat. If I get too hot, I hyperventilate and loose my upper body mobility. It is only temporary, but is scary.

Almost one year to the day after I was diagnosed, I was getting married to my Lenny. And when we returned from our honeymoon, I got a herniated disc. I believe the TM and all the steroids had weakened my already overworked back. My lingering symptoms are bionic headaches on the right side of my head that last for three days at a time. I have over-active reflexes. I get shooting pains through my neck and back. I have that weird shock sensation through my entire body when I bend my head forward. The barometric pressure outside, for who knows why, seems to have a huge impact on the way I feel. I still get tingling in my hands and feet. My sense of balance is terrible. When I get up in the middle of the night, if I

cannot see a light, I will almost always walk right into the wall or doorway. I bump into a lot of stuff and often. I have lost a lot of dexterity and coordination, but I am always thankful of how lucky I am. My body temperature seems to fluctuate very rapidly, getting very hot then very cold, but I usually run very hot. When I get really stressed out and/or sick, I do experience a lot more symptoms. And now I get winded very easily and may have damaged my breathing muscles. I also get very dizzy very easily.

I thought it might also be helpful to mention any other ailments I have had in the past just in case there is any similarity to either other patients or other autoimmune stuff. As a child of four, I got psoriasis all over. I have never been diagnosed with the herpes virus, but I do get something that looks like shingles on the back of my left thigh when I get either really sick or really stressed out. I have stomach ulcers and occasionally get ulcerative colitis, and also have had some weird virus type stuff that was never really figured out. And that's about it.

Thanks for the opportunity to tell my story and good luck to everyone.

Margaret Moran
United Kingdom
Tuesday, 09 March 1999

Dear Fellow TM Sufferers,

My name is Margaret Moran, aged 56 years (almost). I have been married to Terry for 34 years and have two married sons and three granddaughters.

I awoke on the morning of Monday 21st January 1997 with pins and needles in the soles of my feet – thinking at first something was wrong with the carpets!!! The next day this tingling sensation had reached my ankles. So, I consulted my doctor. He suggested I had a trapped nerve and to return in a week, if there was no improvement. Ten days later the pins and needles had reached my waist and I was having difficulty walking. I visited an acupuncturist for treatment but on this occasion there was no satisfaction.

Matters came to a head on Monday 3rd February when I was woken with an excruciating pain around my rib area. It disappeared with the help of a hot-water bottle. This was about 2 AM. At 4 AM I was woken with a violent headache in the middle of my forehead. I thought my head was going to burst.

My husband called for an ambulance and off I went to the Lincoln County Hospital. At first, meningitis was a possibility, but after further investigations, this was discounted. I was then flown by Ambucopter to the Royal Hallamshire Hospital, Sheffield, about 50 miles away, for a MRI scan as our local hospital did not have one. I was seen by the consultant neurologist. I still attend his outpatient clinic every six months.
The first MRI scan was on the base of my skull/top of my spine. It showed I had Arnold-Chiari Malformation, which I was born with (the hole at the base of the skull where the spinal cord enters is larger than normal). A brain operation was discussed, but fortunately, as I had had no previous problems in my 55 years, more investigation was required.

Four days later, I was given a lumbar puncture and then allowed home for the weekend. I returned on the 10th February when my optic nerve was tested. By this time, Transverse Myelitis, MS and other conditions had been mentioned, but I still needed further scans to confirm a diagnosis.

On the 14th, 15th and 16th February, I was given one gram of Prednisone by drip. I was struggling to keep walking and my right leg was dragging considerably, but I was determined to keep mobile. I was also given Baclofen to ease muscle spasms, but this did not help at all. Eventually, on Thursday 20th February, both my brain and spine were scanned and Transverse Myelitis was confirmed. The infection had reached level T6.

I was seen by a Physiotherapist to make sure I could walk straight, keep my balance and walk upstairs. I left the hospital the next day!

Since then, I have gradually improved so that I can walk short distances and drive the car. The pain, pins and needles, stiffness and discomfort in my feet, legs and body up to T6 continues 24 hours a day. I was prescribed Tegretol Retard, but stopped this medication as it was not effective, only making me feel very tired, but not reducing the pain.

I have always been a keen gardener, growing both flowers and vegetables. This is one activity I have had to give up, although I can sit to "pot on" seedlings, etc. in my greenhouse.

My husband has been wonderful, looking after me, taking on all the housework and cooking, especially as he had never had to cook before! Hopefully, things will gradually improve even more, although my

doctors are non-committal. I have a checkup at the hospital every six months and occasionally visit my own doctor just to have a chat.

I hope this isn't too boring for you all. We've only been using a computer since Christmas so it's all very new to us!

Keep cheerful,
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March 12, 1999

Sandy, I was diagnosed with TM in September 1991. I fell out of a bathtub while showering and landed flat on my back. I was at a Holiday Inn in Virginia Beach, VA while traveling for the government. I fell while on the job, which is the reason I was able to file for a Worker's Compensation Claim. I will talk more about that later. Anyway, the evening I fell happened to be my 48th birthday, the 28th of August. I had just dropped 40 pounds of weight from my six-foot frame three years prior. I quit both drinking and smoking cold turkey. I felt in the best shape of my life. After reporting the accident to the hotel management that evening, I ate dinner and then retired to my room for the night. I had, at the time, just a slight discomfort and soreness in my lower back as a result of the fall but no real problem.

The next morning I drove the truck back to my duty station in Philadelphia. I reported the accident to my boss when I arrived back and went home. The holiday weekend was coming up and I was looking forward to being off the next four days. I must state here, I had nothing wrong with me prior to the onset, no flu shots or upper respiratory infections, colds, or any other maladies that I know of affecting me at this time. Following a pool party at my home on Saturday afternoon the 31st of August, I awoke early to go urinate and could not. So, I went back to sleep, got up at five to go golfing, tried to relieve myself again, but could not. By the time I finished my round that morning I was busting.

I contacted my primary physician's office and was instructed to go to the ER and to have a catheter inserted and a urinalysis done. I was discharged to go home four hours later with the Foley still in me, with a slight UTI and instructions to follow up with my primary and a urologist on the third of September. The morning of the third I awoke and immediately had a hard time keeping my balance and had trouble walking. When I saw my primary that morning, she thought that I was having trouble walking because I was nervous about my urinary problem. She made me an appointment for me to see a urologist later that evening and sent me home. My gait deteriorated steadily during the day and by the time the other doctor saw me, without even an exam, he blurted out that I had a ruptured disc and had to go to the ER ASAP. My wife got me to the hospital in ten minutes. While being wheeled from my vehicle in a wheelchair by hospital personnel, I became completely paralyzed to level T-6. Beside the urinary retention, I started bowel incontinence. I was admitted, transferred to another hospital immediately for a MRI, and then sent back to the original hospital. I was treated with prednisone and had another MRI done the next morning. I also had a CT scan, EEG, EMG, x-ray and spinal tap.

Two weeks later after the process of elimination and a misdiagnosis of Gullian Barre, I officially had TM. I spent another two weeks in this hospital and was then transferred to a rehabilitation facility. My bowel incontinence reverted to constipation by this time and I was taught how to digital stem. I also lost my sense of taste. I had been taking Effexor for a previous depressive problem and I had started slipping further from reality. So, they changed me over to Prozac, which caused a severe hallucinatory problem. I had to have a watch posted in my room for four days till the drug left my system. I spent a month at the rehab facility.

I really was not feeling any pain at this time. After outpatient visits and my therapy at home, I eventually graduated from wheelchair to walking cane. I returned to work in April of 1992 driving a van equipped with adaptive devices since I still had no sensation in my legs. Even though I had no sensation, I was able to ambulate on my own. Everything was going along well except for the retention and my bowel problems. I was cathing four to six times daily, and my wife and I were slowly adjusting. Thank G-d, my mother-in-law was living with us at this time; my wife worked and mom took care of me during the day.

I had to have a penile implant done in July of 1989 since my function had not returned. More disturbing was the fact that about June of 1993, I started collapsing with no warning. I had to file for government disability since, at that time, I still had not been approved for Compensation. They were saying that there was no causal relationship between the fall and my

condition. So, my lawyer filed an appeal.

My urologist has diagnosed me with interstitial cystitis. She is an expert in her field. Only ten percent of men are diagnosed with this condition. My hematologist also has diagnosed me with cryoglobulinemia. How's that for a triple bagger? Anyway, strange things started happening. I started having the sensation of being on fire at times from my lower back to my ankles and, at the same time, my feet would feel like they were frostbitten. My neurologist tried medications from a to z to try to alleviate my pain but wound up frustrated and apologetic because nothing helped. Then in August of 1996 sitting in a pharmacy waiting for medication I looked down and, lo and behold, my pants and floor were wet with urine and I didn't even know it. After five years I thought a miracle had occurred. I was so happy I broke out crying. The pharmacist made sure I got home all right.

