❖The Transverse Myelitis Association❖

Volume 4 Issue 1 March 2001

From the Editor
Sandy Siegel

Being a caregiver is one of the most difficult jobs one will ever face during their lifetimes. And it is certainly one of the most complicated. There is no education or training you receive for this job. You learn how to do the job while you are doing the job; much like parenthood. For most parents, however, the job usually gets easier. For most children, they complete their education, they find jobs, they start their own families, and they eventually begin to pay their own insurance premiums. So, the job becomes less demanding, intensive, and energy and time consuming. This is not always the case for a caregiver. Sometimes our loved ones do improve and the job does get easier. And sometimes, our loved ones do not get better, and the job becomes more and more difficult.

It is also not a job people consider applying for; it just happens to us by virtue of life circumstances. Let's see, a job that one does not ask to have and one for which a person receives no education or training. Sounds like a job that would not get done very well. Over the course of my involvement with people who have TM, I have met worldclass caregivers. I have come to know caregivers who perform their jobs with tremendous devotion and intensity, people who relate to their loved ones with great care and nurturing, people who perform their tasks with diligence and competence and people who behave with incredible responsibility and loyalty. The tasks are not easy, and staying with it takes tremendous emotional and physical stamina. And the tasks involved can be really complicated and require great skill and care. Taking care of a loved one who is on a ventilator and taking care of a loved one who requires catheterization throughout the day and night is asking a lot of a person.

Taking care of a person who requires assistance with their day-to-day physical functioning is a difficult job. But the job entails so much more than all of those difficult physical activities. Caregivers are also emotional and spiritual supporters, they are schedulers and chauffeurs, they are therapists (physical and psychological), and they are shoppers and organizers and homemakers. And perhaps one of their most important and difficult jobs, they are gladiators with the medical and insurance and social service bureaucracies.

An interesting and difficult element of the process of being a caregiver is that there are no or only very minor societal resources that are focused on the caregiver. When a person contracts a serious illness, there is a rallying of family and friends to support the patient and the primary caregiver. Families often live all over the country and world and cannot maintain that support for very long; they have their own families to take care of, and their jobs and lives to which they need to return. And it is a very rare friend who can take on the role of a family member and maintain a long-term care relationship. It does happen, but it is not the usual course of events. Caregivers most often find themselves on their own without a great deal of assistance; even from family and friends.

Much the same may be said for the manner in which the medical community deals with the caregiver. When a person becomes ill, attention and energy are focused on the patient; the focus is diagnosis and treatment. There are few resources directed at the caregiver, and yet, the illness that has stricken one's loved one also has the most profound impact on the caregiver. The caregiver most often goes it alone from the perspective of the health care community. Should a person require long-term rehabilitation and therapy, the caregiver is in the process alone for a very long time. And there is nothing easy or convenient about the process.

Every member of society holds many different positions. For instance, I am a father, a husband, a son, a brother, a teacher, an employee for the State of Ohio; a friend, a newsletter editor, a caregiver and many more. Each of these positions has a complex range of behaviors and expectations associated with them. In all societies, cultures ordinarily operate such that the roles and expectations from all of the positions a person holds are consistent with each other; the roles from one position are not in conflict with the roles of the different positions a person possesses. This consistency allows a person to function efficiently and

effectively and is really fundamental for a person's emotional and psychological health. When the roles from different positions are in conflict with each other, it causes a person tremendous stress. For instance, when a woman in our society has a full-time job and is also a mother, wife and homemaker, the roles associated with these positions often times are in conflict and a woman can experience considerable stress from the role conflicts. If there are traditional expectations of a woman, and her husband and children do not realign their expectations and share in the behaviors associated with her positions as wife, mother and homemaker in order to account for the demands she has on her at work, she is often going to suffer emotionally and psychologically from this conflict.

Such is the case also for the positions we hold in our lives when the position of caregiver is added to our collection. Many of the conflicts are obvious and are a consequence of the demands of energy and time on the caregiver. For example, being a caregiver can certainly impact one's job; some people have to change employment after becoming a caregiver in order to accommodate the new roles that are required of this new position. Becoming a caregiver may change that person's relationships with other members of their family. For instance, a parent of a child with TM may experience conflicts because the demands of time and attention that are required to care for their child with TM does not allow them to behave in ways they expect of themselves in their relationships with their other children.

Not all of the sources of conflict are so easily identified and some are very difficult to resolve. Some role conflicts are created for the caregiver that result from a change of expectations and behaviors from those that are customary for a particular relationship. It is the normal course of events for a child to become an adult, develop independence and have less and less reliance on a parent. When a parent is a caregiver for an adult child, the roles can become complicated for the individuals involved, because what is customary in this relationship, as defined in American culture, may not transpire. An adult child may be somewhat uncomfortable with remaining dependent on parents at a time in their lives when they should be independent of a parent. And this is particularly the case when the parents have to assist with the most basic physical and personal issues for the adult child.

Likewise, children are raised with complete dependence on their parents. While that dependence diminishes with time, a parent will always feel responsible for a child. When a person becomes a caregiver for a parent, these roles become reversed; the parent who cared for the child now has to be cared for by the child. The relationship may become uncomfortable for the persons involved, because these are not the behaviors we were raised to expect from these relationships.

Becoming a caregiver may cause difficult role conflicts for a husband or wife who become caregivers. Maintaining a long-term relationship is often a balance of reciprocity and mutual support. Couples usually are looking for equality in their relationships. Men and women bring different skills into a relationship, and different strengths and weaknesses, but on balance, we are seeking to be valued and treated equally. When one of the couple becomes a caregiver, the delicate balance may become seriously skewed. Some persons may have a difficult time negotiating their roles as a caregiver with those of a lover.

There is little in life experience, training or education that prepares a person for the issues they have to face as a caregiver. There are quite serious mental gymnastics required of a person to balance and adapt to the different positions they have in their lives, all of which make demands on their time and energy. And they need to develop the ability to negotiate between positions and roles in such a way that stress and conflict do not become a constant background noise in their daily lives.

Being a caregiver for a loved one, be they a child, a parent, a husband, wife or companion/lover, a brother or sister or a close friend is going to change that relationship. A nurse and doctor have a professional relationship with the patient; it is a well-defined relationship and the behaviors and expectations between the professional and the patient are molded by custom, ethics, and the law. This is not at all the case between the caregiver and the person requiring care. The relationship between a husband and a wife is defined by our culture, and we all participate in various forms of that same set of behaviors and expectations. For the relationship between a husband with TM and a wife/caregiver, the roles and expectations are not at all clearly defined by our culture. You are going to be making this up as you go. And some are going to do this creation really well, and some are going to flounder.

I have no brilliant skills or strategies to impart to resolve all of these difficult issues. True to my anthropological profession; we can tell you what's wrong, but we haven't the slightest clue as to what you might do to fix it.

I wrote the following words to

Pauline after we lost our 16-year-old dog, who we both loved very much:

The really wonderful thing about life is that there is constant change; it is also a really frightening part of life. Turmoil is a constant. One of the reasons that relationships are so complicated is that people often have difficult times traversing the journey of turmoil; it is done on the inside with the constant battle one has with their own emotions and perceptions of the world. It is a one-person operation. But when you are in a relationship, you become a part of the dynamic that the other person has to relate to and adapt to as a part of their dealing with all of the turmoil. How that process is negotiated and balanced is an important factor in how relationships are maintained or destroyed. You can let each other into the process and grow from it, or you can cut each other out and be pulled apart from it. And with all else in the relationship, you influence each other even in this process. You can allow each other to feel safe to share the turmoil and nurture each other, or you can feel defensive or vulnerable toward the other person and close them out. All very complicated stuff. Being there for each other can make the ***us*** *stronger.*

As I wrote these words to her, my thoughts and feelings went back to the times when Pauline had first contracted TM. Our going through the experience of Pauline's TM has made **us** stronger.

I wish I had some magic formula to explain why it is that some people can accept the things that happen to them and find a way to be positive about their current life circumstances. It is a blessing that they have that skill and that view of the world and themselves. I just marvel at people such as Helena Lubin and Myk Lazzeri and Cathy Dorocak; it is people such as Helena and Myk and Cathy who have taught me something of the capacity of the human spirit. What they are capable of giving out of love is truly incredible. The TMA has so many caregivers who are giving to a loved one in just this way; you are all my heroes!

The TMA is for people who have TM. The TMA is also for caregivers. **You, too, are not alone!**

From the President
Deanne Gilmur

Please take good care of yourselves and each other.

Happy 2001 and greetings to all of The Transverse Myelitis Association membership and its supporters. With this new year, TMA is involved in many critical upcoming efforts. The registration form for the Second International Transverse Myelitis Symposium is contained in this newsletter. This conference will be hosted and sponsored by Johns Hopkins Hospital July 12-15th. Dr. Douglas Kerr, TMA Medical Advisory Board member and co-director of JH's Transverse Myelopathy Center has spearheaded efforts to pull together a topnotch gathering of professionals and experts to explore future treatments, causes and diagnostics associated with tm. We hope many of you will attend. Remembering our first symposium, I feel assured that all of us, family members, professionals and persons with a TM diagnosis, will come away with much information and support. I can't wait to see everyone who attended the Seattle conference again, and I can't wait to meet more of you.

In addition to information about the conference, you will read in this edition of the newsletter about the Reading for Rachel program, a wonderful way to assist in fundraising for TM research that most of us can accomplish in our local areas. While March is Reading for Rachel month, its good to know that every other month can be too. So, if you missed a chance at participating in March, use the same information/forms available at the TM website and use them for any time period that meets your needs. Remember, summer is a good time for reading too.

So many members have worked hard to find ways to support TMA and, most importantly, to identify ways to work for a cure to TM. These efforts are so apparent in the numerous articles of this newsletter as well as all the letters, emails and phone calls the Board Members receive on a regular basis. It is my hope that each of you will feel a bit more hopeful for the future and a lot less isolated from others as you read about the progress that is being made and the many who are here to support each other.

Sandy, as most of you know, has been our Vice-President and newsletter editor since TMA's inception. He has agreed to take on the presidency of the organization at this time while I am immersed in job and family matters. Unfortunately, circumstances change and I now have many responsibilities which are eating away at the time I have been able to dedicate to TMA. So, Sandy is stepping up again. This is no small gift as TMA is significantly growing. I will continue on as an active member of the Board. Paula, Debbie and Jim also remain indefatigable in their hard work for the Association. We are lucky, all of us, for the hard work and commitment of so many. I believe that it will make a

Urological Problems in Transverse Myelitis
Michael Mayo, MD

difference towards the hope and dream of making a cure for transverse myelitis a reality.

Dr. Mayo is a Professor in the Department of Urology at the University of Washington School of Medicine, Seattle, Washington. Dr. Mayo has subspecialty interests in neurogenic bladder disorders, urinary tract reconstruction, endourology, and stone disease.

Introduction

Transverse Myelitis is a rare disease affecting 4.6 per million of the population per year. It has many causes and/or associations including multiple sclerosis, parainfection (especially following upper respiratory infection), spinal cord ischemia; in many patients the cause is unknown. Its course is variable with approximately half of the patients in the multiple sclerosis and parainfectious group able to walk and empty their bladders on discharge from hospital. The remainder, especially the ischemic group, have variable recovery. Some individuals, from any group, who initially recover may relapse.

Pathology of Bladder Dysfunction

Control of the bladder and urethral sphincter takes place in the mid brain and cerebral cortex. Damage to the tracts in the spinal cord in Transverse Myelitis interrupts the normal sensory messages ascending, and the motor messages descending, to the nerves that directly drive the bladder which lie in the sacral segments (S2, 3 & 4).

In the acute phase, especially if the Transverse Myelitis is complete and all the fibers are interrupted, the bladder is totally paralyzed and fills without the individual being aware of it. As the spinal cord recovers there is a parallel recovery of bladder function which may be complete. Later on, if there is no recovery of spinal cord function, the bladder reflex usually returns. However, instead of the control being in the brain it is in the sacral segments due to rerouting or short-circuiting of the impulses from the sensory directly to the motor nerves of the bladder. Although the bladder may start to empty, its function is erratic and uncontrolled and emptying is incomplete.

Urinary Symptoms in Transverse Myelitis

With the onset of acute Transverse Myelitis, the patient's bladder has little or no sensation and fills with urine. If the bladder is allowed to become very distended, urine will start to dribble continuously, and this is called retention with overflow incontinence. Some form of catheterization program, either indwelling (Foley) or intermittent, is started to prevent the bladder muscle over-stretching.

Later on, as the spinal cord recovers function, patients will begin to be aware of bladder filling and be able to urinate although emptying may not initially be complete. With regard to symptoms, patients will usually have frequency of urination and urgency with perhaps some urge incontinence before they can get to the bathroom. Once in the bathroom, urination may be delayed (hesitancy), the stream may be interrupted, and emptying incomplete. This incomplete emptying of the bladder is due to a combination of a reduced contraction and discoordination of the urethral sphincter muscle. Over several weeks or months further recovery of function may occur as the spinal cord recovers.

In patients who have no recovery of spinal cord function, the new reflex in the sacral segments will start to produce some bladder emptying. However, in this situation the patient has no sensation and leaks urine without being aware of it (reflex incontinence). Emptying is usually

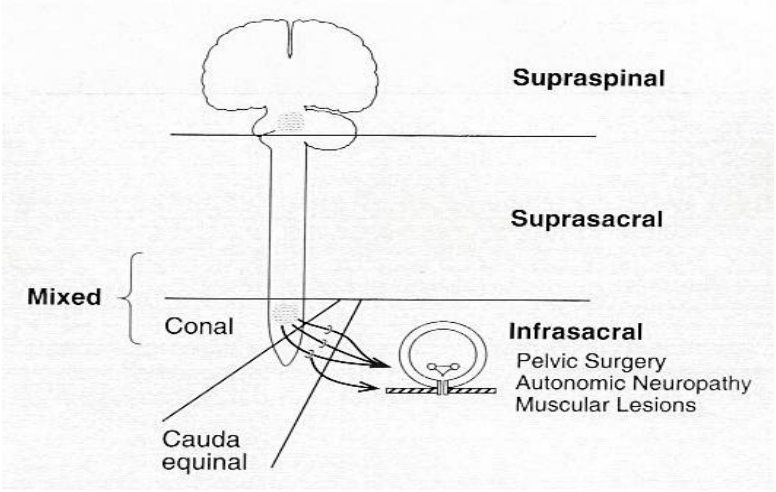


Figure 1 Nerve Supply to the Bladder and Urinary Sphincters
Transverse Myelitis affects the spinal cord in the suprasacral region between the two horizontal lines in the diagram. The mid-brain and sacral centers (stippled) are disconnected from one another.