Well, Sandy, the happiness was short-lived because then I became bowel incontinent again along with the urinary incontinence. I was going crazy. All the time my wife did the best she could to keep me focused. My wife and my mother-in-law again pulled me through this stage. The bowel incontinence again returned to constipation after a month, and since they couldn't control my urine flow, I had a suprapubic catheter inserted in 1996. I also had to have a Baclofen and Morphine pump implanted in the beginning of 1997. I had started leg spasms and pain that was extremely severe. The pain had become so severe that I tried taking my life. How my wife got to the gun before I pulled the trigger, I'll never know.

Presently, I am having severe bladder spasms. A new surgery is scheduled for next month so that another implant can be inserted. I think they're going to start calling me the bionic man. I'm currently unable to ambulate but have been assigned a PT nurse at home who has me walking some with a walker.

My Workmen's Compensation Claim was finally approved in January of 1998. From what I understand, between my neurologist and one of their own doctors they agreed that there was nothing else pointing to the TM except for the occurrence of the fall. They approved it, because they could not disprove that the fall caused the condition.

After my wife passed away, a chair lift I had ordered was finally installed and I can finally reach another level. Good thing, because now mom has been diagnosed with arthritis of the spine. She has just had two epidurals done and I'm trying to help her as much as I can. Helping her is keeping me occupied and also keeps me from thinking about my own problems. If it had not been for my wife and my mother-in-law, I never would have made it on my own.

My case experience seems to be closely related with Debbie Ziler's story, and like her and everyone else, I still consider this a nightmare. At least that's the way I feel. With all the ups and downs, I never know what to expect.

Well, that's it, Sandy. I hope I haven't bored everybody and I hope I've helped someone in some way. If anyone wants to contact me, my e-mail address is golfjoe@earthlink.com. Thank you.

I am 21 and diagnosed with Transverse Myelitis.

I woke up on Tuesday morning the first of June 1999, to a numb feeling in my feet. I figured it was nothing, just that I slept wrong. I got dressed and drove myself the 45 minutes to work in Santa Rosa, CA. I arrived at work at about 7:15 that morning and the numbness had traveled a little farther than my ankles. I work in a mortgage company and am on my feet all day. By about 11:00, my legs were numb up to about my knees. It was

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then that I decided that I had better call the advice line at the hospital. I described my symptoms and they said that I should probably come in to be seen. I decided to finish up some work, so I didn't have as much to do the next day. I left work at about 3:30, having numbness up to just below my hips, and drove myself the 45 minutes back to my local hospital in San Rafael, CA.

I arrived in the emergency room at about 4:15, and again described my symptoms. They told me to take a seat and the triage nurse would be right with me. The nurse said that she thought that I just may have pinched a nerve and that I should go home and come back for a 6:30 appointment in urgent care. I let her know that I didn't think I could drive any farther since I was having trouble feeling the peddles. She then decided to have me stay at the hospital. At approximately 4:45, a nurse took me back to a room, followed shortly by one of the ER doctors. He ran a bunch of tests consisting of hot and cold, pressure, muscle control/resistance, pin pricks, reflexes, cotton swabs and vibration. I could move my legs fine, feel the hot and cold, reflexes were fine, but I couldn't feel sharp or dull (cotton swabs). After running these tests, he said that he would like to talk to the neurologist and would be right back. I

figured that he would just tell me to go home and rest and take a day or so off my feet. He came back in about ten minutes and said he wanted to run a spinal tap. And that's when it hit me that I had a real problem.

They did the spinaltap and decided right then to admit me into ICU. To make sure that I was not holding any residual, they had me urinate and then inserted a catheter. Luckily, I wasn't holding any, so they took it out within five minutes of insertion. They gave me a couple of possible diagnoses, everything from transverse myelitis (TM) to Guillian Barre Syndrome. As they were getting me prepped and ready to send up to ICU, they then allowed me to call my parents. The only thing that my parents knew is that I was going to emergency because my legs were numb.

I arrived in ICU and they got me all hooked up to the EKG, IV (for the steroids), checked all my vitals, and had the respiratory therapist come in to check my lung capacity. My parents arrived at about 7:30 with my contacts, brush and magazines. All the stuff a 21-year-old needs. :-) The doctor came in and spoke with my parents and explained to them what was going on and what the recovery process would hopefully be. They also gave me some Vicodin and Valium, so I could get some sleep.

In a way, it felt ridiculous to give me Valium, since they were waking me up every two hours to check my vitals. My temperature was good, usually 98.2 to 99. My lung capacity gradually grew with time. It was generally around 3.08 or so. They also decided that since I was taking the steroids, they should also check my blood/glucose levels. From taking the steroids, or from eating, it almost always jumped to about 180. Occasionally they would give me an insulin shot, so it didn't get too high. I never got over 190 the whole time I was there.

The next morning, Wednesday the 2nd, when I awoke, I was happy because I had slight feeling from my toes to my knees. So, they decided to move me to the 5th floor. They had set up a MRI appointment for 1:00 that day, so I had something to look forward to for the day. Half way through lunch (pizza, apple juice and milk) the EMTs showed up with the stretcher to get me. The MRI building is across the parking lot (total of one mile), but due to insurance reasons, they have to take you in an ambulance both ways. The MRI took two hours. They first took pictures of the cervical and then the thoracic spine area. After the first set of pictures, the anesthesiologist came in and inserted a dye of some sort into my IV and then they redid the pictures. The dye supposedly makes things clearer. The EMTs then took me back to my hospital room.

When I got back from the MRI, the doctors came to see me again. I now had no feeling from my toes to about an inch and a half above my belly button. They were going to send me home Thursday, but since it had progressed farther up my legs, they said no. They were still checking my blood/glucose, vitals, and lung capacity, but has taken me off the EKG when I moved from ICU. At least since I was not in ICU, I could use the phone, have friends over and walk to the bathroom without help. I never totally lost muscle control, so I could stand.

The food was amazingly pretty good. Omelettes, French toast, or pancakes for breakfast. Pizza, chicken, or pork for lunch and chicken, spaghetti and the like for dinner. I had plenty of friends and family come by to keep me company, so that kept me from going insane. I made and received plenty of phone calls, and just tried to keep my hopes up, knowing nothing about TM.

Thursday they brought me a walker, so that I could get up and walk around the hospital. I needed the walker because I couldn't feel the floor with my feet. Later that day, they transferred me to a cane. Thursday was mainly a day of recovery and to see how my condition progressed. They decreased the 2-4 hour checks and instead were running the tests two times a day with steroids in the morning and blood/glucose three times a day.

Friday morning, after my steroids, the doctor came in and told me that today was the day I would be released! Yeah!!!! The numbness and tingling was now about three inches above the belly button. I was having pretty bad spinal tap headaches, but with Vicodin and not moving around too much, those were livable. As I was getting ready to leave, I decided to count my puncture wounds one last time. Let's see... three blood collections, two IVs, one anesthesia before spinal tap, one spinal tap, seven blood/glucose checks and three insulin shots. That's a lot! I'm sure not as many as some, but for me, that's a lot. I have a follow-up appointment for a week after discharge with one doctor, and an appointment with another doctor in 2 1/2 weeks after that. I'm not allowed to drive for three to four days, or until I can feel the peddles, and can't go to work for at least a week. I was told that we would discuss the driving and work situation when I go to the first appointment.

I have been discharged for two days and am really beginning to feel like my legs are stiffening up. I guess I need to do some more walking and moving around.

I hope in some way my story helps those reading it; whether it is family and friends trying to understand what I went through and am going through, or people that have been diagnosed. Either way, hold your head high and just remember that nothing is worth giving up on. Happiness is wanting what you have, not having what you want.

It is refreshing to read the various TM experiences as it makes living with its effects a less lonely experience. Here is my story, different in some ways, but, oh, so common in many other ways.

I awoke on the morning of August 2, 1997, my husband's birthday, and went down to the kitchen to prepare a special breakfast for him. While filling the coffee carafe with water, I experienced an excruciating pain between my shoulder blades (T3). Trying to continue with breakfast proved impossible so I went back upstairs to bed until the pain subsided. Well, the pain did not

Beth Gambrell
Lawton, OK

subside, it intensified and I began experiencing muscle spasms in the same T3 area. I could not stand the pain and asked my husband to take me to the hospital. The ER doctor prescribed Tylenol with Codeine for the pain, and muscle relaxants to be taken once every 6 hours. He also instructed me to lie flat on a hard surface for a day or two until my back felt better. I followed his instructions to the letter, and stayed in bed the entire day. Missing my family, I tried to join them downstairs in the evening, but that didn't work at all due to discomfort, so I went back upstairs.

It was about 11:00 PM when I got up to go to the bathroom and my legs felt rather numb and didn't work very well, but I was no longer in severe pain. I was due to take another muscle relaxant and skipped it thinking that they were working too well. About 5:00 AM I again got up to go to the bathroom and I fell by the side of the bed. I thought to myself how strange that the muscle relaxants were still too effective even after having skipped the last dose. I decided to go back to bed and see how I felt in a couple of hours. When I awoke at 7:30 AM, I really had to go to the bathroom but discovered that I couldn't move. I even had trouble doing much more than lifting my arms. Being more concerned with relieving my bladder than lack of movement, I asked my husband to drag me into the bathroom. I had no results and decided it was time to go back to the hospital.