Diana Carderas and Michael Mayo, "Management of Bladder Dysfunction," Figure 27-4, Chapter 27 In Randall L. Braddom, MD, MS, Physical Medicine and Rehabilitation, Second Edition, Philadelphia: WB Saunders Company, 2000.

more incomplete than those with recovery of spinal cord function due to worse coordination of the urethral sphincter. The secondary effects, such as high bladder pressure, urinary tract infections, and eventually kidney damage, are worse in patients who make little recovery.

Natural History

The recovery of bladder control and emptying in Transverse Myelitis parallels the recovery of function in the legs. Early and full recovery of the spinal cord dysfunction will usually lead to complete bladder and sphincter recovery. Why the spinal cord in some individuals recovers and in others it does not is beyond the scope of this article. Although it is difficult to determine from the literature how many patients have permanent problems, at least 20 percent of patients have some residual bladder and urethral symptoms, and most of these also have some impairment in the lower limb function. In patients with residual problems, the symptoms and the lower urinary tract manifestations may change as they age. In men the growth of the prostate may cause obstruction to the outflow of urine. In women pelvic floor descent and stress incontinence may occur especially in those who have had vaginal deliveries. In both men and women, if the bladder pressure is high and infections frequent, the bladder muscle and often the upper tracts will undergo pathological changes that further affect the lower tract and kidney functions. Long-term surveillance is therefore recommended in patients with residual bladder symptoms following Transverse Myelitis.

Evaluation of Urinary Tract Symptoms

Soon after the onset of the acute illness the patients will often be managed with a catheter. Urine analysis and culture are performed once or twice a week. Base line kidney function is assessed with a serum creatinine and a creatinine clearance. Those patients making a quick recovery need no further evaluation. In others that have some residual problems at the time of discharge, a renal ultrasound is usually done. Other kidney evaluations with computed tomography, intravenous pyelography, or renal isotope scan may be recommended if there is any evidence on ultrasound, or clinically, of upper tract problems such as stones, dilation, or prior abnormality due to congenital or acquired disease.

Evaluation of the lower tract is also deferred in those patients making early recovery. In those that are not recovering, a cystometrogram is performed. Here, the bladder is filled via a catheter while bladder pressure is monitored. This will determine the bladder sensation, the bladder size and elasticity (compliance), and whether there is overactivity of the bladder reflex. A full videourodynamic study includes the filling study (cystometrogram) and the bladder-emptying phase. X-rays are also combined so that, not only can the bladder wall outline and the presence or absence of urethral reflex be determined, but also the function of the urethral sphincters be assessed.

Treatment

Initial treatment in the acute phase usually consists of continuous bladder drainage with an indwelling Foley catheter. When the fluid balance status has stabilized, intermittent catheterization is begun by the nursing staff. Later on patients learn self-catheterization depending on their age and motivation. In men, as the majority have thoracic or lumbar lesions, there should be few physical impediments to self-catheterization. In women, although they also have thoracic and lumbar lesions, the spasticity of the lower limbs and the need for many to lie down to catheterize, may limit their ability to continue with this program after leaving the hospital. It is important for patients to empty their bladders on time so that the muscle is not over stretched. In an average sized adult 500 to 600 ml should be the maximum volume retained in the bladder.

In the first few weeks, depending on the degree of spinal cord recovery, the bladder sensation and the ability to void may return. Good prognostic factors are the ability to walk before 20 days from the start of the illness and a history of retention only rather than retention plus overflow incontinence. The later probably leads to over stretching of the muscle which delays recovery. Early catheterization at the onset of the acute illness is essential.

If recovery of the spinal cord function is very incomplete or absent, the bladder reflex will usually occur in an uncontrolled fashion leading to reflex incontinence at small bladder volumes. Treatment with medication that suppresses bladder contractions, Ditropan (oxybutynin), and Detrol (tolterodine), are the commonest agents used. If these fail to suppress the bladder reflex and the patient wants to continue with self-catheterization, surgery to enlarge the bladder and lower the pressure (augmentation) can be considered. This involves taking a twenty-five to thirty centimeter segment, usually from the small bowel, and sewing it into the opened bladder as a patch. In women who find catheterization via the urethra difficult, an artificial urethra can be constructed from the bowel and placed on the abdominal

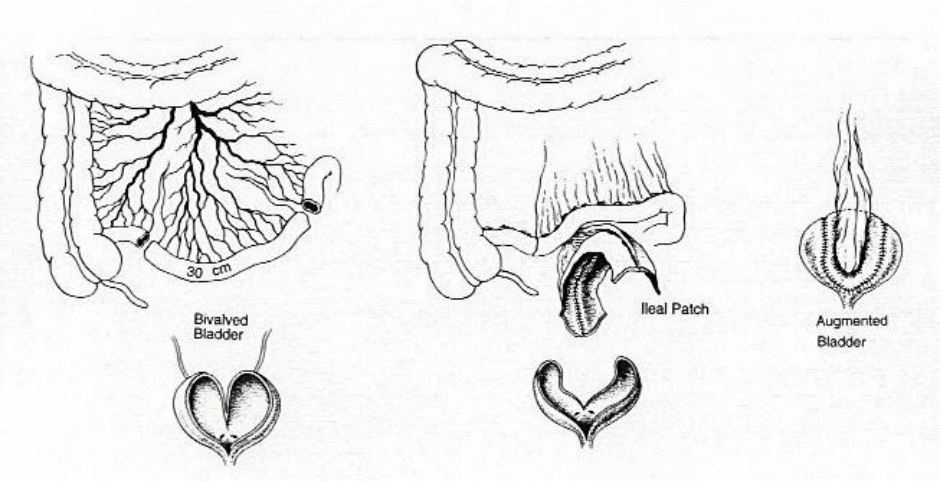


Figure 2 Bladder Augmentation
A 30 cm. segment of small bowel is made into a patch and is sewn into the opened (bi-valved) bladder.

Diana Carderas and Michael Mayo, "Management of Bladder Dysfunction," Figure 27-6, Chapter 27 In Randall L. Braddom, MD, MS, Physical Medicine and Rehabilitation, Second Edition, Philadelphia: WB Saunders Company, 2000.

wall so that they can catheterize sitting in their wheelchairs.

An alternative in men who can wear an external (condom) catheter is a procedure to keep the sphincters open either by cutting them (sphincterotomy) or by using a stainless steel stent. The stent gets incorporated into the urethral wall as a permanent implant. The bladder automatically empties down the urethra into the condom as

the sphincters can no longer obstruct the flow of urine.

A new treatment has recently been introduced into the United States for complete spinal cord injury patients. It can be used in both males and females and would be suitable for many individuals with complete Transverse Myelitis. The bladder is made to contract by stimulating the sacral motor nerve roots at S2, 3 and 4. This is done via a totally implanted set of electrodes on the nerves connected to a receiver under the skin of the abdomen. An external controller and a transmitter drives the implant to cause bladder evacuation. At the time of implantation, the sensory roots at S2, 3 and 4 have to be cut to abolish the reflex bladder contractions which has the disadvantage of abolishing reflex bowel activity in both sexes and reflex penile erections in men. However, both of these may be restored in the majority of patients using stimulation with different characteristics to those that cause bladder emptying.

Finally, in some patients, the only practical method of bladder drainage is using an indwelling catheter either via the urethra or in the suprapubic area. Bladder complications such as stones, infections, and possible bladder cancer are more common with this method of management.

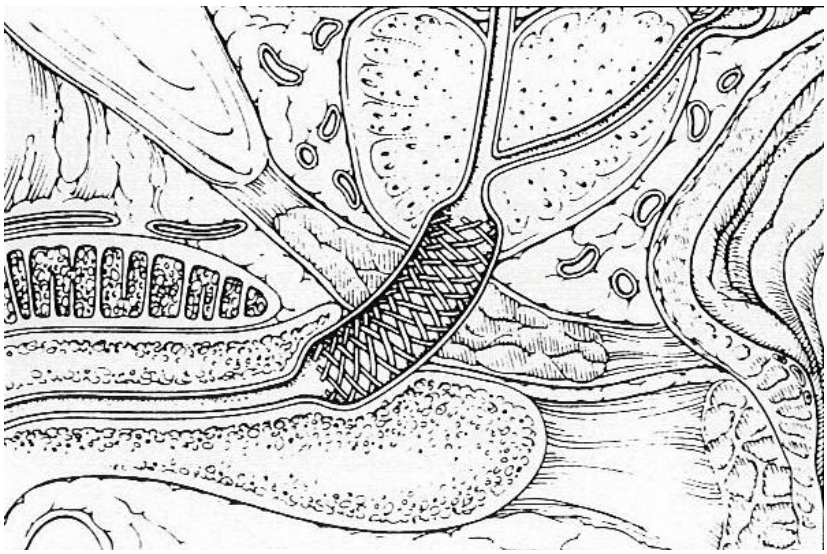


Figure 3 Urethral Stent
The stent lies in the center of the picture extending through the urethral sphincter.

Figure 3, Contemporary Urology, October 1996, p. 20.

Complications of Neurogenic Bladder in Transverse Myelitis

Urinary Tract Infections

Whatever the method of management used, urinary tract infections are a risk but are most common with an indwelling catheter and least with sacral root stimulation. Management of these is controversial but generally treatment is not recommended unless there are significant symptoms. These would obviously include fever, flank pain, malaise, increased frequency of bladder contractions with incontinence, blood in the urine, and very cloudy urine with a strong odor.

Some patients have more non-specific symptoms such as increased spasticity. Mild cloudiness and odor may clear on increased fluid intake and more frequent catheterization. Treatment with antibiotics should be short term otherwise organisms resistant to oral antibiotics may start to appear. Long term or prophylactic antibiotics are not recommended for the same reason. The presence of bacteria in the urine without symptoms is not a reason to treat with antibiotics.

Urinary Stones

The risk of kidney and bladder stones is increased in any acutely paralyzed individual if recovery does not occur within two to three months. Decalcification of the skeleton results from disuse of the muscles and bones, and the extra calcium is excreted in the urine, which may lead to metabolic kidney and bladder stones. Later on, urinary tract infection itself may cause stone formation. For treatment, bladder stones are broken up and removed under anesthesia using instruments through the urethra. For kidney stones, externally generated and focused shock waves (ESWL) can be successful for stones less than 2 to 3 cm maximum diameter. For larger stones, instruments introduced via the ureter using energy from a Holmium laser can be used. More effective is an approach via the skin of the flank directly into the kidney using a telescope and various forms of energy to break up and remove the stone fragments. Chemical dissolution of the stones in the bladder may be successful if they are very small (3 to 4 mm.), but generally non-surgical methods are unsuccessful.

Urethral Problems

In men, repeated self catheterization of the urethra four to six times a day can lead to damage of the urethral lining and it is estimated that 15% of individuals develop some urethral problems after 10 to 15 years on this program. Most of these can be treated successfully and catheterizations continued. Occasionally, if their problem is so severe, the urethra may have to be abandoned. In this situation, either an indwelling or suprapubic catheter, or a cathetertizable suprapubic artificial urethra will have to be considered.

In women, strictures are less common but in some, particularly those who have had an indwelling Foley catheter for many years, the urethra enlarges and urine leaks around the catheter. Here, the bladder neck has to be closed and some form of suprapubic catheterization, either permanent or intermittent, used.

Research

There are several areas of research using chemical and biological agents to affect the nerves in the bladder and the muscles of the urethra. Recently, the sensory nerves responsible for the overactivity of the bladder reflex have been identified. Chemical agents related to the chili pepper (Capsaicin) and a similar manufactured substance (Resiniferatoxin) are under trial. Introduction of these into the bladder can abolish the reflex for several months and may be an alternative to the oral medications, some of which have troublesome side effects, and are certainly less risky than the major surgery of bladder augmentation. Botulinus toxin has also been used to try and paralyze the urethral sphincter by injection. As an alternative to the urethral stent, it has not yet been shown to be very effective or durable in producing paralysis and further agents are awaited.

In the surgical field, an alternative to dividing the sacral sensory roots when implanting the stimulator are being sought. Various electrode configurations and stimulation paramaters are being tried to achieve bladder emptying without stimulating the whole reflex via the sensory nerves. If this can be achieved, the main objection that many patients have - the dividing of intact nerves - will be eliminated.

Finally, my task as a urologist is to treat the symptoms and side effects of the organs (bladder and sphincters) that are abnormal because of a spinal cord disease. Clearly a cure for the neurological problem in the spinal cord would be the ultimate goal and make today's urological treatments obsolete.

Chronic Pain in TM Patients

Douglas Kerr, MD PhD

Dr. Kerr is an Assistant Professor in the Departments of Neurology and Molecular Microbiology and Immunology, Johns Hopkins Hospital. He is also the Co-director of the Johns Hopkins Transverse Myelopathy Center. Dr. Kerr serves on The Transverse Myelitis Association Medical Advisory Board.

Many patients with TM report symptoms of chronic pain. In our experience at the Johns Hopkins Transverse Myelopathy Center, approximately 2/3 of patients report severe pain at some time in the acute or convalescent stage. In approximately 40% of patients, pain continues as a major feature in the convalescent stage. Each patient describes the pain differently, but many phrases are commonly used to

describe chronic pain from TM: "burning", "shooting", "aching", or "pins and needles". Other patients report an ill-defined uncomfortable sensation that cannot otherwise be characterized.

What are the reasons for this pain and what can we do about it? I am not a pain specialist, but I will try to illustrate some of the basic principles in neuropathic pain and its treatment. Subsequent articles will explore additional treatment options. For this article, I will excerpt generously from an article by Dr. Peter Staats, my colleague at Johns Hopkins and a member of the JHTMC (Ashburn and Staats, The Lancet 252, May 1999, p. 1865-1869).

Hundreds of millions of people worldwide suffer from chronic pain. Neuropathic pain is a subset of chronic pain due to irritation or damage to peripheral or central nervous system cells. The end result is conduction of impulses to the brain that convey the sensation of pain. In TM patients, chronic pain may be due to one or several mechanisms. There may be damage to sensory nerves outside the spinal cord (nerve root damage), or demyelination or neuronal injury to the region of the spinal cord that mediates sensory input to the brain (the dorsal column). Other mechanisms may include aberrant regeneration of nerves following the acute injury. This mechanism, termed collateral sprouting, has been demonstrated following peripheral nerve injury and may account for the fact that many TM patients report pain only after the acute injury. One final possible mechanism for chronic pain is called disinhibition: removal of tonic descending input from the brain that normally serves to inhibit pain due to the TM. I should mention that not all chronic pain in TM patients is neuropathic pain. Following the acute stage, patients perform even the (previously) simple tasks differently. Without knowing it, your body invokes new strategies to carry out a task, whether that task is walking or urinating or having sex. This creates a new burden on the musculoskeletal system. Muscles that previously were not important in this task are called into action; ligaments that were previously "quiet" now become stretched in unusual ways; and joints experience pressures that are new, often leading to arthritic pain. This mechanism for chronic pain illustrates the need for continuous and aggressive physical therapy to strengthen and adapt the musculoskeletal system to the new stressors (see below).