Arriving at the hospital unable to move, I saw the same ER doctor from the previous day and he was obviously puzzled. My husband and I joked about the situation, as it was too absurd to comprehend. No one wakes up paralyzed! While a nurse was tending to me, she overheard me joking to my husband, "I know that my work is stressful, maybe this just proves Freud's theory." I later learned from the floor nurses that the ER nurse reported this to the doctor and they took it quite seriously; they included a rectal exam to rule out psychosomatic illness.

My family practice doctor arrived at the hospital and took over my care. We are a military family and were stationed in Fairbanks, Alaska at the time. Medical care works very differently in the military and in Alaska. I received a low dose of steroids intravenously and the doctor conferred with the civilian neurologist; the military neurologists were all stationed in Anchorage, which is six hours away. They transported me, along with my doctor, by ambulance to the local civilian hospital for a MRI and to see the neurologist. They determined that it was not a tumor, which never entered my mind as a possibility. I assumed it was Multiple Sclerosis, but had no previous experiences to establish that diagnosis.

For several days I was a puzzle to the doctors. The nurses made an ink mark on my chest to make sure that the paralysis did not move upward and interfere with my breathing. They also made frequent checks. As there was a low census on the floor, and my case was intriguing, I received excellent care and a lot of attention. They were surprised at how well adjusted I was emotionally. I can only attribute my positive outlook to my deep faith in God, and the wonderful support, love, and care that I received from family, friends, and everyone at the hospital. At no time did I ever feel as though my life lacked meaning or luster. Quite the opposite; I learned that my life was deeper and richer. Walking is an accessory. Not being able to do it doesn't devalue your life, it makes it different and that is all. My one concern was that of not being able to run after my then 10-month-old baby. In fact, she learned to walk before Mom did!

It was several days before the neurologists in Anchorage made the diagnosis of acute TM and they did this over the phone. No one in my little hospital had heard of this. The nurses immediately got information from the Internet and forwarded it to me. I had begun physical therapy and had regained more use of my arms. I still could not sit up on my own or remain upright. They began a daily regimen of 500 mg intravenous steroids over a five day course. This apparently helped, as within a week I

was able to sit up, with difficulty. My mode of transportation became the wheelchair, although I didn't have the strength to maneuver it myself and relied on others. Another week and I could wheel myself around. A week later and I was using a walker for very short distances. My progress was fast in some respects, yet slow when I look back and compare it with my present abilities.

After spending a month in the hospital, the last two weeks were spent waiting to move into handicap accessible quarters. I left the hospital using a cane for short distances. I returned to work two weeks later working part-time for four months then returning full-time. I had absolutely no business at all working during those months. Feeling exhausted, I took naps in my office. Unable to lift much, co-workers carried my files to meetings for me. However, my biggest concern was memory deficit. Once priding myself on excellent memory and reasoning abilities, I found myself unable to remember current conversation let alone anything else. I adjusted by carrying a notebook and post-it notes. Although my short-term memory currently remains impaired, it is not as debilitating as it was two years ago.

Since moving to Oklahoma, I have chosen not to work. I nap almost daily and move about much more easily; the last year has proven to be one of tremendous healing. I currently walk without a cane most of the time, although I do have the infamous left leg limp. I was diagnosed with MS a little over a year ago, but I mystify my new neurologists as lab results and MRIs still do not support the MS diagnosis. When I do have an exacerbation, I am given 1gram of Solu-Medrol daily for 5 days. I have seen tremendous improvements following each exacerbation. I have even water-skied this summer, it's not frequent, fancy, or for long, but I'm up there! However, these neural improvements may just be the result of time.

I continue to have a positive outlook and realize that I may not be among the walking for much longer. But my faith and family is stronger than ever and I have much for which to be thankful.

Glenn & Beth Gambrell
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Hello, folks. Transverse Myelitis – I had never heard of it; at my age, 69, I was well aware of all the bad things that can take you out. I had the check up every year, had kept the weight where it belonged and generally was in good shape.

In the summer of 1993 everything was fine. We were planning a trip to the West Coast to see family members and gather for a birthday party. Mine was July 11, my sister on July 25. Everything went fine. I felt fine. No symptoms or discomfort. Came back home about August 1. Went back to our regular work, and was sailing right along.

Ed Eaton
Lometa, TX
April 21, 1999

On the night of approximately August 30, I was preparing for bed, and went upstairs and noticed a slight weakness in the legs. I didn't think much of it. It had been a hot day, and I had done some heavy lifting, but noticed nothing at the time. In the morning it was still there. No symptoms other than the weakness.

In the following weeks, I went on about my work, but being plagued by back weakness. I went to my GP about November 1. He took some x-rays and examined them. He remarked that one disc looked slightly compressed, but didn't think that would cause my problem.

Well, we rocked along working and the other things people do. The weakness not getting much worse. But after the first of the year, 1994, I decided to see a back specialist. He offered nothing. Saw him again in a few weeks, still zero. Well, I thought, maybe I can wear this thing out, and surprisingly nearly did.

I think in February, a cold winter day, the legs felt 90 or 95 percent. But it was short lived. In a few days, I was going downhill again. Went back to the back-man a third time. Finally, he said, go on home, you'll be okay. This was on April 4, 1994.

By the end of April, I was barely able to walk and sought out a third back-man. He asked me a few questions, and looked at my walking, and said, "you don't need me, you need a neurologist." I told him, name me a good one. He did and we saw him on May 5th. A MRI the next day, another two days later. When we looked at the film a day or two later, the trouble was right there at T6 on down. The doctor commented to my son, "we have to do something for your Dad or he will lose the use of his legs."

Well, we saw him several times in the next few months. Took some steroids, but no benefit. Finally, I told him, where could I go to get some help? He replied, Baylor Medical Center in Houston. Got here about August 1, 1994. Saw the head neuro, took another MRI. During consultation his statement was, "you got something going on in there, but we don't know what it is." I replied, "well, let's find out, and do something."

The sad truth is there is nothing you can do, in my case anyhow. I stayed there five more days, took a lot of steroids, no help. In fact, after two days, I had to use a walker. After I got home, the latter part of August, my walking improved and quit those steroids thereafter.

From then to the end of 1994, it was a steady decline until by Christmas it was nearly wheelchair time. We sought help a couple of other places, but nothing good came of it so it is not worth going into details.

Now, as to everyday life, it isn't too bad. I use a Foley catheter and have had good luck with it, no complication. As to the bowel actions, I have made it predictable by careful eating and use of senna tablets taken at the right time learned by trial and error.

Most of the time, I feel good; do a little real estate work from my home mostly by phone. TM is a mysterious disease. Thank goodness we don't have much of it. Treatment of nerve disorders is very difficult, nearly impossible, simply by the way we are made.
To other TM victims, make life the best you can. Help your caregiver. Very important, think positive, keep busy, do something productive and do something for those who help you. If I can help anyone with anything, talk, encouragement, please call me any time.

It's a beautiful day in Texas!

Best regards,
Ed Eaton
PO Box 93
Lometa TX 76853
(512) 752-3626
My name is Doreen Bronstein. I live at Morwell, which is in the Gippsland area of Victoria, Australia. This is my story.

It was the 22nd of September 1994, my Birthday, and I was turning 57 years young. I awoke at the usual time and followed my normal morning rituals, toilet, wash, etc. I then made myself cuppa and returned to my bed as it was too early to get up. When getting back into bed, I got this itch in my left leg and then in my right leg also. So, I got out of bed and went and sat in the lounge room on one of the chairs. Within 10 minutes I was paralyzed.

I sang out to my husband, Harry, and

Doreen Bronstein
Morwell, Australia
July 13, 1999

told him that I had lost the power in both of my legs. By this time panic really had set in as I didn't know what was wrong. Harry rang the ambulance and they then took me to our local hospital. By this time I was paralyzed and I was scared stiff.

I was in sheer agony all that day and they did all the relevant tests and discovered that I had TM. I was affected from T12 waist down, losing the control of my bowel and bladder. I spent 12 days in the hospital in Melbourne and until the 16th of December in Rehabilitation.

I had very mixed emotions about going home. It was up to me to pick up my life and to not wallow in self-pity. The re-adjustment was very hard on both my family and me. Over time, things are getting much easier for every one, and things have returned back to some semblance of normality for all. I was a very independent person before this happened. This was my hardest lesson to learn, how to rely on other people for help and to be tolerant and to be patient.

The best thing that has come out of this is my enjoyment of simple things and my realization that I have to live life to the fullest. One of my greatest joys is my little Chihuahua puppy, "Freckles". She came into my life two years ago when I probably was at my lowest ebb. She was only 3 months old when I got her, and she has enriched my days and is my greatest comfort. I love her to pieces.

My TM has been improving through time. Every little step forward is a miracle. In five years I have gone from a wheel car to a walking frame, to crutches and now I only use a cane. They told me I would never walk again and I am living proof that with perseverance and courage, anything is possible. To the other people out there that may think TM is the end of their world, take heart and never ever give up.