We know that damaged neurons conduct impulses differently, often leading to a perception of pain (or other uncomfortable sensations). A variety of neurochemical changes occur to propagate the pain impulses: inflammatory mediators (such as prostaglandins) are released in the peripheral nervous system and spinal cord that make the pain conducting nerves more irritable, neurotransmitters (such as substance P, bradykinins and endorphins) are differentially produced and secreted, and sodium channels that are responsible for the ability of nerves to conduct impulses are differentially produced and localized. The end result of these changes is that nerves that normally conduct pain impulses do so at a lower threshold, and nerves that normally don't conduct pain impulses now do so. Though these changes are complex and are not understood well even by experts, I include this information to convey the message that the pain you are experiencing is real, not imagined.

I quote directly from Dr. Staats' article to illustrate the central principle of treating chronic pain:

Whatever the cause, the effect of chronic pain on the patient tends to be more pervasive than that of acute pain: it often profoundly affects the patient's mood, personality, and social relationships. People with chronic pain typically experience concomitant depression, sleep disturbance, fatigue and decreased overall physical functioning. As a result, pain is only one of many issues that must be addressed in the management of patients with chronic pain. Single modalities of treatment are rarely sufficient to treat chronic pain. Indeed, pain therapy that addresses only one component of the pain experience is destined to fail…Thus, the goal of therapy is to control pain and to rehabilitate the patient so that they can function as well as possible…In the interdisciplinary management of chronic pain, the core team typically comprises a pain management physician, a psychologist, a nurse specialist, a physical therapist, a vocational counselor, and the pharmacist…In many cases, the most realistic treatment goals for patients are: the reduction, but not elimination, of pain; improvement in physical functioning, mood and associated symptoms such as sleep; the development of active coping skills and a return to work.

Pharmacological Therapies There are several pharmacological therapies that have been employed for patients with intractable neuropathic pain. None of them works for every patient, and unfortunately a "trial and error" approach is usually required since there are no known features that predict responses to particular approaches. Non-steroidal anti-inflammatory agents (NSAIDS) including medicines such as ibuprofen, indomethacin, naprosyn and the newer COX-2 inhibitors Vioxx and Celebryx have a role in some patients with chronic pain from TM. These medicines are often more

effective for the musculoskeletal pain triggers described above. The use of opioid analgesics such as Demerol, Percocet, and Morphine is controversial because of the risk for addiction and common adverse side effects: constipation, sedation, rebound pain and impaired cognition. Tricyclic antidepressants, such as imipramine, nortriptyline and amitriptyline, have a benefit in chronic pain that is independent of their anti-depressant activity, and can be very beneficial in TM patients with chronic pain. However, because of the anti-depressant effect and the beneficial effect on sleep, these drugs may "get two or three birds with one stone." Patients on these drugs need to be aware of the important side effects including urinary retention, constipation, dry mouth and sedation. Anti-convulsants such as carbamazepine (Tegetol) and gabapentin (Neurontin) function by stabilizing sodium channels thus decreasing firing of irritable nerves. This mechanism explains the manner in which they protect patients from seizures and probably underlies the ability to decrease neuropathic pain (especially burning or shooting pain). Several other medicines such as Ultram, clonidine, baclofen and dextromethorphan (the last of which is an inhibitor of glutamate receptors on neurons) have been tried in patients with neuropathic pain and have been successful in some.

Behavioral/Cognitive Therapies Behavioral approaches have been used with success in patients with neuropathic pain with some successes. "Cognitive-behavioral therapy is a psychological method that attempts to change patterns of negative thoughts and dysfunctional attitudes to foster more healthy and adaptive thoughts, emotions and actions in the patient. Relaxation and hypnotic techniques utilize imagery, distraction or directed relaxation to obtain attention focusing" (Ashburn and Staats).

Interventional Methods Nerve blocks can be performed to modulate pain perception and can be performed in multiple areas of the body. Unfortunately, these blocks are rarely helpful in TM patients unless the primary pain generator exists outside of the spinal cord (in the pelvis, for example). Epidural steroid injections are more likely to be helpful and involve the use of a needle to inject steroids into the space just outside of the spinal cord. This approach results in decreased edema in the area and decreased synthesis of pain mediators and can be beneficial in pain that is in a localized area of the back with or without radiation to the front of the body or buttocks.

Implantable methods Two implantable methods of pain therapy are often employed in patients with TM: pump delivery of medicine to the epidural or subarachnoid space in the base of the spine, or spinal cord stimulation. Each of these approaches is invasive and presents a risk of surgical complication or infection. However, for intractable pain, these can be procedures that allow restoration of function in some TM patients.

An important predictor in whether or not chronic pain can be controlled in a given patient is the undertaking of an aggressive multidisciplinary approach. In many cases, patients have to be the aggressor with their health care teams. Many physicians are uncomfortable treating patients with pain. If this is the case with your physician, fire him or her. Or at least, get a referral to see a pain specialist. Ask your physicians about the modalities described here. Each may or may not be appropriate for a given patient. I would even suggest reading the article that I have referenced here and any others that discuss neuropathic or chronic pain. Family and caregiver support is critical. And most importantly, once you have received input from the

Member Questions and Answers from Norman J. Uretsky, PhD

health care team, sit down with your family or close friends and decide on how **YOU** will beat this and begin to function better. Taking control and setting goals are critical!

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.

My doctor has me on a combination of Neurontin (gabapentin-300 mg three times a day) and mexiletine (Mexitil-150 mg three times a day). Can you discuss how this combination of drugs works to decrease the paresthesias. The combo seems to

work better than a higher level of Neurontin alone, and without the brain fogginess that the Neurontin causes.

A paresthesia is a spontaneously occurring abnormal sensation, which sometimes can be painful. The sensation is usually caused by a type of neuropathy that produces an impairment in the function of sensory nerves in the periphery or spinal cord. The sensory nerves send spontaneous nerve impulses, which create the abnormal sensation. Paresthesias frequently respond poorly to standard pain therapies.

The therapeutic approach to neuropathic sensory complaints is to administer drugs to inhibit the elevated spontaneous activity of the neuron. There are a variety of drugs that will do this, including anticonvulsant drugs and antiarrhythmic drugs. Neurontin, which is widely used to treat neuropathic conditions, is classified as an anticonvulsant drug. At the present time, its mechanism of action is unclear. Some pharmacologists believe that the drug blocks calcium ion entry into nerve cells, which would inhibit the release of neurotransmitters within a sensory pathway. Other scientists believe that Neurontin enhances the effects of the inhibitory neurotransmitter, GABA. The drug has a wide dose range but at high doses, it produces among other effects, sedation, blurry vision, and dizziness. I assume these equate with brain fogginess.

Mexiletine (Mexitil) is an orally active analog of the local anesthetic, lidocaine (lidocaine is not orally active). Like lidocaine, it is used primarily as an antidysrhythmic drug to correct abnormal rhythms of the heart. Like lidocaine, mexiletine has also been shown to be effective in certain neuropathic conditions.

Mexiletine and lidocaine produce their effects by blocking sodium channels of excitable tissue, like heart and nerve cells, preventing sodium ion from entering the tissue. Such an action would inhibit spontaneous overactivity in nerve cells without inhibiting normal nerve activity. The drug when taken orally does not produce a numbing sensation like that produced by the local administration of local anesthetic drugs. Mexiletine, like Neurontin, also has dose-limiting side effects.

Mexiletine and Neurontin have different mechanisms of action in inhibiting the spontaneous nerve impulses in nerve cells. Frequently two drugs that produce their effects by different mechanisms are used in combination because it is possible to achieve a greater therapeutic effect than that produced by each drug alone. The combination therapy may, therefore, allow lower doses of each drug to be used, thereby reducing the adverse effects produced by each drug.

What is the effect of the drug sildenafil (Viagra) in women? How does this drug produce its effects? Is there research going on regarding drugs that are designed to assist women who experience sexual dysfunction from neurological conditions?

Three Stages of the Sexual Response

In order to understand the effects of drugs on sexual function, it is useful to divide the sexual response into three stages. The first stage, libido, refers to the desire for sex or sex drive. Libido is influenced by sexually-related thoughts and sensations. It is also influenced by hormonal factors, such as levels of estrogenic and androgenic hormones. Current evidence suggests that androgenic hormones released from the primary sex organs (testes and ovaries) and the adrenal gland play a significant role in determining the intensity of sex drive. In addition, since libido is a drive for a type of pleasure or reward, it is in part mediated by dopamine transmission in the nucleus accumbens and other forebrain regions. Dopamine transmission at these sites is postulated to mediate the rewarding sensations associated with drugs of abuse, such as heroin, cocaine, and amphetamine. Finally, dopamine transmission in the hypothalamus also plays a role in the sex drive.

The second stage of the sexual response, which is referred to as arousal, is initiated by a subjective sense of sexual excitement, experienced as anticipation and desire. This feeling induces an increase in nerve impulses that travel from specific sites in the brain through the spinal cord to peripheral neurons. These neurons, which innervate blood vessels carrying blood to erectile tissue (penis, clitoris, etc.), synthesize and release nitric oxide, a gas, from their nerve terminals. The released nitric oxide diffuses into vascular smooth muscle and binds to and activates an enzyme, guanylate cyclase, which induces the formation of a compound called cyclic GMP. The newly formed cyclic GMP mediates the relaxation of vascular smooth muscle, resulting in dilation or opening of arteries that carry blood to erectile tissue. As a result, blood will flow into erectile tissue, producing tissue enlargement and swelling (men and women) and increasing mucus secretion (women), which is responsible for lubrication. The dilating action of cyclic GMP on blood vessels is terminated by its interaction with the enzyme, phosphodiesterase type-5, which

metabolizes (chemically changes) cyclic GMP to an inactive metabolite. Thus, this enzyme, phosphodiesterase type-5, plays an important role in terminating the swelling of the erectile tissue by metabolizing cyclic GMP. It is worth noting that acetylcholine, a neurotransmitter released from parasympathetic nerves, also plays a role in erection. The acetylcholine is released from neurons and produces a constriction of veins. This serves to occlude the outflow of blood from erectile tissue, resulting in a further increase in pressure in blood vessels of erectile tissue, producing additional swelling.

The third stage of the sexual response is referred to as the orgasm or the climax of sexual pleasure. In the male, this stage involves ejaculation. In the female, it involves the contraction of various muscles throughout the body, as well as the rhythmical contraction of the muscles of the vagina and uterus, which is produced by spinal reflexes. The eventual removal of blood from erectile tissue is in part the result of the metabolism of the cyclic GMP by phosphodiesterase type-5 (as described above) and the activity of sympathetic nerves that innervate blood vessels. Norepinephrine released from sympathetic nerves activates alpha adrenergic receptors on the smooth muscle of arteries, producing muscle contraction which results in constriction or narrowing of the blood vessels. This would decrease the flow of blood to erectile tissue. In addition, released norepinephrine can activate beta adrenergic receptors on the smooth muscle of veins, and the resulting dilation of veins increases the flow of blood away from the erectile tissue.

Sildenafil (Viagra) Actions in Treating Male Sexual Dysfunction

It has been estimated that 20-30 million American men have difficulty or have been unable to achieve an erection that is sufficient for sexual intercourse. There are many possible causes of this condition. For example, a neurological impairment would interfere with the functioning of nerves carrying impulses from the brain to the peripheral neurons regulating the accumulation of blood in erectile tissue. In addition, certain drugs (for example, antidepressants that inhibit serotonin reuptake), as well as psychological problems, e.g., depression, may also interfere with the activity of neurons that regulate erectile tissue. Presumably in these circumstances, insufficient nitric oxide is released from neurons, resulting in an insufficient formation of cyclic GMP. As a consequence, the level and/or duration of cyclic-GMP in smooth muscle would be inadequate to produce or maintain sufficient dilation of the blood vessels of erectile tissue in response to sexual excitement. In males, this would be expressed as the inability to produce a penile erection. An inability to produce an erection could also be caused by performance anxiety. This anxiety activates the sympathetic nervous system (fight or flight reflex) causing the excessive release of norepinephrine from sympathetic nerve endings. The subsequent activation of alpha-adrenergic receptors produces a constriction rather than a dilation of the arteries of erectile tissue, thereby inhibiting blood flow and erection. Another mechanism to explain impaired erection is that the arteries supplying blood to erectile tissue may be partially blocked (by atherosclerotic plaques), preventing the increased blood flow into erectile tissue. In all of these conditions, the arousal phase of the sexual response in which sexual excitement leads to the swelling of erectile tissue would be impaired, and a higher concentration of cyclic GMP during the arousal stage might induce the dilation of erectile tissue arteries, when a lower concentration would be ineffective.

Sildenafil (Viagra) was introduced in 1998 to treat erectile dysfunction (impotence) in males, and the sales of this drug have been tremendous, reaching approximately $1 billion dollars with physicians writing 40,000 prescriptions a day. The drug is reported to reverse erectile dysfunction in a majority of men. The drug produces its therapeutic effects in this condition by *enhancing* the dilation of blood vessels of erectile tissue induced by nitric oxide released from peripheral neurons. It does this by prolonging the effect of the nitric oxide induced, newly formed cyclic GMP. As indicated above, the action of cyclic GMP is terminated by its metabolism, which is catalyzed by the enzyme, phosphodiesterase type-5. Viagra inhibits this enzyme, thereby blocking the chemical breakdown of cyclic GMP. Therefore, after Viagra administration, cyclic GMP can accumulate in sufficient quantities to permit erectile tissue arterial dilation. The resulting increase in blood flow into erectile tissue causes swelling resulting in an erect penis. It should be noted that Viagra will only be effective in a sexually excited individual. What this means is that Viagra will only be effective if neurons are actively firing and producing and releasing sufficient nitric oxide to stimulate the formation of cyclic GMP in smooth muscle. Viagra will not enhance erections if neurons are not actively releasing nitric oxide or if blood vessel walls are so damaged (atherosclerosis) that they are unable to dilate. Interestingly, Viagra has been reported to be effective under a variety of circumstances. For example, some men with spinal cord injury

(impairment in nerve impulses to peripheral tissue) are reported to be helped in achieving an erection with Viagra. In addition, some men with psychological problems but without an obvious organic disorder are also reported to be helped by the drug. It, therefore appears that in both of these conditions, the individual can be sexually excited, and nitric oxide can be formed, released from peripheral neurons, and induce smooth muscle relaxation in blood vessels of erectile tissue.