Regards,
Doreen Bronstein and "Freckles"
jaycol@vic.australis.com.au

My name is Rob Hudson. I am 35 years old. I've been in great physical shape my whole life. I've been in the fitness business for 15 years and have operated my own fitness center for 10 years. I was diagnosed with Transverse Myelitis June 27, 1997 by a neurologist. My worst symptoms were intense bladder pain and strain to urinate, severe right hip and leg weakness and numbness and quivering in my lower extremities. I was in the hospital for three days while they performed numerous tests. Intravenous steroids were administered immediately and continued orally for two months. It's been three months since my diagnosis and my bladder and bowel function is fine. I still have low back and leg weakness and shakiness and some foot numbness. Coping with Transverse Myelitis has been ex-

Bob Hudson
Carmel, IN

tremely challenging emotionally. I have always taken great pride in my body and my strength.

I would like to talk to anyone who has had a case that is similar to mine.

Sincerely,
Bob Hudson
3733 Zuker Court
Carmel, Indiana 46032
(317)876-1050

The Transverse Myelitis Association Symposium, August 1999
Debbie Capen

Deanne has done a wonderful job of summarizing the Seattle Symposium for those of you who were unable to attend. There were informative presentations made by the doctors and other specialists, and the Association accomplished some very important business over this weekend. But if you asked anyone who attended the meetings, all would tell you that the most memorable part of the symposium for them was meeting others with TM and establishing relationships that will last a lifetime. I asked Debbie to write down her thoughts about the Symposium from this perspective, in order to convey some of the very emotional experiences people shared during these meetings.

The First International Symposium of The Transverse Myelitis Association was a "dream come true." The dream began in February 1998, when the National Organization of Rare Disorders (NORD) invited The Transverse Myelitis Association to attend a joint conference with FOP (Fibrodysplasia Ossificans Progressiva) patients. It was our first lesson on "how to run a conference," and it was also our first opportunity to meet others afflicted with transverse myelitis. Most of the Board Members of TMA attended this conference in Columbus, Ohio.

This TMA/NORD conference was very educational; we learned how people with severe and worsening disabilities survive in this able-bodied world in which we live. The highlight of attending this conference was meeting others who were living and coping with transverse myelitis. There was only a small group that was able to attend; enough to fill one banquet table. Way back then, over a year ago, the emotional bond was strong and unforgettable. We were able to talk to others who were experiencing the same "numbness/tingling," "burning/freezing" sensations, all of those terms to which only another tm'er could relate.

We had the opportunity to meet Dr. Levy and Dr. Lynn for the first time, and discovered what caring, down-to-earth people they were. And as an added bonus, discovered that Dr. Levy is a VERY talented fiddle player! I remember when he sat with us at our table at the banquet, the small group of people with transverse myelitis, he told us that he enjoyed sitting with us, because we were the "fun" table!

At that time, we determined an approximate date to have our First International Symposium, to be held in the summer of 1999. Inevitably, the location of the symposium was to be Seattle since Deanne and Dick Gilmur, the founders of the TMA, and Paula and Jim all live in Washington. Deanne, Dick and Paula did the majority of the "legwork," putting together what would be an "awesome" (to quote one member) and educational symposium.

Fast forward to August 12-15, 1999. The symposium had begun. People from all over the world came together to meet others with transverse myelitis. Most of the attendees were from all over the United States, but people also traveled to Seattle from Canada, Ireland, England, Wales, Venezuela and Australia. All of us were overwhelmed with the closeness that we felt for one another.

The speakers that Deanne and Dick invited to the symposium presented their information so well. They spoke in plain English, and did not use a lot of medical terminology. They were easy to understand. They answered many of our questions; many of these questions which had previously been unanswered for such a long time.

During the breaks between the speakers, we were able to visit with all of our "brothers and sisters." I don't want to make this sound like a "religious revival," because it was nothing of the kind. But when you sit down at a table with a total stranger, and begin to ask questions about how they came to "discover TM," you suddenly find yourself saying, "I know exactly what you are going through." I never thought I would ever meet another person who could understand my experiences!

After only a day or two, that "fun table" from over a year ago was a

"fun room" full of long-lost "family members." So many people with transverse myelitis in the room, each one with his/her own personal experiences to share with the rest of us. The hardest thing for me was meeting the children who have to live with transverse myelitis. One of the speakers in the panel discussion, named Hayley, was only 17 years old. She had been diagnosed at four months of age. She felt that she was one of the "lucky ones," because she had never known what it was like to be "normal." She felt sorry for the adults who had gone through their entire lives without disabilities, and then lost normal functioning, having to adapt to a new way of life. We, as adults, felt that *we* were the lucky ones, because we at least knew what it had been like to run, jump, skip; do all the things that kids do. It seemed as if there was nobody in the room that was wrapped up in "self-pity." We all felt in our own way that we were "lucky ones." It was like being on an "emotional high" for four days.

I was able to reunite with old friends and made many new friends. I hope that even more people will be able to attend the conference in Baltimore in July 2001. I am looking forward to my "family of friends" continuing to grow. It really has made living with transverse myelitis a lot easier, knowing that I have so many friends who share in my feelings and experiences.

The complete agenda of presentations made at The Transverse Myelitis Association's First International Symposium is now available as a five-tape Video Set. The Association has priced the Video Set to recover the cost of copying the tapes, as well as the materials and shipping costs. We are not able to sell tapes of certain portions of the Symposium or particular presentations. The cost of producing various versions was prohibitive; therefore only the entire five-tape set is available for purchase. If you are ordering the tapes in the United States, the cost of the Video Set and shipping is $40.00. The Video Set will be sent to you via the United States Postal Service, Priority Mail. If you are ordering the tapes from anywhere outside of the United States, the cost of the Video Set and shipping is $50.00. The Video Set will be shipped via the United States Postal Service, Small Packet Surface Rate.

To order the Video Set of the

Ordering a Videotape Set of the First International Symposium
Paula Lazzeri

Symposium, you must send us your complete postal address and a check or cashier's check made out to "The Transverse Myelitis Association." We cannot send any orders until we have received your full payment for the tapes. For all of the international orders, we are requesting that you use a cashier's check for the amount of 50.00 U.S dollars. All of the tapes will be shipped in VHS format. We are sorry for the inconvenience that this may cause some of you who live in countries where different formats are used. We are asking that you perform your own conversions of the tapes. The complications associated with our trying to do this and the costs associated with the process were prohibitive.

Your order, complete postal address and check or cashier's check should be sent to:

The Transverse Myelitis Association
P.O. Box 64086
Tacoma WA 98464-0086

Please allow six to eight weeks for delivery in the United States, and longer for international delivery.

Finally, I would like to offer special thanks to my brother, Perry Peltier, who donated a tremendous amount of time to this project. Perry taped the entire symposium and devoted long hours to the process of editing the tapes. The project and the availability of these tapes would not have been possible without his very generous offer of time and creative energy. Perry, we are all greatly appreciative of your hard work and your kindness.

Last year while at the "Abilities Expo" in Anaheim, California, I met the new Ms. Wheelchair California. I immediately thought, "Wow, this is something I can do!" I waited and waited but no information arrived. First I called Georgia and then wrote to them, still no information. When I got the flyer for this year's Expo, I saw several e-mail addresses, so I e-mailed someone to get information for the Pageant. I was very determined to participate and wanted to make sure I tried every way I knew how. When I got the phone number for the state representative, I did not hesitate to call her, even though it was long distance.

When Patty, the Pageant Coordinator, answered the phone I tried to be polite when all I wanted to do was shout: "SEND ME THE APPLICATION!" Even though it was not in my budget, I sent in the application fee along with my photo and application. Not once did I ask what the role of Ms. Wheelchair California was, or what platform I should adopt. I just knew I wanted to be there. One friend e-

Abilities Expo and the Ms. Wheelchair California Pageant
Hinda Lee Sheffer

mailed me to ask what the prizes were. Prizes - I never asked about them, I just wanted to participate.

In the back of my mind was the fact that if I won, I would have the chance to get the word out about TM. Of course, everyone I spoke with had never heard of it, big surprise.

But the biggest surprise was yet to come.

Debbie Capen also lives in Southern California and had gotten the same flyer I had. She sent out a mass e-mail to let everyone in the area know about the Expo and encouraged them to attend. I answered her and told her that not only was I attending, but that I was entered in the Ms. Wheelchair California Pageant. With my permission, Debbie notified the TMIC of my participation. What a surprise I was in for! Several people sent me good luck wishes and one person offered to be a sponsor for me. Although I am not a member of the TMIC, I was very touched by the outpouring of enthusiasm for me.

On Sunday, May 16th, I was up early. After all, it takes a gal a while to get ready. When I entered the Convention Center and told them my name, I was given a name badge and free entrance – a benefit right there. An escort took me to the Ms. Wheelchair booth, which was all the way at the back of the auditorium. No wonder I had such trouble learning about the pageant; they were relegated to Siberia.

There were seven other women beside myself who were in the Pageant. Prior to our individual sessions with the judges, we had a chance to get to know each other. This time was important because there was to be a Ms. Congeniality Award given during the Pageant. We were from all walks of life, with varied disabilities, and from all over the state of California. At this time, the reigning Ms. Wheelchair California told us about some of the things she had done in the past year. The others could relate to post polio, cerebral palsy, multiple sclerosis or being in an accident, but no one had heard of TM or why I had become disabled.