Sildenafil (Viagra) and Female Sexual Dysfunction

After Viagra was deemed to be successful in treating male erectile dysfunction, the question was raised whether Viagra would also be effective in treating sexual dysfunction in women. Viagra would be expected to have the same effect on erectile tissue in women as it does in men. Thus, the erectile tissue in women (clitoris and labia) is almost identical to the erectile tissue of the penis and is controlled in the same way by parasympathetic nerves which release nitric oxide. In addition, phosphodiesterase type-5, which metabolizes cyclic GMP, is found in human clitoral erectile tissue, and this activity can be inhibited by sildenafil (Viagra). Consequently, it was expected that Viagra would produce the same increase in genital blood flow in women as it does in men. However, the importance of enhanced genital blood flow in relation to sexual dysfunction in women is unclear. Sexual dysfunction in women has always been considered by experts in this field to be more complex than that in men and attributed more to psychological problems than physical problems (such as insufficient genital blood flow). Remember, Viagra does not stimulate sexual desire and excitement; rather, desire and excitement must be present in order for the drug to be beneficial. If psychological problems constitute the major factor responsible for sexual dysfunction in women, than it should not be expected that an increase in genital blood flow would reverse sexual dysfunction?

The major conclusion of studies to date on the effect of Viagra in women is that the drug is not a universal panacea for sexual dysfunction. While Viagra appears to increase genital blood flow and vaginal lubrication, it did ***not*** produce a statistically significant reversal of sexual dysfunction. Interestingly, the studies illustrate the importance of comparing the effects of Viagra with those produced by placebo (inert drug). In one study in post-menopausal women, 25% of the subjects taking Viagra claimed improvement in overall sexual function. Although a placebo group was not tested, the improvement in function of these subjects was interpreted as a placebo effect. This conclusion was supported by a much larger trial sponsored by Pfizer, the company that produces Viagra. This study was conducted double-blind in which neither the participants nor the physicians knew which women were getting Viagra or placebo. Approximately 30-50% of women that received either Viagra or placebo claimed that their sexual function was improved, and there was no statistical significance between the responses of the drug-treated and placebo-treated groups. This suggests that the effectiveness of drugs on sexual function may depend to a large extent on the expectations and beliefs of users. Actually, this is not a surprising observation, since placebo effects are an important part of the therapeutic response to Viagra in males. The Viagra studies suggest that while the drug can increase blood flow to erectile tissue in females, this effect is not associated with an enhancement in sexual desire, arousal, or the ability to achieve orgasm. Thus, these observations suggest that for women psychological influences are more important than physical influences in determining sexual dysfunction.

Do the results of these studies mean that Viagra is ineffective in treating all types of sexual dysfunction in women? The answer is no. Studies completed to date do not exclude the possibility that Viagra may be useful in treating certain subgroups of women with sexual problems. Thus, Viagra may be effective for certain conditions. It was reported in a Newsweek article that one researcher from the Pfizer study felt that this study may have incorporated women with too many varied complaints to be definitive on the issue of the effectiveness of Viagra in treating certain types of sexual dysfunction. In support of this statement, it has been reported that Viagra is beneficial in women with normal arousal patterns whose sexual dysfunction is related to pelvic trauma or surgery, such as hysterectomy. Its effectiveness in women after hysterectomy suggests that some peripheral neurons are intact and can mediate arousal. In addition, Viagra may be effective in postmenopausal women who are receiving hormone replacement therapy (estrogen and testosterone). It is still an open question whether Viagra is effective in treating sexual dysfunction in women with specific neurological disorders, including spinal damage? As mentioned above, the drug has been reported to be beneficial in some men with spinal injuries. Viagra has also been shown to be effective in treating women who experience sexual dysfunction produced by using certain antidepressant drugs. Selective serotonin reuptake inhibitors (Prozac, Zoloft, Paxil, Luvox, Celexa) may

produce a decreased sex drive and a decreased ability to achieve orgasm. Viagra is reported to reverse the latter effect. This suggests that the decreased difficulty in achieving orgasm associated with the use of these antidepressants may be related to a decrease in nitric oxide formation and release from neurons.

Other Drugs Used or Tested for Sexual Dysfunction

Aside from Viagra, what other drugs are now being used or tested for their effects on sexual dysfunction? To my knowledge, the following drugs are postulated to be useful in treating sexual dysfunction. Phentolamine medylate (Vasomax) is an oral medication that is used to treat male erectile dysfunction. This drug antagonizes the constrictor effects of norepinephrine on blood vessels supplying erectile tissue by blocking alpha-1adrenergic receptors on arterial smooth muscle. As a result, there is increased blood flow to erectile tissue. Vasomax is likely to produce the same effects as Viagra. While, unlike Viagra, Vasomax can be used if the patient is also taking nitroglycerin or other nitrates, this drug may produce a higher incidence of hypotension. Its effectiveness in treating female sexual dysfunction is an open question.

Prostaglandin E (Alprostadil) is a substance that has been used locally to increase blood flow to erectile tissue in males. The drug, under the trade name, Caverject, is injected directly into penile erectile tissue (the corpora cavernosa), which then dilates blood vessels of erectile tissue, resulting in the rapid development of an erection. This effect lasts approximately 1-2 hours. Unlike the effects of Viagra and Vasomax, the erection produced by prostaglandin E is maintained regardless of sexual stimulation because it is not dependent upon peripheral nerve activity and nitric oxide formation and release. It will even be maintained after ejaculation has occurred. Prostaglandin E can be applied as an ointment, cream, or transurethral suppositories. While I am unaware whether this drug has been tested in women, it would seem that it could be used by topical administration or by suppository to increase blood flow to erectile tissue in women. Its effectiveness in treating sexual dysfunction in women is not likely to be better than Viagra.

Apomorphine (Uprima) was in trials for erectile dysfunction in males; however, it has recently been withdrawn by the manufacturer. This is a new dosage form of apomorphine, which is available as Zydis for the treatment of Parkinson's Disease. It is useful for this disease because apomorphine directly activates dopamine receptors in the brain. When used for erectile dysfunction, Apomorphine (Uprima) is taken sublingually (under the tongue) prior to sexual activity. While the exact mechanism of action of this drug is not known, it is thought to enhance sexual desire and arousal by activating receptors for the neurotransmitter, dopamine, in the nucleus accumbens and paraventricular nucleus of the hypothalamus. This compound might be useful in treating psychologically-induced sexual dysfunction in women. The major side effects of apomorphine are nausea, vomiting, hypotension and fainting. The manufacturer has indicated it will resubmit its application at a later date.

The hormone, testosterone, appears to increase sexual desire in women whose desire is reduced, possibly due to a deficiency in endogenous androgen levels. It has been reported that women who receive very low doses of testosterone (1/10th of the dose given to males) experience an increase in sexual desire. There are different ways of administering testosterone, including injection, topically, sublingually (under the tongue), and orally. While oral preparations are available, they are generally not recommended because of the danger of testosterone impairing liver function. Recently, it has been reported that a combination androgen/ estrogen replacement therapy improved sexual desire to a greater extent than estrogen replacement therapy alone or placebo. Thus, this might be a legitimate way of reversing sexual dysfunction caused by a lack of sexual desire.

Bupropion (Wellbutrin and Zyban) is an antidepressant drug that blocks the reuptake of released dopamine in the brain, thereby increasing dopamine transmission. Drugs that enhance dopamine transmission are generally associated with an increase in sexual functioning. For example, psychostimulant drugs, such as amphetamine, methylphenidate, ephedrine and cocaine, appear to enhance sexual desire and drive. Since dopaminergic activity in the brain is involved in the experience of pleasure (nucleus accumbens) as well as sexual functioning (paraventricular nucleus), bupropion would be expected to exert a positive influence on sexual desire and drive. The results of trials with this drug have been positive. In addition, bupropion has been used effectively in reversing the sexual dysfunction caused by the selective serotonin reuptake inhibitor antidepressants.

Yohimbine (Yocan, Aphrodyne, Yohimex) is a drug derived from the bark of a West African evergreen tree that has been used to treat erectile dysfunction in men. Yohimbine is believed to act in the peripheral and central nervous systems to improve

erectile function. In the periphery, the drug blocks a type of alpha-adrenergic receptor (alpha-2 receptor) located on the smooth muscle of arteries, thereby preventing the constricting action of the neurotransmitter, norepinephrine. The resulting dilation increases the blood flow into erectile tissue. The drug also increases acetylcholine release from neurons, further constricting penile veins, which prevents outflow of blood from erectile tissue (see above). In addition to peripheral effects, the drug is thought to act in the central nervous system to increase sexual desire. As yohimbine can produce a variety of adverse effects, its use requires medical supervision.

The Second International Transverse Myelitis Symposium
Douglas Kerr, MD, PhD

We are pleased to announce the Second International Transverse Myelitis Symposium. It will be held at the Holiday Inn, Inner Harbor in Baltimore from July 12th-15th 2001.

This symposium promises to be an amazing opportunity for patients and caregivers to meet other patients with TM, to discuss issues with other patients and with health care providers, and to hear what the scientific community is doing to figure out this disease. Many of you have not met other TM patients, and I think all of us would agree from the Seattle symposium that this is a really important opportunity. Further, there will be several discussions by various physicians about how to manage the ongoing symptoms of TM until we develop better treatments for them.

The symposium will have several overlapping goals. Several prominent physicians and scientists have committed to attend, and this promises to foster an exciting exchange of scientific information. Lectures will discuss the underlying causes of TM, acute treatments and chronic treatments (including neural stem cells and other strategies aimed at restoring function). We will also discuss when we may initiate stem cell trials in humans! Through the symposium, we will formally establish a network of hospitals providing excellence in care to TM patients. This consortium will serve to further our goals of understanding this disease and improving treatments. Finally, we hope to educate patients and caregivers about this disease, treatment options and what the future may hold.

The Holiday Inn was selected because we wanted to keep the room cost as low as possible. The Hotel has several wheelchair-accessible rooms available, but we may need to have some people stay in nearby hotels if the demand is too great.

An Early Registration and a Welcoming Reception will take place Wednesday evening, July 11th from 4:30 - 6:30 p.m. at the Holiday Inn, Inner Harbor Hotel on the Rooftop Level. Regular registration and continental breakfast will begin on Thursday morning on the Lobby Level. The program will start immediately following and continue all day Thursday, Friday and Saturday with a half-day session on Sunday.

The details regarding the registration process are provided in the following information. We are also providing you with two registration forms, which are included with this newsletter. Each registrant (each person planning to attend the sessions and paying the registration fee) is being requested to fill out a form. You may also register on-line at the following website: . If you register on-line, be sure to fill out a separate registration form for each registrant. We appreciate your taking the time to register in this fashion; it will assist us in keeping accurate records.

We are looking forward to seeing you in Baltimore.

The Second International Transverse Myelitis Symposium: Registration

Sponsored by The Johns Hopkins University School of Medicine
Thursday through Sunday
July 12 – 15, 2001

Target Audience: Physicians and other health care providers (i.e., physical therapists, occupational therapists, social workers), scientists, transverse myelitis patients and their caregivers.

Course Description: This symposium is designed to foster understanding of the clinical and research features of transverse myelitis and to facilitate interaction and discussion among patients with TM and caregivers.

Objectives: Upon completion of this program, the participant should be able to:

- identify the clinical features of transverse myelitis;
- identify current treatments for transverse myelitis;
- understand current research and potential future interventions; and
- recognize issues of management of TM patients.

General Information

Meeting Location and Accommodations

Holiday Inn, Inner Harbor
301 West Lombard Street

Baltimore, Maryland 21201
(800) HOLIDAY
(410) 685-3500
Fax: (410) 727-6169

Conference Rate: $159 Single/ Double plus 12.5% tax

Hotel Cut-off Date: June 24, 2001
Conveniently located in downtown Baltimore, the Holiday Inn is within walking distance of the Inner Harbor, the site of many attractions, shops, restaurants and clubs.

Call the Holiday Inn directly to make your room reservation and be sure to mention the Johns Hopkins TM meeting to receive the special group rate. Fully handicapped accessible rooms are limited. Additional handicapped rooms are available at the Days Inns Hotel, which is two blocks from the Holiday Inn. You may call the Days Inn directly at (410) 576-1000, if you are unable to secure a room at the conference site. The Cut-off date for the Days Inn is June 11th.

United Airlines Discounts: ID # 549TJ
Call (800) 521-4041 for discount rates.

Ground Transportation from Baltimore-Washington International Airport (BWI)

Handicapped-Accessible Light Rail Service is available from the International Wing (East Wing) of the BWI Airport, from the lower level, which is also the baggage level. You will see a sign over the door "To the Light Rail." The light rail runs from 5:20 a.m. to midnight, weekdays and Saturdays and from 11:00 a.m. to 8:00 p.m. on Sundays.

You should take the Northbound train to the University Center-Baltimore Street stop, a ride of about 25 minutes. The stop is on Howard Street between Baltimore and Lombard Streets. The hotel is on the corner of Howard and Lombard Streets; you will see the hotel on your left as you travel north to the stop. Regular fare is $1.35 one-way and only $.45 one-way for those in wheelchairs.

****

The ***BWI Airport Van*** is available with 24 hours notice. There are nine vans available that can handle one wheelchair at a time. Call (410) 859-1102 or 1103 to make arrangements. Cost is approximately $20 one-way to the hotel.

****

BWI Airport taxis are readily available on the lower level of the airport.

****

The ***Super Shuttle*** ($11 – one way) makes regularly scheduled stops at the hotel. The vans are available on the lower level. There is one wheelchair-accessible van. To make arrangements for this van, call 1-800-258-3826 ahead of time. The van can accommodate one chair and four guests or two chairs and two guests. The cost is also $11.

Registration Fees

Physicians: $400
Residents & Fellows (with verification of status), and Allied Health Professionals: $300
The Transverse Myelitis Association Members: $200

The registration fee includes instructional materials, refreshment breaks and luncheons. Foreign payments must be made by credit card or with a U.S. Dollar World Money Order, and government payments must be made with IMPACT credit cards.

Please note: The registration fee for pre-registered participants must be received by the start of the meeting. Payments received after that date, including on-site registrations, will be assessed a $25 surcharge. A certificate of attendance cannot be provided until payment has been received and processed. Certificates for registrations received within five days of the start of the course and for on-site registrations will be mailed within four weeks of the completion of the course.

An enrollment confirmation will be sent to each registrant. If you do not receive a confirmation by July 5th, please call (410) 955-3169 to confirm that you are registered.

Cancellation Policy: If you must cancel, notify the Office of Continuing Medical Education by phone, (410) 955-2959, or fax, (410) 955-0807. An administrative fee of $50 will be retained on all refunds, which will be processed only after written notice is received. Cancellations received after July 5th are non-refundable. The Johns Hopkins University reserves the right to cancel this course at any time. In this event, the full registration fee will be returned to the registrant.

Registration and Reception: An Early Registration and a Welcoming Reception will take place Wednesday evening, July 11th from 4:30 - 6:30 PM at the Holiday Inn, Inner Harbor Hotel on the Rooftop Level. Regular registration and continental breakfast will begin on Thursday morning on the Lobby Level.

Social Events

A reception and tour of the National Aquarium will be held on Friday

evening at 7:00 PM and a banquet at the conference site will be held on Saturday evening at 6:30 PM for registrants, faculty and their guests. Please indicate your attendance on the meeting registration form. There is no additional cost for attending these events.

Accreditation

The Johns Hopkins University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to sponsor continuing medical education for physicians. The Johns Hopkins University School of Medicine takes responsibility for the content, quality and scientific integrity of this CME activity.

For Further Information:

Office of Continuing Medical Education
Johns Hopkins University School of Medicine
720 Rutland Avenue, Turner 20
Baltimore, Maryland 21205-2195
(410) 955-2959
FAX (410) 955-0807

cmenet@jhmi.edu

Program Updates: The website will be updated regularly with the program schedule, faculty listing and credit information: . A map of Baltimore, which locates the Holiday Inn, Inner Harbor is also included on the website.

Some of you may have heard about the publicity surrounding our recent data concerning the use of neural stem cells in animals with viral induced spinal cord paralysis. We presented this data at the Society for Neuroscience meeting in November, and it was picked up by all of the major news organizations (ABC, CBS, NBC, FOX, Reuters and AP). What we have done is to inject neural stem cells into animals that have previously been paralyzed by a virus (Sindbis virus). The stem cells were administered into the spinal fluid that bathes the spinal cord (essentially we did a lumbar puncture on the animals, but instead of withdrawing fluid, we injected the stem cells). We then observed the animals for functional recovery. To our delight, we observed that the stem cell-treated animals began moving their hind limbs after 8 weeks. Some had only slight recovery while others were able to flex their legs and bear weight on that limb.

So what is the relevance of this to TMA members? Well, this line of experimentation is early, but we certainly hope to advance these studies to ultimately consider the use of stem cells in human patients with TM. What we have to do now is to extend these findings in larger animals (monkeys). We also have to carry out long term experiments to show that the recovery is permanent and that the stem cells don't ultimately cause harm. This will take several years, so please be patient. But also understand that we are working very hard to advance these findings as rapidly as possible!

We also are continuing to investigate the mechanisms of neuronal injury in the spinal cord. We reason that if we better understand why neurons die in the spinal cord, then we can devise ways to halt this death. Dr. Irani and colleagues recently published these findings in the Journal of Virology, while I published two papers with colleagues in the Proceedings of the National Academy of Sciences and in Molecular Cell detailing the important role of the Survival of Motor Neuron (SMN) protein and other proteins in protecting motor neurons from death.

TM Research: An Update
Douglas Kerr, MD PhD

The Johns Hopkins Transverse Myelopathy Center: An Update
Douglas Kerr, MD PhD

I would like to take this opportunity to provide an update on the Johns Hopkins Transverse Myelopathy Center. We have now been in existence for approximately 15 months. In that time, we have seen 185 TM patients (and counting). So, already we have seen more TM patients than anybody in the world. I certainly hope that for those of you who have come here, you feel that we have provided you with information about your disease, and have given excellent care. Many of you have come from far away and our primary role after the initial visit is to make recommendations to your other doctors. We have often "strongly encouraged" physicians by a letter or phone call to obtain a standing frame or more aggressive PT or bladder medications for a patient, for example. Many of you who have been here have filled out one or more questionnaires regarding your case of TM. The information you have provided has been invaluable in creating a database that is currently being analyzed. From this, we hope to gain information on such questions as what are the clinical features most common in TM both in the acute and convalescent phase, is there a relationship to vaccinations, to trauma or to preceding infections.

The website is soon to undergo renovation. There will be new text added and there will be instructions

and recommendations to physicians who may be seeing an acute TM patient for the first time. It is hoped that such a physician may see this while the patient is in the emergency room and would then initiate treatment more quickly than otherwise.
Having said all that, we certainly are having some growing pains, so I respectfully ask that patients have patience. Philis Carbonell (my secretary) and I are involved with most of the TM patients who come here, and we try to do the best we can. But we are sometimes overwhelmed! So, we may not call back right away, and sometimes we drop the ball on certain issues. We ultimately hope to hire additional personnel and we are attempting to procure funding for this, but until then we may have busy periods.

If anybody thinks that Philis has done a great job in setting up the visit to the JHTMC, I would urge people to let her (and her bosses) know. She works very hard and would be very appreciative of kind feedback (or even negative feedback if that be the case). Notes could be sent to Philis Carbonell at Johns Hopkins Hospital, Pathology 627, 600 N. Wolfe St., Baltimore MD 21287-6965. Please cc Jane Hill at Johns Hopkins Hospital, Meyer 8-181, 600 N. Wolfe St., Baltimore MD 21287-6965.

We Don't Want to Lose You

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

In Their Own Words

In each issue of the newsletter, we will bring you a column that presents the experiences of our members. Their stories are presented ***In Their Own Words*** by way of letters they have sent us. We are most appreciative of their willingness to share their very personal stories. It is our hope that through the sharing of these experiences, we will all learn something about each other and about ourselves. It is our hope that the stories will help us all realize that we are not alone. You may submit your stories by sending them either by e-mail or through the postal service to Sandy Siegel.

Violet (Joyce) Chandler
Woodville Alabama

In October 1993 I was living and working in Southern California (Huntington Beach). My boss encouraged all of his employees to take the flu shots that were offered by the company, because we were working on a critical government program. Many of us would be working lots of overtime hours and he didn't want anyone to get sick. So I got in line and took the flu shot. Later during the Christmas holiday, I had several family members staying at my home who were sick with the flu.

On January 1, 1994, I awoke with a swollen and very tender stomach. Throughout the day, my discomfort grew worse. I suspected I might have a bladder infection. The next day I called my doctor and he was able to see me right away. His diagnosis was possible appendicitis, but he wanted to watch me over a few days to see what would happen. He placed me on a liquid only diet regimen and I went to his office every day for about a week. After a week I seemed to be getting better so he allowed me to return to work but wanted me to call if I had any sign of further pain. Throughout the month of January, I didn't quite feel right. I normally walked two miles each day, but found that I would become weak after just a short walk.

On February 1st of 1994 I was at work and during my lunch hour I went for a long walk. I didn't get far when I felt a strong weakness around my mid-section (I cannot describe it), I just felt very weak. I went back to my office and rested through the duration of my lunch break. A couple of hours later, I had to go downstairs to the first floor of my building and on the way back upstairs, my legs went weak on me and I almost fell on the stairs. When I got to the top of the stairs, a numbing sensation started at my toes and quickly climbed up my legs to my waist. I limped back to my desk and sat there for a while trying to figure out why the lower part of my body had gone to sleep. I got up and tried to walk it off, but my lower back started hurting. I decided I'd better go see a doctor so I left work and walked to my car. My home was just two miles away and I drove straight home to get my husband. Just a few minutes after arriving home, I felt extreme pressure to urinate and have a BM and went into the bathroom. I was able to get everything started, but

it stopped in midstream. I wasn't able to complete the elimination. I immediately started to feel the most intense pain in my back and yelled for my husband to help me finish dressing. I told my husband I needed to go to the doctor immediately and explained the numbness and pain.

My husband rushed me to our doctor's office. Our GP ran me through a battery of tests. He asked me to close my eyes and stand on one leg. I couldn't balance myself on either leg. He asked me to stand on my tiptoes; I couldn't do that either. He asked me if it was OK for him to call a neurologist to discuss my symptoms. I said yes, of course. He called a neurologist and after explaining my situation told me to go immediately to the emergency room and the neurologist would meet me there after he finished with his office patients.

Arriving at the hospital, I had to lean on my husband in order to walk from the parking lot to the ER. Once inside, I was basically ignored by the ER staff and I waited for the neurologist to arrive. By the time the neurologist arrived, approximately two hours later, I was very weak in the lower part of my body and had difficulty and pain when I walked.

I was placed on a hospital bed and almost immediately paralysis was evident. I could feel my internal (female) organs going numb also. I was paralyzed from the waist down and was very weak. I was admitted into the hospital and was told that I would need a series of medical tests and x-rays. I was confused and worried.

I found that I could not lift my legs at all, I could not use the bathroom, I had no appetite, I was disoriented, I had terrible headaches, nausea, and I was in a state of total confusion. This was the sickest I had ever been in my life.

I remember telling the nurse that I had to urinate and she told me to get up and go to the bathroom and then left the room. I couldn't get up and told her when she returned later. She then brought a bedside potty-chair and left my room again. I dragged myself out of the bed and hoisted myself up on the potty-chair but couldn't go. I then had to manipulate my body back into the bed. All through the night I told the nurse I had a full bladder and I was in a lot of pain. She called the doctor and then gave me a pain shot. But not until she scolded me for bothering her and she said to me, "are you sure you're in pain, or are you just scared?" I assured her I was in pain. The next day, I was taken across the hospital parking lot to an MRI facility where I was given the MRI. It lasted at least two hours. I was also given a multitude of tests to check for any viruses (Lupus, HIV, TB, spinal tap, x-rays, and others that I cannot remember) plus a brain scan and kidney scan. I was given my diagnosis shortly after the MRI scan. It was Transverse Myelitis, which I had never heard of and I didn't know what to expect.

I guess the doctor discovered through the MRI scan that my bladder was full and ordered a catheter. This was about 24 hours after my initial onset. Once the bladder was drained, a lot of my pain was alleviated. The nursing staff at this hospital virtually ignored me for the full week I was there. I wet the bed several times before given a catheter and they were not real happy with me. I also continued to suffer from blinding headaches, nausea and dehydration.

Seven days later I was transferred via ambulance to a rehab hospital. I was assigned new doctors because my original neurologist did not practice at this new hospital. I was very sick for the first few days and I had lost 16 pounds in just eight days. I was heavily medicated, but cannot recall at this time what medications I was given. I know I was given prednisone in heavy doses and an antidepressant. I hallucinated from the prednisone and later learned that the nursing staff, having forgotten to give me the medication on time, had "doubled up" on the medication, on several occasions, which caused me to have increased heart rate and hallucinations. I was dizzy when sitting up and felt faint. I had no appetite and refused to eat. I was getting weaker instead of stronger. I also noticed that I had blurred vision and a ringing in my left ear. These symptoms disappeared after a couple of weeks.

After I complained to the medical staff about the medication blunders, the nurses were more careful not to over medicate me and I started to get over the dizziness. After a week in the rehab hospital, I was able to begin physical therapy.

My physical therapy consisted of learning to transfer from wheelchair to car, shower bench, therapy mat and bed. I was taught how to force my bowels to move using suppositories and to self-cath, to dress myself lying down, and to make a bed from a wheelchair. Once a week I was taken to a local gym so that I could use their equipment for exercises. Later, I was able to take a few steps using the upright parallel bars. After getting a little stronger, I was using various exercise equipment to help strengthen my arm and leg muscles. A pair of leg braces were made for me to help me to walk. After about four weeks, I was able to walk with the use of a walker. My balance was very poor and my legs were weak but I eventually gained more strength as

time went by. I started noticing that feeling was starting to return a little bit at a time to portions of my legs.

On March 15th I was released to go home, but I had to return three days per week for three months to continue my physical therapy. I fell at home several times due to the walker getting stuck in the carpeting. I worked hard at my home exercises. My ability was very limited. I could not get up from the sofa without help. I had muscle spasms in my legs that kept me from sleeping at night. I had many mishaps with bowel and bladder incontinence. But I was determined to recover as much function as I could. I started walking around the house by using the walls and furniture to keep me upright. I graduated from the walker to a crutch. Eventually, I was able to take a few steps by myself, but I always made sure I was near something that I could crab onto for support. My balance was very bad, but I kept practicing to stand alone. Eventually, I could walk around the house with confidence without having to hug the walls or furniture.

I returned to work, against my neurologist's advice in July of 1994. This was a big mistake, but I was determined to give it my best. I soon found out that my incontinence problems caused me to constantly worry that I would make a mistake and be embarrassed. Well, I did make mistakes, lots of them. I somehow hid most of my incontinence errors, but I'm sure others noticed on occasion. I had other problems too. I realized that my toes on both feet were starting to turn under (hammer toes). They eventually were so badly deformed that I could not wear certain shoes because of the pressure and pain to the toes. I had a bladder and uterus prolapse due to paralysis and it became obvious that I would require surgery for these problems.

In November 1994, 1 had the left foot surgery to correct the hammer toes. I had the right foot surgery done in February of 1995. In November of 1995, I had to undergo a total hysterectomy and have the bladder lifted. Unfortunately, the bladder fell again and in June of 1997, I had to have a complete cervical reconstruction surgery. This time the bladder had to be sewn to my backbone in order to help prevent another prolapse. Following this last surgery, my doctor strongly recommended that I not return to work and that I should file for total disability. Which I did.

In March of 1998, I was diagnosed with Graves' Disease. Another auto-immune disorder. I was told that it could have a relationship to TM since both were considered to be auto-immune illnesses.

Today, I am living in Alabama still dealing daily with TM and Graves' and just trying to make the best of it. I have not worked since April of 1997. I am walking a little bit better, but still use a cane when away from home. I often lose sleep due to muscle spasms and a burning sensation in my left leg. I have recovered some feeling to my legs, more so in my right leg than the left. I still tire easily and have serious balance problems. Incontinence is something I live with and try to control through self-cathing several times a day and watching what I eat so that my bowels function property. I don't go out much, don't attend too many social events, don't travel much. I'm able to do household chores, but have to rest often. It has now been six years since my diagnosis of TM and I don't expect much further improvement. I take each day at a time and don't have time to feel sorry for myself. My best wishes go out to other TM victims. It is my hope that someday this disease can be cured and that TM patients and their problems will be understood by the medical profession.

One last note. On every occasion of my seeing a new doctor or specialist, I have had to EXPLAIN to them what Transverse Myelitis is! They don't have a clue about it. I had to fight for my disability benefits from Social Security and a privately held long-term disability plan, because no information was available to them on TM so they assumed that it was a made up disease and that I wasn't truly disabled. Once I asked the head nurse at the rehab hospital for some printed material on TM and she said to me "Oh, TM just means that we don't know what's wrong with you; It's a diagnosis we use when we don't know." Until I found your Association on the Internet, I had no place to go to get ANY information whatsoever on this disease. Even my neurologist was unable to give me any information, pamphlets, etc. He said that the disease was so rare that little if any information existed. I have only once met another person with TM and she was not willing to talk to me about her situation. She was 16 years old and had pretty much had a full recovery. That's all I knew about her. It has been so frustrating and isolating to have a disease and not know anything about it other than what you're suffering with. Thank you so much for the TM Association. I feel like I am not alone now. I was 48 years old at the time of diagnosis. I am now 54.