After an informal discussion, it was decided we would meet the judges in alphabetical order. Guess who was number seven out of eight? I went to get a sandwich and fix my make up. It might not have been a beauty pageant, but I was determined to look my best. The judges were in a curtained-off area, so we gathered around waiting our turn. One contestant returned in tears and announced she had gotten the judges to cry! Now, that is a tough act to follow.

Finally, it was my turn to talk to the judges. This was no "puff" event and the questions were not easy. I quickly learned that my mistake had been in thinking this was a "fun" thing to do! To my advantage, I grew up with a father who was slightly disabled and for 19 ½ years, I was a volunteer at the Los Angeles Unit of the Shriner's Hospital for Crippled Children. I hope I gave intelligent answers, I have few recollections of the ten minutes I spent in there. I believe it is anxiety amnesia! I do know that I educated five more people about TM. Naturally, none of them had heard of it.

When the last contestant was finished, we then had the interminable wait for the second part of the Pageant to begin. In the brochure I had received we were told there would be a private session with the judges followed by an event open to the public. The schedule said it would be a "judged speaking event". I have a B.A. in Speech/ Communication and have judged speech contests so I *thought* I knew what to expect; I was wrong.

The contest coordinator, Patty, introduced each of us to the audience. This time we were in a random order. By chance, I was second. The "judged speaking event" entailed answering two questions. Patty selected the first question and the second was the same for all of us. The first question was so varied for each of us that it seemed a bit unfair to judge us based on the answers. I wish I had had the question, "what haven't you done that you want to do." That would have been easy for me, ride in the Goodyear Blimp! The second question was, "If you could have five minutes on a national TV show, what would you want to tell people". My answer was the same one I told my kids at Shriner's, "I am no different than anyone else, and please treat me the same."

When the judges went back to decide our fate, we heard from the current Ms. Wheelchair America and the current Ms. Wheelchair California. The judges returned and the awards were announced. Although it was not a beauty pageant, I have to be honest and say that the most attractive and, possibly, youngest women won. We all received a bag of "goodies," a stuffed bear, a pen, some body lotion and other odds and ends.

Debbie Capen's husband, Michael, made a video tape of the public ceremony. To my knowledge it is the only one in existence. Debbie and Michael were part of my "rooting section" that included three very dear

friends of mine. As I write this, I'm waiting to pick up my pictures from the photo shop. I participated in a promotion between AOL and Kodak so my pictures will also be sent to an Internet address. By the time you get this, they should be on the TMIC list for all to see.

This was a very rewarding activity for me. I hate the trite saying about it not being who wins or loses, but that is very true in this case. I had a wonderful time and I've been encouraged to enter again next year. I want to take this opportunity to encourage all of you to attend your state pageant. I would like to see more TMers involved in the Pageant also. This is an organization that needs a lot more support and publicity. I have long been an advocate for the disabled and this is a good platform from which to get the message across about Transverse Myelitis.

Thank you Debbie and Michael for coming out and supporting me. Thank you to all the TMIC members who sent me good wishes.

The inaugural Transverse Myelitis Awareness Day in Australia was held on May 12, 1999. Ian Hawkins is the Facilitator of the Transverse Myelitis Support Group. Those in attendance at the meeting heard a presentation from Clare Dean, a Physiotherapist from the Princess Alexandra Hospital's Spinal Injuries Unit. She spoke to the group about TM and she also answered questions. There was a lunch for the group following the presentation. The Australian Transverse Myelitis Awareness Day is an important step for those in Australia who have this condition. The Transverse Myelitis Support Group is planning their next Transverse Myelitis Awareness Day for May of 2000. If you are a TMA member from Australia, or if you are a TMA member and just happen to be in the neighborhood, we encourage you to contact Ian Hawkins.

Ian Hawkins, Facilitator of the
Transverse Myelitis Support Group
PO Box 5651 West End
Queensland 4101
Australia
(07) 3206 4618
PQAQ@GIL.COM.AU

Inaugural Transverse Myelitis Awareness Day in Australia

I would like to offer a summary and some comments, including my personal involvement, and observations about the TM Awareness Day. I would also like to present an outline of procedural steps necessary to obtain a proclamation/resolution for Transverse Myelitis Awareness Day to those TMA members who wish to do so in their respective states.

Because the disease has had such a profound and devastating impact on my life, I decided to gather support and build awareness for Transverse Myelitis. As a long-time political activist in my community and vice president of the local political club, I have become acquainted and worked on campaigns for several candidates who later were elected to the New York State Legislature. This entry paved the way for me to lobby my local assemblyman, Brian McLaughlin (D–Flushing) to sponsor a Transverse Myelitis Awareness Day in the legislature.

I had the good fortune to renew my acquaintenship with Assemblyman McLaughlin at a local event, where I was exhibiting literature and information about drugs and alcohol

June 6, 1999: Transverse Myelitis Awareness Day in New York

Pamela Schechter
Flushing, New York

in my capacity as Outreach Manager for Citizens Against Substance Abuse, a local volunteer community anti-drug organization. I spoke to him about sponsoring the resolution and he agreed to discuss it further. He suggested that I send him information about Transverse Myelitis. I contacted Deanne Gilmur, as President of The Transverse Myelitis Association, to write a cover letter to Assemblyman McLaughlin requesting his help in sponsoring the resolution. Later, I had several conversations with his staff members regarding the date of the proposed resolution and any additional information I could give them to help craft the language of the resolution.

On March 3, 1999, I received a letter from Assemblyman McLaughlin telling me that the resolution proclaiming June 6, 1999 "Transverse Myelitis Awareness Day" was passed unanimously in both houses of the State Legislature. From that time on, I wanted to plan a ceremony and luncheon support meeting to commemorate that important date. I decided to invite other TM members in New York State. The response I received from these invitations was very gratifying and we had twenty-five attendees, including TM members with their friends and families.

The event proceeded along these lines. There was a short ceremony acknowledging and thanking Assemblyman McLaughlin and his staff for their efforts in sponsoring and the passage of the resolution. There was a reading of the resolution by a staff member of Assemblyman

McLaughlin's office and a briefing by her explaining that his office was a possible funding source for the organization and suggested we write a proposal for grant money. We shared our individual experiences and struggles with this disease and how we cope with it on a daily basis. Further discussions included various drug treatments, the benefits of physical therapy and referrals for doctors for those who wanted further consultations. Literature about Transverse Myelitis was made available for everyone on a special table set up for that purpose. I had obtained the copies from my local library using their computer printouts. There were also copies of The Transverse Myelitis Association brochure.

Judging by the favorable comments of the attendees, I considered the luncheon a resounding success. They repeatedly stated that this luncheon support meeting was the first time they were able to meet others with the same condition as themselves. As suggested by the attendees, I mailed each one a copy of the attendance record complete with addresses and telephone numbers. Because of the satisfactory reception of this event, I scheduled another meeting for October 1999.

For those members who wish to obtain a proclamation/resolution for "Transverse Myelitis Awareness Day" in their respective states, there are several methods you can use to accomplish this. There is an informal and a formal procedure that is acceptable. The formal procedure involves the following steps. You must petition the state legislature to pass the resolution by submitting the petition with as many signatures as you can gather from various sources, such as churches, business organizations, friends, family and even door-to-door canvassing. When you head up the petition, you might use the following as an example. Begin by stating, We the undersigned petition the state legislature to pass a resolution declaring (members must choose a date prior to writing the petition to be inserted here) as "Transverse Myelitis Awareness Day." At this point in the petition, I suggest you describe what TM is using as a guide, the text from the TMA brochure headed, "What is Transverse Myelitis." The reason for doing this is because people want to know what they are signing. Compose a cover letter incorporating the symptoms, the pathology of Transverse Myelitis and certain data, such as who gets TM, the incidence rate and so forth. The letter can be written on the letterhead of the TMA and signed by Deanne Gilmur, President, if you feel it will carry more clout with the legislature. I would also include a copy of the resolution I obtained from the New York State Legislature as a further guide in crafting the language of the resolution.

Next, submit a cover letter, petition, a copy of the resolution to the state officials who are members of the state legislature in your district, as well as to four or five other state legislators in other parts of the state outside of your district. At the bottom of the cover letter, please indicate the names of the state officials who have received the same information.

The other method would be to appeal directly to your local state-elected official. Send him or her a copy of the resolution, cover letter and some literature about Transverse Myelitis. The article written by Dr. Levy and Dr. Lynn of our Medical Advisory Board would work well for this purpose, and can be printed from the TMA web site. Then follow up with a call to ask for an appointment to meet with him or her or a member of his or her staff. When the interview has been arranged, I suggest you bring copies of the same material you previously sent to him or her and copies of current newsletters of the TMA.

The two options I discussed in obtaining the resolution for "Transverse Myelitis Awareness Day" provide a useful guide in reaching that goal. However, any valid modification of your own can be used to obtain the same result.