I know that this story is long and I apologize for that, but it is all pertinent to my situation and who knows, it may reflect the same problems others have faced.

Joyce Chandler

Jackie Farmer
Moran Texas
December 2, 1999

I want to share my story with you in my own words. Today is my eight-year anniversary! Sometimes it seems like a lifetime, and sometimes like only yesterday.

I was sitting in an art class at Howard-Payne University in Brownwood, Texas. I was weaving a basket when I realized that my right leg was feeling cool, almost cold but not. I thought maybe I was sitting crooked and was cutting off circulation or something. When I stood up, I realized that from about halfway between my knee and foot was dead, all the way to and including my foot. That was odd! I went over to the library where my husband was working and told him. I thought that perhaps I needed to see the chiropractor and get an adjustment. So, that is what I did. After the adjustment, I didn't feel any different, except that now the coldness and deadness was coming up my right side to my abdomen including my buttock. Our daughter, who was attending the college at the time, went with us to lunch. I drank a lot of coke and had tacos. After lunch I noticed that the "feelings" were going across to my left side and down that leg. My husband and daughter took me to her apartment to lie down for a while. They went back to work and to school. I thought I might rest, but couldn't get comfortable. I even felt sick to my stomach. After about an hour, I called my husband and told him I thought he needed to take me to the doctor.

I walked in the office, and got to see the doctor right away. He examined me and asked me to get a urine sample. Well, I knew I had consumed quite a bit of soda and actually needed to use the bathroom, however, once I got in the bathroom, I could not urinate. That is when I knew something was definitely wrong. After he catheterized me, he sent me over to the hospital for a sonogram of my gall bladder. It was about 3 PM at this point. When I got up to leave, I couldn't stand. Surprise! After the trip to the hospital, we came back to his office. He said the sonogram showed nothing abnormal with my gall bladder, so he gave me a shot for the pain, which was getting pretty intense by then. I got in the back seat of our '95 Blazer. We picked up our son from school and headed for home. At that time we had just moved to a small town 12 miles north of Stephenville, Texas. My husband is a pastor and we had been called to this small church about a month and a half earlier. We had only been living there about two weeks. It is about 95 miles from Brownwood to Morgan Mill; a very long drive.

My husband got me out of the vehicle and into the house. He put me on our daughter's bed in the spare room. We got our 11-year-old son situated, and we all went to bed. I woke up at about midnight in such pain I could hardly breathe. My husband called a sweet lady just up the road to come be with Wendell, and we headed to Stephenville to the ER. Once there and on the table, my legs would not be still. They moved as if they had a mind of their own. That's fun! :) The ER doctor called another doctor in town and described my symptoms, and this doctor diagnosed TM. Well, none of us had ever hear of such a thing. Surprise again! The ER doctor gave me another shot and sent me home with instructions that if I was not better the next day, to go see the doctor that had diagnosed me.
Well, needless to say, I wasn't better. We got to his office about 9:30 AM, and he saw me right away. He said he would call a neurologist in Fort Worth, and wanted me to go to Harris Methodist Hospital there. He also called the ER and ordered a cath to be put in and another shot. Then the fun started. My sweet husband drove home to arrange for the care of our son. He called his parents, called my parents, and called someone to tell our daughter, Karri Anne. And then we headed out. Dumb, dumb. We had no idea where the hospital was. I would wake up every once in a while and caution him not to drive too fast. What a couple! Needless to say, we finally made it to the hospital. The doctor was upset, because it took us so long to get there. Ha!

Things are a little foggy for me from the first day or two; except that the sheet hurt me. Everything was so sensitive. I cried and apologized when they touched me to move me. Finally after two days of tests, you know the drill; she (the doctor) gave me some cortisone in my IV and the pain stopped. Yea!

My folks got there and were waiting for me after my MRI. Here I was totally paralyzed on this silly gurney, looking up at my mom and dad, encouraging them. Telling my crying mother that every thing was O.K. I was fine :) For a year or longer when I talked to my dad on the phone, he cried before we hung up.

I was in the hospital on my 44th birthday. What fun! I came home nine days after I was admitted to the hospital. My son and husband had the Christmas tree up for me (we usually put it up on my birthday, December 9th). No decorations, but it was up! The physical therapy people wanted me to stay in the facility at the hospital for six weeks for PT. But I

told them I couldn't stay away from my family that long. God had a much better plan for me. He sent me to the physical therapy department at Harris Methodist in Stephenville, to a Christian PT. Not only did she encourage me, but she prayed for me. G-d is so good! My lesion is at T4. It effected my shoulders, my breathing, and feelings up to my neck. I am so grateful that my arms weren't effected (my heart goes out to those of you that are effected higher than I was; you are in my prayers.)

I'll not go into the details of my PT at this point. I was in PT for the first six months after my onset. I learned to walk on legs I could not feel. The only way I knew they were there was by looking. I have pushed hard, being determined to be able to walk with my children and grandchildren (when they came). I have also been determined not to complain, no matter what. That has been hard to live up to, but when we are alone, my precious husband holds me and lets me cry as long as it takes.

I have worn leggings from the beginning. It helps to keep my other clothes from hurting me. They are wonderful. It is hard to comprehend how you can be paralyzed, and yet have hypersensitive skin. Huh? Sometimes our brains have to accept things that don't seem quite right.

I have had about a year and a half of PT, in and out of water. The water is the best! It just amazes me that I can have new (better) feelings after walking in the water.

We have also dealt with this situation with a **lot** of laughter. It's the only way to go. When I was in my chair, my kids really **pushed** me around! Sandy, we need to write a book, we need to be on TV, so the world can know about **us**. I wrote Oprah once, but never got a reply. People need to know.

I have so much more I want to write, how the changes have come, the fatigue, and the pain; the help and the lack thereof from the doctors and hospitals. But I will close for now. Thank you for listening, and letting me share. I want so much to meet others like me. It has been a comfort to know someone else has gone through what I have. And yet it is heartbreaking to know that others have gone through what I have, and that there will be others. Thank you for this organization and your correspondence.

May God bless you real good is my prayer.
Jackie Farmer
coejack@yahoo.com

During Carnival 1997, precisely on Monday, 10 February 97, in Condado, PE, Ana Cristina showed symptoms of dengue (acute infectious disease characterized by headaches, severe joint pain, and a rash), that is, high temperature and body aching all over, particularly in the legs. She took some Tylenol and the next day she came to Recife and continued taking the same medication.

Report on **Ana Cristina Gomes dos Santos**
Recife Brazil 10 July 1999
José Dias dos Santos
(Ana Cristina's Father)
jose_dias@uol.com.br

The following week she returned to work and was even able to participate in a two-day workshop. On Wednesday, 19 February, she felt ill and was taken to the emergency room of the Hospital Memorial São José where she was given Voltaren and subsequently released. She continued taking the medication at home. At about midnight she went to bed but her legs felt heavy (tired legs). The next morning, 20 February, at about 6:00 AM, she tried to get up, but was unable to because her legs did not respond to her efforts. She was immediately taken to Hospital Neuro, where she remained for 18 days. Her stay at that hospital was from 20 February to 8 March 1997.

During the first days of her stay in the hospital, the paralysis reached one of the arms and the thorax. She was treated with medication containing corticoids. The paralysis regressed, and remains the same to this day, at the navel level. Since she left the hospital, on 8 March, she continued treatment at home. This treatment involved a psychologist, a nurse's aide, and a physiotherapist, as she was unable to handle her physiological needs on her own.

While she was hospitalized at the Neuro, she was subjected to a series of tests aiming to reach a diagnosis for her condition, which to this day has not been determined. After some months without any change in her condition, she was again hospitalized, now at the Hospital Sarah Kubitschek, in Brasília, where she stayed from 21 May to 12 July 97. Again a new series of tests were performed but, unfortunately, the team of neurologists of the hospital were still unable to reach a conclusive diagnosis. With the uncertainty of the diagnosis, we decided to take her to Hospital Santa Isabel in São Paulo, where she stayed from July 14 to 20, 1997. A new series of exams was conducted but, as in the other hospitals, no conclusive diagnosis was reached.

In June 1999, Dr. Alex Caetano requested three magnetic resonance images of the different areas affected. After an analysis of the reports, he

assured us that what she had was Multiple Sclerosis. He then requested her hospitalization to start treatment with Sygen Monossialotetraexosilgangliosídio-GM1). She stayed at the Hospital Português, in Recife, from 27 July to 10 August 1999. She is still taking Sygen without any positive result so far.

The "dance" of the diagnosis started at the Hospital Neuro when it was said that it could be sub-acute viral encephalomyelitis and then that it was possibly transverse myelitis. After that, at the Hospital Sarah Kubitscheck, it was suggested that it might be a case of multiple sclerosis, but this was not a conclusive diagnosis. Then came the team of the Hospital Santa Isabel, which discarded the hypothesis of multiple sclerosis and confirmed the possibility of transverse myelitis. Finally, other neurologists were contacted but the diagnosis is still doubtful. The most recent neurologist seen, Dr. Alex Caetano, says there is no doubt this is a case of multiple sclerosis. Thirty months have elapsed without a firm diagnosis of Ana Cristina's condition.

During all this time, she has been hospitalized in three hospitals of recognized standing in this area of medicine. In Recife, she stayed 18 days at the Hospital Neuro. In Brasília, she stayed 45 days at the Hospital Sarah Kubitschek; in São Paulo she was six days at the Hospital Santa Isabel, and in Recife again, another 15 days at the Hospital Português. All hospitals of reputation in this specialization.

Following are some of the examinations and tests done during the 30 months of her illness:
At the Hospital Neuro:
Liquor Cefalorraqueano (LCR) (20 Feb 97)
Magnetic Resonance of the Spinal cord (21 Feb 97)
Nuclear Magnetic Resonance of the Cranium (24 Feb 97)
Liquor Cefalorraqueano (LCR) (27 Feb 97) – Spinal tap
Electrocerebral Responses Evocate by monocular visual estilmulation with checkboard pattern stimulus (03 Mar 97)
Ultrasound of the urinary tract (5 Mar 97)
Psychological and physiotherapy follow-up

At Home:
Urine Summary (13 Mar 97)
Electrical stimulation of a sensore periferal nerve of the lower members (8 Apr 97)
Urodinamic Avaliation (11 Apr 97)
Urine Summary (28 Apr 97)
Leucogram (30 Apr 97)
Feces Parasitology(7 May 97)
Rotavirus de Fezes (7 May 97)
Microbiology in the urine (7 May 97)
Feces cultures (7 May 97)
Feces parasitology (8 May 97
Psychological and physiotherapy follow-up

At the Hospital Sarah Kubtistchek
Liquor (27 May 97)
Electrocerebral Responses Evocate by monocular visual estilmulation with checkboard pattern stimulus (26 May 97)
Protein electrophoresis (27 May 97)
Three Magnetic Resonances (Jun 97) - Imaging
Blood, Urine, Feces (June 97)
Psychological and physiotherapy follow-up

At the Santa Isabel
Liquor (15 Jul 97)
Magnetic Resonance (16 Jul 97) - Imaging
In Recife
Luetic test (13 Feb 98)
Anti-phospholipide (13 Feb 98)
Anti-cardiolipina (13 Feb 98)
Protein C (13 Feb 98)
Protein S (13 Feb 98)
Prolactina (13 Feb 98)
Lupico antibody(13 Feb 98)
Antitrombina III (13 Feb 98)
Ative Parcial Tromboplastine (13 Feb 98)
T. Bleeding/T. Coagulation (13 Feb 98)
Urea (8 Feb 99)
Creatinine (8 Feb 99)
Potencial Evocado Visual (23 Feb 99)
Liquor (with a study of oligoclonal bands) (23 April 99)
Physiotherapy follow-up
Magnetic resonances (three) (22 Jun 99) - Imaging

Neurologists consulted:

In Recife: 16 listed
In Brasília: 4 listed
In São Paulo: 3 listed

THANK YOU!!!
When I found your web site I cried. There really was somebody someplace that knew something about the disease I had endured. When I

Deborah J Hall
New Richmond Ohio
debhall7@juno.com

contracted transverse myelitis in 1987 I couldn't find any information in libraries or even many doctors that knew anything about it. I was very fortunate; my case was not near as severe as many who contract TM. But nonetheless I suffered plenty. It's been 13 years and many of the smaller details are not fresh in my mind, but I will provide a brief synopsis.

In December 1986 we went to Florida for the Christmas holidays. I became feverish and starting aching and believed I was getting the flu. The next morning I seemed to be OK. It didn't make much sense but I was relieved since we were on vacation.

That winter was supposed to be a bad flu season so for the first time in my life I got a flu shot around the 10th of January. Within a couple of days, I was running a low-grade temperature (99+) and felt feverish. I called my family physician who said I was probably having a reaction to the flu shot. After about 10 days, he decided to run some blood tests for anemia, etc. All tests turned out negative. I kept getting weaker and in more pain. I was taking Tylenol and trying to get a lot of sleep.

In February my family physician sent me to a neurologist. He ran an EMG along with a spinal tap (from which I developed horrendous spinal headaches; he sent me home immediately following the tap sitting up in a car). His diagnosis was that he definitely found diminished muscle strength but had no idea what was causing this. My strength kept deteriorating and the pain was getting steadily worse. I continued to work during this period of time but it was on sheer guts that I made it.

There would be days that I would drive home and be in such pain that I would be almost bent over the steering wheel. Unfortunately, I had an employer who was not the least bit understanding. Because of the fact that the doctors couldn't determine the source of my disease or put a name to it, they constantly pressured me to be at work and in many instances insisted on 5-10 hours of overtime each week. My husband was a farmer and I was carrying all of our insurance. Needless to say, it was mandatory that we keep insurance during this time period. The middle of March, my family doctor sent me back to the neurologist for further tests to determine if there was any discernible change. During my follow-up conversation with the neurologist he stated, "You definitely do have some muscle damage and weakness but I can find no reason. Are you sure that this isn't all in your head?" I was devastated and cried all the way home. My family doctor, who at this time had tried everything he could, decided to send me to the Mayo Clinic. He was following up on arrangements when he called and said he wanted to try one last physician in Cincinnati.

He sent me to Dr. Beverly Carpenter, an arthritis and immune disease specialist (who unfortunately died of cancer in February of this year). In describing my symptoms to her, extreme pain, sleeplessness, fatigue, loss of bladder control, difficulty in moving, she said she thought she might know what was wrong but wanted to run tests. After numerous blood tests (30+), two MRI's were scheduled. MRI's are quite different today. In 1987 each segment of a test would last from 6 to 20 minutes. By the middle of April, it was determined that I had transverse myelitis. For the next two months, Dr. Carpenter treated me with Prednisone.
Unfortunately, I had terrible side effects from the Prednisone for many years. I constantly had a reoccurrence of the symptoms which of course put me in a panic every time it happened. All together I had MRI's on six different occasions to be certain the myelitis was not returning. I feel that I was very fortunate, especially after reading some of the cases in the newsletter. According to the doctors, a lot of what got me through this was my bullheadedness. I refused to give in; but sometimes it was difficult, almost impossible. There were a couple of times I really wondered if the pain and enduring the treatment I was receiving at work were worth it. Once I even thought for a minute about just running the car into a concrete abutment. But then I remembered I had a husband that had supported and loved me every single minute even though he didn't understand what was going on and was scared. I also had two daughters that had already endured the pain of losing their Dad to a heart attack at the age of 41 and they surely couldn't endure much more.

I left my old employer and took a "dream job" with a bank. Everything I had endured through the initial onset of TM, and particularly as it related to my employer, was in the past. I was still having problems, some of which I'm not sure were related to the effects of the myelitis or simply "old age." The bank allowed me to work four days a week which definitely helped. Muscle strength was definitely deteriorated. I continued to take Prozac and Moduretic to counteract the side effects of the megadoses of Prednisone. A recent bone density test indicated that I have some deterioration which may or may not be related to the myelitis. The end of April 1999, I began to deteriorate again. At first I thought it was because I was just pushing too hard (as usual) and with enough additional rest everything would be fine. It wasn't. Again the battery of tests began. This time even more extensive than before. I had mononucleosis. I couldn't believe it; I was 51 years old. Rest, rest and more rest would be the solution. But I didn't improve. More tests. I was diagnosed with fibromyalgia and chronic myofascial pain syndrome. Just my luck. To get another disease that I knew nothing about. So again, I started researching and found a specialist here in Cincinnati. With the most recent diagnosis, our whole life has changed. I can no longer work. I do very limited driving. My husband has "retired" from farming to help me. We have moved into another home that is designed to make everything easier for me. I have lost a great deal of my independence, doing yard

work, playing with grandchildren, grocery shopping, etc. This illness has been even tougher psychologically because "I beat" transverse myelitis, but it was obvious I wasn't going to defeat this. Giving up independence and being dependent on others has been the toughest part. I'm living in constant pain, most bearable but some not. Whenever I get discouraged, I remember how much worse I could be. I'm convinced my belief in God and the fact that everything happens for a reason helps me get through. Plus, I have terrific support from my husband, my daughters and especially the overwhelming love and smiles from my grandchildren. My life certainly did not turn out exactly the way I envisioned, but it could certainly have been worse. Bless you for getting the information out. The worst part of transverse myelitis was going through it at a time when no one had any information and, at times, I really did wonder if it was "in my head." Now, I wonder if anyone else has contracted fibromyalgia and/ or chronic myofascial pain syndrome after transverse myelitis. I'm researching, but so far to no avail.

I appear to be one of the "new kids on the block." I had an acute attack of Transverse Myelitis just last Father's Day, June 22, 1999. Since my symptoms were so instantaneous, my recovery progressive, and medical team suggestions so helpful, I want to share my happenings to help benefit others. A thank you, also, goes out to all those who contribute to making the TM Newsletter a reality; it helps dealing with this rare devastating paralysis by realizing we are not alone.

Joyce Heritage
Wilmington Delaware
One-Year Ago on
Father's Day

Last year I was enjoying Father's Day dinner with my husband at my daughter's house at 6:00 p.m. The day until then was quite enjoyable – Mass, movie, and dinner out. I experienced leg cramps in both my calves, which relieved after standing and stretching. After finishing dinner, I played with my grandson. My husband and I started the drive home around 8:00 p.m. At home as I started to remove my stockings, I realized I couldn't feel my toes or feet. At first I thought the earlier leg cramps must have caused this unusual sensation. After changing and going to bed, I remembered I forgot to use the toilet. I got out of bed and fell against the bed and end table – 10:00 p.m. By this time the calf cramps were back and I was calling for my husband to help walk me down the hall in hopes of getting some relief. After walking with his support, I tried using the toilet. Upon standing up, I walked like I had frog feet, which were flopping in. After lying back down in bed, I was hit with unbearable leg cramps, again. We knew whatever was happening was beyond our ability. The ambulance was called, and I was transported to the emergency ward at the Christiana Hospital.

My initial exam ensued with three MRI's, EMG, EEG, x-rays, blood work, and IV steroids were started immediately. The suspicions while the tests were being conducted were Transverse Myelitis, Gillian Barre, or Lyme disease. The final diagnosis was TM of the T-12 spinal column. It is believed that since I had been healthy with no ill symptoms before the attack, it hit me low on the spine, and I received medication so quickly, my recovery so far appears to be remarkable. Upon arrival at the hospital, I couldn't raise my feet more than a few inches from the bed, and had little feeling in my legs, buttocks, and lost control of my bladder and bowel.

After trying to get over the shock of the diagnosis, I faced the fact my full time position in a computer-consulting firm was on hold. I focused on my goal – walking, and tried to lose sight of my obstacle – being paraplegic. I was transferred after a week to a local rehabilitation unit at the Wilmington Hospital – a four star rating in my book. It was run like a summer camp! I was up by 7:00 a.m. and dressed by 7:45 a.m., wheeled to the dining hall by 8:00 a.m., had my first session of physical therapy at 10:00 a.m., occupational therapy at 11:00 a.m., lunch at noon, and back for my second session of physical therapy at 2:00 p.m. Needless to say, thereafter, I was wiped out and slept. After spending a month in rehabilitation, I was discharged walking 27 steps with my walker and plastic molded leg braces to face the real world. I did regain the functioning of my bladder and bowel after two weeks. My gastroenterologist suggested using the non-habit forming Senekot-S to help regulate my bowels and some relief for the buttocks needle sensations while sitting is relieved by Neurontin.

I've continued land physical therapy three times a week from August 1999 through February 2000 for regaining strength with weight resistance and walking skills. I learned of Dr. Douglas Kerr's TM Medical Center at Johns Hopkins Hospital through our last Transverse Myelitis Newsletter. Dr. Kerr evaluated me in March, thought I was making good progress so far, started me on water physical therapy. He suggested I see Dr. Barbara D'Lateur at Johns Hopkins for a reevaluation of how to get the most out of my physical therapy and walking skills training. My major issues are fatigue and increased leg numbness while walking and

backache. Although, I walk on familiar ground at home – when rested – with braces without a cane, I couldn't conquer the barrier of being able to leave my home without holding onto someone's arm. My toes wouldn't come up and I have fallen spraining my right ankle three times. Dr. D'Lateur scripted for me to have braces with a flexible hinge that has a 90-degree stop lock which should prevent me from tripping my toe and falling. Since I don't have much feeling from my knees down to my toes, balance is still an issue because I can't feel space for ground sensation.

I continue to struggle with the blues from time to time as I grieve losing the person I once was. However, by holding one hand with the Lord, and one with loving family members, I know the new me will make a fulfilling life for myself.

Joyce R. Heritage
219 Barberry Dr., Wood Creek
Wilmington, De 19808
jheri0801@aol.com

Kelly Major
Philadelphia Pennsylvania

I'm 19, taking classes from Harcourt. I live in Pennsylvania, just outside of Philadelphia. I'm a computer science major. All of my life (well, 12 years) since I had my first episode... I've always wanted to make people aware of TM. And I would do anything to help someone else. And I mean ANYTHING. I'm one of the luckier ones with TM. I can walk, see, and do really anything. But I have my share of problems.

It all began in February of 1989; I was seven years old. I remember this as though it was yesterday. I had a horrible flu. The worst flu I had ever had. I was sleeping on the sofa because I wanted be to closer to my mom's room. I woke up early in the morning, and I had to go to the bathroom. I tried to get up and walk but I couldn't. Step after step I kept falling. I tried to climb my way up the stairs to where the bathroom was. And when I got to the top of the stairs I just sat there and cried. I had lost control of my bladder. I was hysterical. My stepfather came out of the bathroom and didn't know what to do. By this time everyone in the house was awake. I couldn't walk, see, or control my bladder. This was sooooo scary.

I went to Phoenixville Hospital and they looked at me for a little and then didn't know what to do, so they sent me home. I didn't know what was going on. Then I was still unable to walk for the next couple of days, so my mom and dad decided I needed help. I was taken to Children's Hospital in Philadelphia. While I was there, I had to get test after test. MRI's, spinal taps, blood, breathing, and many more.... It felt like I was just a test patient. I was scared when the doctors could not diagnose my illness. First, they said it was lyme disease and then they said it wasn't. I showed lesions on my spine and brain. After all these tests, the hospital said that I was the first child in the United States to have these symptoms. So, they didn't know what to diagnose me with except they called it a "form of MS." This didn't make my mom happy at all. We wanted to know what was going on.

Then I feel as though a miracle happened. I gradually was able to walk again. And I got my vision back. I was sent home. I had to get physical therapy so that I could walk again. Well, as the years went on.... I was pretty much an active kid. But something still happens to me. I have these things that the doctor calls relapses. I go paralyzed for maybe a day to a few days at a time. My step-mom called these episodes "attention attacks." That hurts a lot. But it seems to happen when I'm under stress more then ever. And I usually end up back in the hospital. The hardest part for me is that I feel all alone when this happens. The doctors never know what to do.

When I was in middle school and high school I was very athletic. But I would have my good days and bad days. Some nights I would lay in my bed and cry and hope that tomorrow I would be able to walk and see. I was an all-star field hockey player and captain of my team for three years. I am grateful of this. The doctors once told me I would never walk again and now I disproved them. I never came out and talked about this before because I felt that I was alone. The first time that anyone knew about this was my senior year of high school. I made a speech at a sports banquet and told everyone. They were shocked. I felt a lot stronger after I talked about it. I let many years go by before I went back to the neurologist, because I had to always go alone and I was scared. When I went back last November, the neurologist then diagnosed me with Transverse Myelitis. For me it took them 11 years to tell me what I had.

How I stand now, I am working full time with computers. I'm taking classes. I live with my grandmom. My parents have been divorced since I was five, so that is a frustrating situation till this day. I have problems to this day with my back, legs, eyes, and bladder control. It effected T5 down. Some days my legs feel so weak to do anything. Other days I can run forever. My bladder will never be better. I want to get this looked at but it takes me going back to my doctor and then another. I get sick of it. But

I do what I have to. I never know exactly what to do, because I haven't had any guidance. I've been on my own. I'm willing to go out and help out anyone who needs someone to talk to. It's so good to know that I'm not alone in the world. Also one last thing, sometimes I get so depressed. I just cry and cry. Well, this is my story... in a short version. Sometimes I just really need someone to talk to. If anyone is willing to talk or email me please feel free to do so. I will do anything to get the word out about TM. Thank you for taking the time to read this.

I thought that I just had the flu
but I got so sick
I didn't know what to do
I woke up in the middle of the night
I was so scared and full of fright
When I tried to walk I just kept falling
Then all I knew,
my mom I was calling
When I tried to look I couldn't see
all I kept saying was this couldn't be.
My legs were numb from my chest down
all I wanted to do was just sit there and frown
Many doctors and hospitals I went to
but none of them knew what to do
I went through test after test
but I still had that aching in my chest
I never knew why I couldn't hold my bladder, walk or see
all I knew was at home is where I definitely wanted to be.

After a long time of probing, MRI's, blood, spinal taps,
they sent me home
with out a diagnosis!!!!

Then I got better and could walk and see
But the sad thing is
I'm not the old me.
I still have the problems from my chest down
and some days I'm so depressed
I just frown
but for the past 12 years
I've grown emotionally strong
even knowing that some things are still wrong.
I want to help out others like me,
I want to open their eyes
and let them see.

I know I'll never be back to 100% but with the love and support that is all I need!!!!!

~Kelly

My name is Faye Mansfield. I had always been told at age 50 everything goes down hill. In my mind, I was not going to feel that way. I was a happy, divorced, slim, outgoing, good shape, loving lady. I was having a great time. I had met a man who I was enjoying spending all of my extra time with. I thought I had been through enough hurt and heartache. Already I had lost my two children in two different car wrecks at different times and had lost my father to whom I was very close. I was ready to enjoy life and not let life get me down.

Faye Mansfield
Dresden Tennessee

In February, I was working at a medical clinic. I had worked there ten years ago. I loved the work there and wanted to fill in for a girl who was off to have a baby. This would have been through the winter cold and flu season. I went to work and I took a sinus infection, then cold and pneumonia. It was four weeks of seeing the doctor and trying to work and off a few days and then back to work. So I thought I was over all my sickness. The six weeks of working for the girl who had the baby was over. Thought I had gotten well by now, ready to get on with life. It was time for my yearly check up with my doctor, the one I had worked for ten years. He was also a great friend. It was May 5, 1997; he checked me and I felt great except my ankles had felt a little weak. I told the doctor this and he told me, you know how sick you were when you were working over here a couple of months ago, you may not have gotten over it completely. He gave me some antibiotics. So, I got them filled and took one that night. The next morning, May 6, 1997, I woke up and could hardly walk to my bathroom, which was only about ten feet away. I didn't know what was going on. After going to the bathroom, I always went straight to the kitchen to make coffee. It was just as hard to get to the kitchen that morning. I made my coffee and sat down and tried to figure out what was going on. Just after going to the doctor the day before; I was at a total loss to know what was wrong.

It was about 6:30 AM. I had never called the doctor at home. After working with him, I knew if he had been up all night, he would not be happy at all with me. After about ten minutes, I called anyway. He was so sweet. He said he didn't know what was wrong but that something was because he had checked me over really well the day before. He told me to sit there and call someone to come and carry me to the Neurology Semmes Murphy Clinic in Jackson, which is an hour and a half away. Here I was, hair not combed, no make-up, scared to death. A dear friend of mine, Cathy, came to carry me to Jackson to see the doctor.

She got me to her car with great difficulty. The doctor saw me soon after I got to his office; not saying very much to me while I was being checked. After being around a clinic working for ten years, in my mind, I felt something was very wrong. I was then sent to the hospital for many more tests. Within a few hours, I could not move from midway of my rib cage down.

While in the hospital, I was given three bags of steroids. I had a MRI two days in a row, blood work of all kinds, spinal tap, and tested for MS.

Dr. Misulls had told me he thought it was Transverse Myelitis. I had no idea what that was. By this time, my eyes were not clear at all. My right eye was much worse than the left, but my left side was much weaker. My bladder had become very weak at this time. I thought it was all caused from me having to pull myself up in the hospital bed and trying to stand. It is now working fine and I have to watch my diet and sometimes take something for constipation. As for my learning to walk again, the paralysis, numbness, tingling, burning, and freezing sensations were terrible along with trying to wear shoes on my feet. I would sit with ice packs on my feet. I had told my therapist I wanted to be walking in three weeks. He said, OK, if that is what you want to do. I had no idea that walking in three weeks was not going to happen. First of all, I could not even turn over in bed. He worked with me three times a week and was very good.