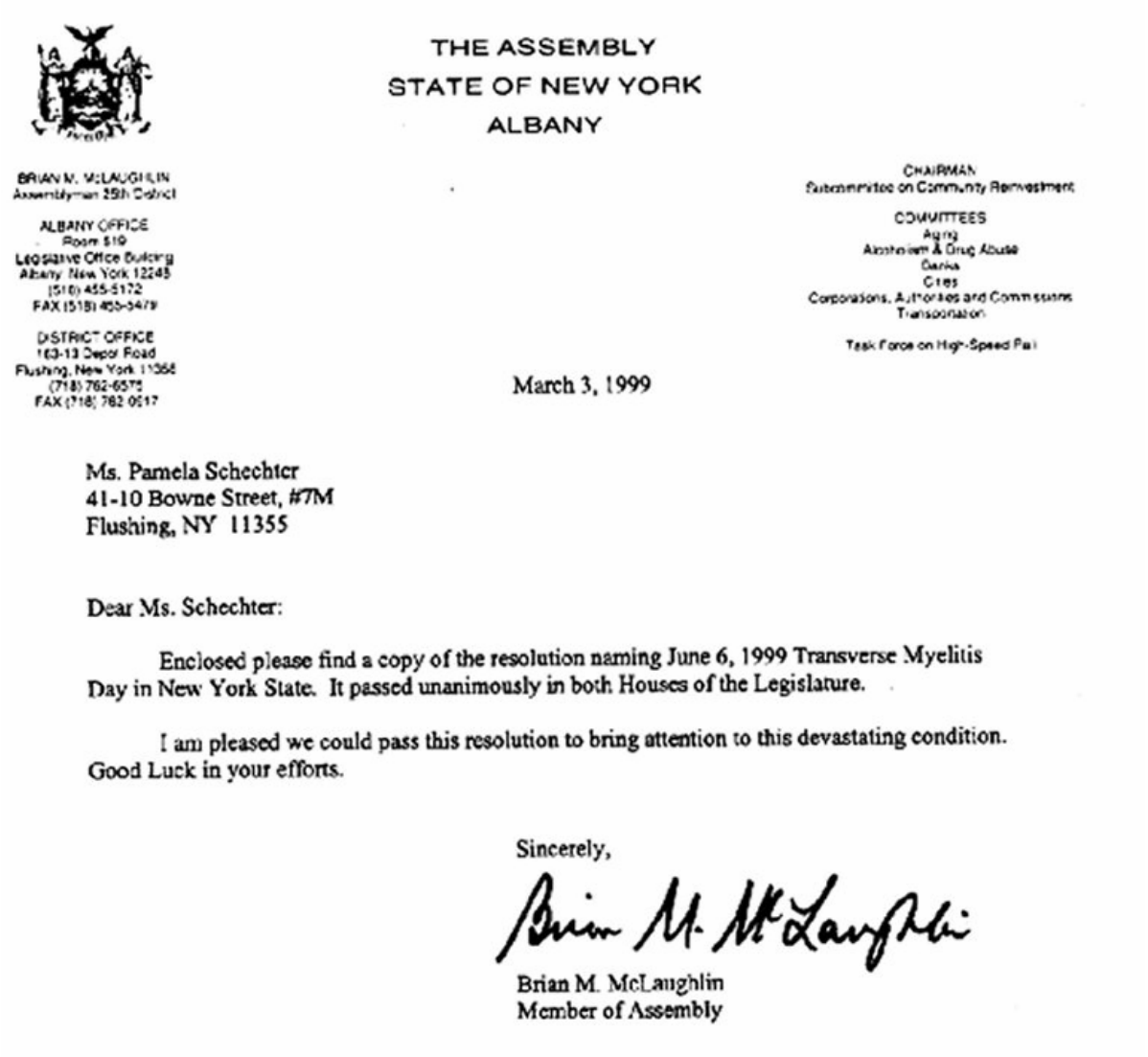
As a format and with some appropriate modifications, the copy of the letter Deanne wrote to Assemblyman McLaughlin would be a good example for the cover letter. A copy of this letter is available on the TMA web site. A copy of the New York Resolution is included in the newsletter for your information and to assist you in your efforts. Best of luck to all of you.

Pamela Schechter
New York State Representative for
The Transverse Myelitis Association

-9

WHEREAS, A disease known as Transverse Myelitis, which adversely affects some 1,250 Americans, is not widely recognized by the medical profession or the general public as being a significant serious spinal cord condition; and

WHEREAS, Transverse Myelitis is a devastating condition that can affect a person in a variety of ways; affecting the neurological system, the spinal cord becomes inflamed which can occur as a single condition or in the presence of an existing illness; and



THE ASSEMBLY
STATE OF NEW YORK
ALBANY

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Assemblyman 25th District

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CHAIRMAN
Subcommittee on Community Reinvestment

COMMITTEES
Aging
Alcoholism & Drug Abuse
Banks
Cities
Corporations, Authorities and Commissions
Transportation

Task Force on High-Speed Rail

March 3, 1999

Ms. Pamela Schechter
41-10 Bowne Street, #7M
Flushing, NY 11355

Dear Ms. Schechter:

Enclosed please find a copy of the resolution naming June 6, 1999 Transverse Myelitis Day in New York State. It passed unanimously in both Houses of the Legislature.

I am pleased we could pass this resolution to bring attention to this devastating condition. Good Luck in your efforts.

Sincerely,

Brian M. McLaughlin

Brian M. McLaughlin
Member of Assembly

90430-01-9

STATE OF NEW YORK

FEB 23 1999

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RULES

The Legislature

In Senate **In Assembly**

LEGISLATIVE RESOLUTION memorializing Governor George E. Pataki to proclaim June 6, 1999, as Transverse Myelitis Day in the State of New York

Senate

Introduced by

Sen. ____________________

The Senators whose names are circled below wish to join me in the sponsorship of this resolution:

Alesi, Balboni, Bonacic, Breslin, Bruno, Connor, DeFrancisco, Dollinger, Duane, Farley, Fuschillo, Gentile, Gonzalez, Goodman, Hannon, Hassell, Hoffmann, Holland, Johnson, Kruger, Kuhl, Lachman, Lack, Larkin, LaValle, Leibell, Libous, Maltese, Marcellino, Marchi, Markowitz, Maziarz, McGee, Meier, Mendez, Montgomery, Nanula, Nozzolio, Onorato, Oppenheimer, Padavan, Paterson, Rath, Rosado, Saland, Sampson, Santiago, Schneiderman, Seabrook, Seward, Skelos, Smith, Spano, Stachowski, Stafford, Stavisky, Trunzo, Velella, Volker, Wright

____

Senate introducer's signature

Assembly

Introduced by

M. of A. McLaughlin

The Members of the Assembly whose names are circled below wish to join me in the sponsorship of this resolution:

Abbate, Acampora, Alfano, Arroyo, Aubry, Bacalles, Barraga, Bea, Boyland, Boyle, Bragman, Brennan, Brodsky, Brown, Burling, Butler, D., Butler, M., Cahill, Calhoun, Canestrari, Carrozza, Casale, Christensen, Clark, Cohen, A., Cohen, M., Colman, Colton, Connelly, Conte, Cook, Crouch, Cummings, Cymbrowitz, Daly, D'Andrea, Davis, Destito, Diaz, DiNapoli, Dinga, Dinowitz, Doran, Englebright, Espaillat, Eve, Farrell, Fess, Ferrara, Feuerstein, Flanagan, Galef, Gantt, Glick, Gottfried, Grannis, Green, Greene, Griffith, Gromack, Gunther, Harenberg, Hayes, Heastie, Higgins, Hikind, Hill, Hochberg, Hoyt, Jacobs, John, Johnson, Kaufman, Kirwan, Klein, Koon, Lafayette, Lavelle, Lentol, Little, Lopez, Luster, Magee, Magnarelli, Manning, Markey, Matusow, Mayersohn, Mazzarelli, McEneny, ~~McLaughlin~~ (circled), Miller, Millman, Mills, Morelle, Murray, Nesbitt, Nolan, Norman, Nortz, Oaks, O'Connell, Ortiz, Ortloff, Parment, Perry, Pheffer, Prentiss, Pretlow, Ramirez, Reilly, Rivera, Robach, Sanders, Scarborough, Schimminger, Scozzafava, Seaman, Seddio, Sidikman, Silver, Smith, Squadron, [illegible], [illegible], Stringer, Sullivan, E.C., Sullivan, [illegible], Sweeney, Tedisco, Thiele, [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible], [illegible]

Brian M. McLaughlin

Assembly introducer's signature

INTRODUCTION OF ALL RESOLUTIONS

WHEREAS, Symptoms which can be physically debilitating include back pain, numbness of the lower extremities, and headache; as the condition progresses the eventual outcome is paralysis, sensory loss and bowel and bladder dysfunction; and

WHEREAS, Historically, scientific research has indicated that Transverse Myelitis was an extremely rare condition happening in only one of every million people; more recent findings have indicated that the incidence of this condition has risen nearly four hundred percent; and

WHEREAS, The Transverse Myelitis Association (TMA), a not-for-profit organization, has seen an increase from 180 members in 1997 to over 1,250 in 1998 and the numbers are rapidly increasing; and

WHEREAS, While spinal cord injuries have been well publicized lately in the media, Transverse Myelitis is often overlooked; and

WHEREAS, Recovering from Transverse Myelitis can also be difficult since treatment may take months with no sure guarantee that improvement will occur; only one-third of those inflicted make a full recovery; many medical professionals are unaware of this condition and the needs of patients with Transverse Myelitis; and

WHEREAS, if this condition was more widely recognized, diagnosis and further scientific research would benefit those who suffer from this condition; and

WHEREAS, It is in the interest of the people of the State of New York to seek ways of drawing attention to Transverse Myelitis in order to increase awareness of this little known condition; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor George E. Pataki to proclaim June 6, 1999, as Transverse Myelitis Day in the State of New York in order to educate the public, physicians, and other members of the medical community regarding the needs and issues of Transverse Myelitis patients; and be it further

RESOLVED, That copies of this Resolution, suitably engrossed, be transmitted to The Honorable George E. Pataki, Governor of the State of New York, and to Deanne Gilmur, the President and Founder of the Transverse Myelitis Association; TMA Vice President Sanford J. Siegel; Paula Lazzeri; Deborah Capen; Jim Lubin; and Pamela Schechter.

RESOLEG
Short Title: Memorializing the Governor to proclaim June 6, 1999, as Transverse Myelitis Day in the State of New York

The New York TM Support Group held its second luncheon meeting on October 23, 1999. There were 26 people in attendance. Hope Klopchin conducted the support group discussion. Hope is a fourth-year Ph.D. candidate in counseling psychology at the State University of Buffalo, New York and a TMA member. The support group meeting offered New York members the opportunity to discuss coping strategies for dealing with Transverse Myelitis and to gain information about research and any new treatments. There was a discussion of the first International Symposium of the Transverse Myelitis Association held in August 1999 in Seattle, Washington. Deanne Gilmur made materials available to the New York Support Group that were distributed at the meeting. The Support Group meeting also provided a wonderful opportunity for socializing and meeting others who have the TM diagnosis. The next support group meeting and luncheon will be held at the end of March 2000.

I started The Disabled Discounts Project while coping with my own disability and listening to people with their

New York Support Group Holds Second Meeting
Pamela Schechter

stories of struggling in life with their disabilities. Many live with pain, loneliness, financial difficulties, and lost dreams; yet have an inner strength for life that others do not see. It is a struggle when you are hit with a disability. It can happen at any age, any time. You don't know what to do, where to go and families can be shattered. There can be real adversity. We expect a lot of help and answers to our problems, but often we find ourselves alone.

Disabled Discounts Project
Gene Murphy

The Disabled Discounts Project is a grass-roots, non-profit organization that you or your organization can start in your state and community, established to make people aware of the financial difficulties facing the disabled in our society. The Disabled Discounts Project is requesting retail stores and business professionals to open new markets in discounts to the disabled, much the same as they do for senior citizens and students. Senior citizens in our society are eligible for discounts on products and services. The disabled are not. Let's change this!

Some of the markets the Disabled Discounts Project is trying to reach are: banking, attorneys, department stores, doctors, dentists, drug stores, restaurants, repair services, movie theatres, transportation, and health clubs.

The Disabled are a new market! If you are interested in participating in the Disabled Discounts Project or in starting a Disabled Discounts Project in your community, please contact me at the address or phone number below.

Gene Murphy
Founder and President
Disabled Discounts Project
200 Dashew Drive Suite 7A
Suffern, NY 10901
(914) 357-7495

The Transverse Myelitis Association Online
Jim Lubin

The Transverse Myelitis Association web site has been visited approximately 17,000 times since March 1999. The web site remains one of the most important tools the Association has for disseminating information, providing education to our members and to the general public and offering support and networking. Our web site is the most effective approach we have for outreach, and it is certainly the most frequently used means for persons with TM to find the Association.

The following list presents the number of visits that are made to our web site from all over the world. It is an interesting illustration of the importance of our web site as a tool for outreach, as well as a reflection of the interest people from all over the world have in Transverse Myelitis. For those of us with TM, it is a very graphic reminder that we are really not alone. (These totals represent the summary period of Oct 17, 1999 to Oct 25, 1999, a typical week of activity from the web site).

51	Argentina
1	Austria
826	Australia
18	Belgium
25	Bermuda
73	Brazil
1073	Canada
53	Colombia
27	Costa Rica
12	Czech Republic
29	Denmark
1	Dominican Republic
44	Estonia
37	Finland
148	France
255	Germany
2	Greece
3	India
4	Ireland
35	Israel
112	Italy
23	Japan
1	Latvia
43	Malaysia
81	Mexico
45	Netherlands
68	New Zealand (Aotearoa)
16	Norway
26	Oman
2	Pakistan
1	Poland
6	Portugal
19	Romania
2	Russian Federation
108	Saudi Arabia
1	Singapore
2	Slovak Republic
48	Spain
18	South Africa
32	Sweden
8	Switzerland
4	Taiwan
3	Thailand
22	Turkey
8	United Arab Emirates
427	United Kingdom
526	United States

Over the past year, I have made some important revisions and additions to the TMA web site. We are now archiving messages at the eScribe web

site. This is a searchable archive that allows you to search by concept for specific information. You can use this as a valuable tool for learning about what other members have experienced from their TM symptoms and from their various treatments and medications. eScribe also includes a chat room and bulletin board where people can post messages to others. The bulletin board currently contains hundreds of posts on a multitude of subjects associated with Transverse Myelitis. Links to the chat room and bulletin board can be found on the TMA home page and TMIC page at :<http://www.myelitis.org/tmic>.

There is a page on the web site where additional resources about Transverse Myelitis can be found. There are numerous references to research and publications. Additionally, there are links to newspaper articles and news releases related to the Transverse Myelitis condition.

I have also added a page to the web site that chronicles the First International Symposium of The Transverse Myelitis Association that was held in August in Seattle, Washington. The site includes picture highlights from the symposium. The Program Agenda is also available with printable copies of the handouts that were provided by the presenters at the symposium. The Seattle page is located at <http://www.myelitis.org/seattle99>.

I also want to take the opportunity to remind our members that if you shop online through the iGive mall or Amazon.com links on the TMA site that a percentage of your purchases go to TMA. For the Association to receive your contribution from your purchases, be sure to go to these Internet sites through the links on the TMA web page. It is an easy and fun way to shop and it is an easy way to raise money for the Association.

The Transverse Myelitis Internet Club continues to be a vital support group and source of information and comfort for those who are newly diagnosed with TM, as well as for people who have had TM for decades. There are currently almost 350 people who are registered on the TMIC list group. If you are new to the Internet, I would encourage you to subscribe to the TMIC and to get involved in this very friendly and supportive community.

Finally, I would like to encourage those of you who have never seen the TMA web site to try to do so in the near future. Receiving the newsletters and the other materials from the Association help us all to feel connected and remind us that we are not alone in our experiences with Transverse Myelitis. The TMA on the Internet is perhaps one of the most powerful ways to experience this support and connection with others. We know this because we hear from people all over the world who communicate their surprise and their gratitude for having found the Association web site. You do not need a computer to share in this experience. Almost every public library in the country offers computer access to the Internet. You do not need any computer knowledge or experience; most will be glad to assist you. You only need to provide them with our web address, which you have in this article, and in various places in this newsletter. If you have trouble getting to a public library, most of you have family members and friends who also have access to the Internet. I think you will find our web site both informative and inspirational. I hope that you get the opportunity to view it sometime soon.
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

Automated Info reply:
info@myelitis.org

Membership related:
membership@myelitis.org

Newsletter related:
newsletter@myelitis.org

TMA Survey related:
survey@myelitis.org

Web site related:
webmaster@myelitis.org

The following are some of the TMA web pages:

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

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

The TMA on the Internet

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

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

The TMA Officers' e-mail addresses:
Deanne and Dick Gilmur:

dgilmur@myelitis.org
Sandy Siegel:
ssiegel@myelitis.org
Debbie Capen:
dcapen@myelitis.org
Paula Lazzeri:
plazzeri@myelitis.org
Jim Lubin:
jlubin@myelitis.org

The Transverse Myelitis Association Annual Report: 1998
Paula Lazzeri

The following tables present The Transverse Myelitis Association Annual Report for 1998. The 1999 Annual Report will be presented in the next newsletter. The TMA General Fund column presents all funds received and expended directly by TMA as recorded in the Association's financial account. The Total Donations and Expenses to Benefit TMA column is presented to help convey the total costs of providing TMA member services during 1998. This column includes funds/activities reported in the TMA General Fund as well as non-reimbursed expenses paid by members of the Board of Directors. These non-reimbursed expenses also are shown as Donations made by Board of Directors under Revenues. The Donations made by Board of Directors line item presents the amount of funds spent by members of the Board of Directors that were not reimbursed by the TMA General Fund.

The Transverse Myelitis Association 1998 Statement of Financial Activities (in US Dollars)

1998 Statement of TMA General Fund Account Balances

1997 End Balance
1,162
Add 1998 Deposits
13,815
Less 1998 Expenses
5,310

1998 End Balance **$9,668**

We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through their generosity that we are able to offer services to our membership; they also make possible the expansion of services to our existing and future members. The following persons and organizations made donations to The Transverse Myelitis Association in 1998. The donations made by members of the Board of Directors include non-reimbursed expenses.

$5-25

Robert Alex
Irene Allen
Cleora Armbruster

	TMA General Fund	Total Donations and Expenses to Benefit TMA
Revenues		
Charitable Donations	13,815	13,815
Donations made by Board of Directors		14,222
Total Revenues	**13,815**	**28,037**
Expenses		
Computer Equipment	-	7,714
Conference (FOP) and Board Meeting	1,100	1,664
Domain Address Subscription (myelitis.org) and Website	402	402
Internet Access	-	609
Mileage & Parking	-	279
Office Supplies	-	595
Postage and Shipping	542	3,178
Printing/Copying	3,255	4,125
Secretary of State Fees	10	10
Telephone	-	957
Total Expenses	**5,310**	**19,531**
Net Income	**$8,505**	**$8,505**

Doris Ballou
Alice Birkenmeier
Natalie Caplan
Frank Carone
Daniel & Barbara Cole
Congregation Beth Tikvah Rabbi Fund
Richard Dolph
Mary Eveld
Sheila Gooch
Thelma & Charles Gilmur

1998 Donor Recognition
Paula Lazzeri

Bonita Hall
Deborah Juster
Marie King
Nora Kirkpatrick
Carin Kjoss
Gerald Kmetz
Elizabeth Knaack
Janice Mastel
Gwendolyn Maupin Ahern
Judy Mayo
R.G. McKay

North American Pediatric Subspecialty Assn. Inc.
Toni Norris
Gerald O'Grady
Marcille Pollack
Timothy Popma
Ronald Reedy
Mabel Reimers
Marjorie Riddle
James Simpson
V.J. Smeltzer
Patricia Surian
Beborah Teal
Glennda Trewin-Cartner
Roberta Trott

$25-50

Bruce Andrews
F.J. Baumgartner
Leslie Baumgartner
Phillip Burcham
Mildred Eidsness
Meg Grossman
Phyllis Haney
Beverly Hoag
Beverly Inman
James Jonas
Elizabeth Jordan
R.D. Jordan
Patricia Joslin
Warren Nichols
Brenda Parkman
Susan Parry
Norman & Gayle Peltier
Charles Rossi
Alton Ryder
Herb Schuette
Joan Taylor
Vera Thyes
Ann Vrbanac

$50-100

Martha Childers
Marshall Brown Gilchrist
United Way (Dick Gilmur)
Patricia Hein
J.A.M. Hutchinson
Patricia Knowlton
Betty Rovenstine
Maureen Wroblewski

$100-200

High Technology, Inc.
Beverly Smith

$200-300

Debbie Capen

$300-400

Jan & Frank Hargrove
Wal-Mart Carwash
(Heather O'Dell)
Wal-Mart Foundation

$500-700

Attachmate Corporation
Attachmate Golf Tournament
(Buddy Peltier)
Diane Davidson
Keller Junior High School
Paula & Myk Lazzeri

$5,000-6,000

Dick & Deanne Gilmur

$7,000-8,000

Claddagh Foundation

> $8,000

Sandy Siegel & Pauline Habib

This newsletter presents several articles that have conveyed the past accomplishments and future goals of the TMA (for example, see the President's Message, Debbie's personal account of the 1999 Symposium, and Jim's information about TMA Online). This edition also contains the 1998 financial report which presents an accounting of charitable contributions received during that year and the operational expenses incurred by TMA to deliver its member services. The financial report also presents non-reimbursed operational expenses incurred by members of the Board during 1998. The TMA continues to grow and develop, expanding not only in the number of members (from 187 in January of 1997 to almost 2000 currently in 35 countries), but also in the range of member services that are provided (such as the 1999 First International Symposium). As the TMA grows, the operational costs continue to increase, as do the costs associated with efforts to provide new and expanded services.

Currently, the TMA provides many basic services that include the Initial

Help Support TMA's Continued Growth and Development
Paula Lazzeri

Information Packet; Membership Directory and Updates; Newsletters; the Web site; TMIC, chat and electronic bulletin boards; Support via mail, phone and e-mail; Symposia; and maintaining contacts and building relationships with medical facilities and providers, agencies, and other organizations that share in our goals of providing information, knowledge and support to individuals with TM and their families. The TMA is also working to expand its services by developing a Children's and Family Network Directory that will be provided to parents of children with TM. The purpose of the Children's and Family Network Directory is to provide a safe means for parents to support other parents and for parents to find other children for their children to communicate with and build friendships/supports with peers. Another way in which the TMA is expanding its services is by strengthening its organizational support and advocacy for cure research. As stated in the President's Message, the continued development of critical partnerships will facilitate implementation of this vital outcome: a cure for TM and other spinal cord injuries and dysfunctions.

Based on our current membership levels and geographic locations, a conservative estimate of the cost of providing the TMA services to an individual or family for the year is $25.00 (U.S. funds). Please consider this information as you decide how you might be able to support the TMA. If you would like to support TMA's continued growth and development, and the expansion of the services TMA currently offers, please consider a larger charitable donation. The future of TMA depends on membership support of the Association's general operational activities and services.

In keeping with TMA's expanded goal of strengthening its organizational advocacy and support for cure research, the Board has established the TMA Endowment Fund. The purpose of this fund is to generate a lasting source of funds that can contribute to ongoing and future TM cure research efforts. Revenues from the Endowment Fund will be used to partner with other organizations and funding sources to support research that is applicable to persons with TM. The Board has set a challenging goal of building the Endowment Fund to $100,000.00 during the year 2000. The Endowment Fund does not support TMA's operational activities and services, so please consider an additional contribution to the Endowment Fund.

Only by working together can TMA reach its financial goals and be a significant force in helping to direct and fund research to benefit individuals with TM. Please support the Association's efforts by giving what you can. An envelope has been provided with this newsletter to assist you. We hope that you will use it to make a tax deductible charitable contribution to The Transverse Myelitis Association. Thank you for your support.
The Transverse Myelitis Association is developing a Children's and Family Network Directory that will only be provided to parents of children with TM. The purpose of the Children's and Family Network Directory is to provide a safe means for parents to support other parents and for parents to find other children for their children to communicate with and build friendships/supports with peers. Please note that the Children's and Family Network Directory is still under development and has not yet been published. Our goal is to also publish annual updates to this directory. ***This directory will only be sent to those TMA members who have registered for and are included in this directory.*** The Association has been collecting information for the Children's and Family Network Directory for about a year, and we have only received a minimal response. We know there is a need for this information, because it is frequently requested from both parents and children. Please take the time to fill out the response form included in this newsletter in order to be included in the directory.

The TMA Children's and Family Network Directory

The Association is 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 a minimal 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 infor-

mation regarding neurologists who treat TM patients. Please help each other out by sending me this very important information. You can send me your neurologist's information by using the response form included in this newsletter.

Referral to a Neurologist

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. **What would you be willing to do to help doctors and researchers better understand Transverse Myelitis, to help them find more effective treatments for the symptoms of TM, and to ultimately help them find a cure for TM?**

Would you be willing to donate an hour of your time and 33 cents? That's what it will take you to fill out the TMA survey and return it to me through the mail. If you send it to me electronically, you can save yourself the 33 cents. It is never going to be too late to complete and return this survey. I will continue to enter the information and we will periodically update the analysis and reporting.

We currently have almost 2000 members in the TMA and everyone has received this survey. It was sent to you with the first newsletter, or you received it when you were sent the initial packet of information from Dick and Deanne Gilmur. I have only received 402 completed surveys. If you have not completed and returned your survey, please do so as soon as possible. You hold one of the important pieces that will help doctors and researchers solve the Transverse Myelitis puzzle. Please share this information; do so for yourself, for everyone who has TM and for all of those who will develop this condition in the future. It is important for you to take the time to record this information. We will be administering additional surveys in the future. As we begin to develop a greater understanding of TM, we will require the collection of better and more detailed information. For instance, it would be important for us to understand how many people have had recurring episodes of TM, not MS; whether there has been more than one additional episode, what symptoms accompanied each episode and what the time span was between each episode.

I have currently entered over 350 of the surveys. As soon as this process is completed, we will begin to analyze the information. We will report it to you as soon as we have a report completed. And we will find ways to share this information with the doctors who treat you and with the doctors who perform research.

If your survey is currently located so many strata below the piles of paper on the kitchen counter that you would need to hire an archeologist to find it, please contact Deanne for another copy of the survey. She will mail you a survey and the instructions for filling it out. If you have access to the Internet, you can download a copy of the survey from our web page. You can mail me the survey through the postal service or you can send it to me electronically.

You can really make a difference. Help yourself and help everyone else in the TM community. Thank you so much, if you have already sent me the survey. For the rest of you – *get busy*! Please.

Please mail the completed surveys to:
Sandy Siegel
The Transverse Myelitis Association
1787 Sutter Parkway, Powell, Ohio 43065-8806

The Transverse Myelitis Association

Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065

The Transverse Myelitis Association celebrates five years of service to its almost 2000 members