After about three months, I was standing up with a walker. I was fighting very hard to get back in the world that I had been taken out of by TM. I still wanted to enjoy the man that was standing by my side and all my friends and the great mother and sister I have. They were all there everyday for me. I was getting out of that wheelchair and off that walker no matter what they said. My friend Cathy would try to keep me looking up, pushing me in the wheelchair like it was a machine made to fly. With her behind you, there was no way you would not laugh even if I had fallen out. I told her I needed a seat belt when she was pushing me. By the last of August, I was walking a little with help. My eyes were still a large disadvantage to me. I had gone totally blind in my right eye for about three days, but it was coming back very slowly. I only saw black, gray, and white for several months. Then I saw blue dots on everything for weeks. My eyes were changing and this just about drove me crazy. Now my left eye has good color and in the right eye, I am color blind. With both eyes open, the left eye rules. In letters from the TM friends, I didn't see anything about eyes. My left eye is pretty good but my right eye is considered legally blind. But, thank God, he gave me back part of what I lost, and he is the only one who can help from now on. Once the optic nerve is damaged, there is nothing anyone can do. But God can, if it is his will to and I pray that it is.

Yes, I still have a lot of nerve damage in my feet, legs and ribcage all the way around and down. No matter how bad it is, I am working and my eyes are pretty good. If the lighting is right for me, I see OK. My eyes won't filter out the bright light.

Yes, I married the man that stood by me and I love him very much. My family and friends are very special to me. I feel much pain but try hard to not talk and dwell on it. I was sent to the Vitrcoretinal Foundation in Memphis, Tennessee after seeing my local eye doctor, Dr. Robert Jordon, whom I have a lot of trust in. I was also sent to Vanderbilt Hospital in Nashville to make sure I didn't have MS. The doctor said that I did not. When I was sent to Vanderbilt, the MRI that was taken when I first got sick showed T5 had swelling and a small spot in the ponds.

I want to thank all my doctors for trying to help me. Most of all, Dr. OK Smith who is a friend and doctor. It meant a lot to me when he took time out to call even when he didn't have to. I still have hope I will get better. It is up to someone greater than I.

Your TM Friend,
Faye Mansfield

My name is Mike Mullally, age 47. I live in Hertfordshire about 20 miles north of London in the UK. I am married to Alice and we have two boys, Kieran age nine and Daniel age six.

I was diagnosed with TM at level T8 on 29th June 1999 and this is my account of living with the condition for the first year.

On 22nd May 1999 I went for a run in the park and noticed that my left knee was out of normal alignment. On 26th May I was again out for a run and it all seemed very difficult but it was not easy to say why. The best description I could muster was that my legs didn't seem to be working properly. On 27th May I had tingling sensation on my lower stomach in the morning and I got pins and needles and some numb-

Mike Mullally
Hertfordshire England UK

ness in my left foot in the afternoon. The next day there was numbness from stomach to toes, more severe mid thigh to shin and varying degrees of numbness and tingling in feet. I went to see the Physiotherapist who tended my sporting injuries and he advised that it was not a structural problem. I went to see my GP who proposed some blood tests.
These were completed on June 1st and the results were "all clean" as reported on June 8th.

The next step was to find a neurologist. During that first week of June, the numbness increased in my stomach, upper legs and lower left back. Walking and driving proved difficult and uncomfortable but was possible with care. My energy levels were seri-

ously depleted compared to normal. Then over the next ten days, most of the symptoms eased and it was possible to function normally except I could not run. On June 15th I visited my neurologist who ordered an MRI scan. This was completed on the 18th and I returned on the 29th for the results. At this time the soles of both feet felt as if they had huge lumps.

At the beginning of July I had a cold/ dead sensation on the left side of my face and neck. I started to have severe back pain that had a creeping effect, first one area, then another and tingling on my abdomen. This eventually presented itself as a very tight band of cold dead flesh around my mid to lower trunk. By 10th July the pain levels were quite high, I was loosing control of my waste disposal systems and walking was very difficult. I visited my consultant again on July 13th. He arranged further MRI scans above the T8 level for the 14th and organised one of his team to be there to interpret as soon as it was available. They found a lesion about 2 cm across on the right side of the brain.

I was admitted to hospital on the 14th and had numerous tests and a lumber puncture. I was also given steroids intravenously. On the 15th both of my legs felt completely dead. I had absolutely no movement in them and could not stand. All the testing and discussions with medical staff could not identify a trigger for TM. No evidence of recent or current infection was found.

During the next week, very minor incremental movements of my legs became possible and I began physiotherapy. My left side was much weaker and slower to recover than my right. By the 20th I was able to roll onto either side as a result of the physiotherapy exercise. A member of staff on the hospital ward acquired a loan wheelchair for me and I regained a small measure of my independence. Sleep depravation was a serious problem in the hospital and I began to push to be discharged. I was allowed home overnight on the 24th and this was followed up by a visit from the occupational therapy team. Our house was not ideally suited to a wheelchair user as there were many steps to be negotiated both externally and internally. Solutions were found to the more immediate problems and I was discharged on 30th July.

During August I returned to the hospital for physiotherapy two or three times per week. The impact of these sessions was varied and often strange. Sometimes there was a burning lumpy sensation in my knees and feet while at other times my legs felt as if they were floating while being very heavy. Towards the end of the month, there was significant spasm activity from both legs. They were extremely touch sensitive but there was little internal feeling. I started swimming and found that with a float strapped between my thighs, I could attempt a reasonable front crawl. Even the movement of my legs through the water caused them to spasm. I also had some acupuncture treatment that created a pulsing sensation in my left shin. My feet were very prone to severe swelling while sitting in my wheelchair. Regular massage and exercises seemed to be a solution but this was somehow difficult. I was keen to get to the first floor of the house to use the shower. With considerable help from my eldest two sons, I was able to climb the stairs one step at a time on my bottom. We then used an old furniture trolley to get me from the top of the stairs to the bathroom. Getting undressed/dressed and transferring into and out of the shower produced some interesting problems that were gradually resolved. It was noted that my feet returned to normal size after one of these sessions.

I was assessed for a place at a rehabilitation centre and was eventually given a start date of mid October. I bought a set of hand controls for my car, fitted them and began driving again. I had to endure extreme apathy and indifference from those that administer the wheelchair system and was forced to approach some suppliers directly in order to find a suitable chair that would enable me to drive without the help of another person. My own wheelchair finally appeared just before Christmas.

During September my leg movements improved. First, I could lift my left foot and then both knees. While lying face down I found I could lift my right leg behind to 90 degrees. The sensitivity and spasm activity also increased. This had a detrimental effect on my sleep as even the touch of the bed covers caused my legs to jump about. The MRI scans were taken again on the 14th and no new areas of inflammation were discovered. Initial attempts were made to get me upright in a standing frame. These were unsuccessful due to spasm activity but a gradual improvement was obvious.

During early October I had my first experience of aromatherapy, which proved to be very relaxing. The sessions in the standing frame were also improving. I started my treatment at the rehabilitation centre. This was largely a continuation of the physiotherapy activity from the hospital. By the end of the month, I was standing in the frame for 20 minutes and swimming once a week. I spent part of my time in the pool walking while holding on to the side of the pool. I was able to recognise a wet mat under my left foot. My knee and hip joints were very stiff.

In November progress was good. I was in the standing frame for up to 45

minutes and got to the parallel bars for the first time. By the end of the month I was taking tentative steps with a Zimmer frame. My left leg was also moving more easily.

In early December I was using the exercise bike in the gym and had my first attempts at walking up the stairs. I also began using crutches and by Christmas week I was able to get to the cinema and shops without my wheelchair. On Christmas Day I completed my first walk around the block aided by my son.

January and February 2000 saw equally good progress. I moved on to walking sticks and my strength and speed improved. I was discharged from the rehabilitation unit and began to drive a manual transmission car without hand controls. I could even do some gardening. However, at the end of February my lower back was very painful and my body tended to collapse after spending time on my feet or taking a walk. My speed and strength reduced dramatically, most of the feeling that had returned to my legs vanished yet again and my energy levels hit a serious low.

I had a pre-planned appointment with my consultant early in March. He ordered a 20-day course of steroids and another MRI scan. The steroids definitely helped overcome the lack of strength but I had to concentrate much more than before when walking to avoid falling. By the end of the month my speed had returned.

At the beginning of April my bladder refused to vent and I got a urinary tract infection. I was taken to my local Accident and Emergency and they found I also had a serious kidney malfunction. This was expected to recover once I had been catheterised but for five days there was no improvement. An ultrasound scan showed no physical damage to my kidneys and about the same time they started to recover. I was discharged from the hospital on the 13th, very weak and tired but pleased. I started my walking routine again during the last week of the month.

Early in May I had another meeting with my consultant. The recent MRI scan of my back showed a 'reduced area of difference' that he interpreted as scar tissue. My brain had not been scanned. My strength and speed improved and I began swimming again. Leg co-ordination was much improved in the pool and I also had my first successful attempt at riding my bike. I did small amounts of gardening daily when the weather permitted.

At the beginning of June my lower back pain started again and I had similar collapsing sensations to those experienced in February. I also found it extremely difficult to bend forward from a standing position. My consultant has put this down as a temporary setback and not issued any steroids. I have started physiotherapy at the rehabilitation centre again. I have urology and physiology clinic appointments planned to help better manage the waste disposal systems later this month.

Mike Mullally
88 Langley Road
Watford Hertfordshire WD1 3PJ
mikemullally@
langleyroad.freeserve.co.uk

Recently, I became aware of the Transverse Myelitis Association and would like to share my story for the "In their own words" section of the next TM newsletter. I was touched by the courage that TM sufferers have shown, and felt the least I could do was to share my experiences with other families that are battling this "one in a million" affliction. Here goes....

anonymous

Growing up in Colorado, I was enjoying the formative years of my life. I was 12 years old, I was surrounded by seven loving brothers and sisters, parents that had scratched and clawed their way through life to give all my siblings opportunities to succeed, and a neighborhood full of friends. I had everything a young boy could dream of. I knew I had special talents. I was blessed athletically and academically, staring on the baseball diamonds and football fields across Colorado. I was pretty proud of myself that when I would travel to Denver or Boulder for a football game or baseball tournament, the kids from the other teams knew my name and went out of their way to shake hands after games. Kids I didn't even know, imagine that.

I had dreams a lot of boys my age had, playing shortstop for the Chicago Cubs or maybe even quarterbacking the University of Colorado to a national championship or hoisting the Lombardi Trophy after leading the Denver Broncos to a 4th quarter comeback in the Super Bowl. Then it hit. It was a Friday afternoon, and my junior high school football practice had just ended. We were preparing for our big game on Monday after school. I couldn't wait to run home and tell Dad that I had earned the starting quarterback position for the big game. The coaches were passing out our game jerseys after practice. I was first in line. I chose #10, my favorite number of my favorite NFL quarterback, Fran Tarkenton.

When I got home, I carefully placed the neatly folded jersey on my dresser so as not to disturb it before

Monday's game. Little did I know I would never put that jersey on. I wouldn't score the winning touchdown in front of the whole school or make a single tackle on defense.

Saturday morning, I woke up and quickly got ready to go to my volunteer assignment of helping my dad referee midget football games in Longmont. As I was getting dressed, I felt the dreaded tingling in my legs. They began to feel heavy and I had intense shooting pains in my back and chest. I told Dad that I didn't feel up to going and that I had better lay down for awhile. He was apprehensive at first, but I think he understood that something was not right. Dad went off to the games. Mom quickly rushed to try and soothe my pains. I took several warm baths, chicken soup, tried to take a nap, and various other home remedies that had always worked in the past. But this time, for some reason, I was not improving. I was scared.

My best friends, Jeff and Craig and the other neighborhood boys came over Saturday, and again on Sunday, to see if I could join in on our daily football games in the backyard. I couldn't get off the couch. I could hear them outside having the time of their lives. It was killing me. No matter how hard I tried, I couldn't move my damn legs. I went to bed Sunday night praying for a miracle. I would wake up Monday, feel fine, get dressed and go to school. I would be on the field as I had dreamed, right? Wrong...

Monday morning came and went, and my parents rushed me to Boulder to the local community hospital. Things are sketchy at this point, but I remember days and days going by and me just laying in my hospital bed getting poked and prodded by various people. I even remember getting wheeled into a psychiatrist's office who proceeded to try to convince me that my problems were in my head. The bastard heckled me to get on my feet and walk out of his office. Weeks went by with no improvement. I was sent home after a few weeks. I couldn't wait to get out of the hospital and away from the "jello loaf surprise" assortment of meals.

About a month before Christmas, my parents took me to Children's hospital in Denver to try to find an answer for what was going on. My older sisters had been bringing me homework from my teachers. I was so focused on my problems, I didn't even think about how hard these times must have been on my family. Not knowing anything, and having to deal with the questions from friends, schoolmates, etc. I couldn't concentrate on schoolwork. I thought I was in a battle for my life.

At Children's, I remember different tests, even getting dye injected into my spinal cord. I remember an enthusiastic Doctor Moe that was upbeat and seemed to have at least figured out what had caused this nightmare. He had diagnosed me with TM. He had told me that there was a chance I would feel my legs again and that maybe I would even get out of my wheelchair. Things seemed to have taken a turn for the better. I remember visits to the hospital from some of the local sports stars. Weeks went by again, but still no improvement. I was sent home again in a wheelchair and my parents convinced me to go back to school.

I remember my first day back at school, getting out of my parent's van and the stares from my schoolmates that I had not seen in months. That didn't bother me though. I had convinced myself that I had to go on with my life, and I kept hanging on to the words of Dr. Moe that I may start to feel something again, and maybe, just maybe I would walk again. Those first few days were tough. I remember sitting in my favorite class, Social Studies, and urinating on myself and a puddle forming under my wheelchair. The other kids started laughing, I was totally humiliated. I went home from school that day vowing never to return. What a contrast to the joy I had felt a few months earlier leaving school with my neatly folded #10 jersey.

Within a few days, I was back at Children's. Dr. Moe had suggested physical therapy. I thought he was crazy. If couldn't move my legs, why does someone need to stretch my legs or put me in a pool? As you can imagine, I was discouraged and developed a bad attitude. Weeks of going to the pool and physical therapy went by. I had begged my mother to talk to the hospital about better food. She would even sneak hamburgers into me after visiting hours. Then one morning it happened!!! I moved my right big toe. I was so excited, I think I pissed myself. I screamed for my parents, doctors, nurses, anyone that I could find. Everyone came running into my room. There was hope in my life again. I wanted more therapy. I wanted someone to take me to the pool at 2 AM. That night, I had a dream of putting on my #10 jersey and running for an 80-yard touchdown. Over the next few weeks, I was able to move both of my legs. I was excited, but I knew I had a long journey ahead.

I returned home just before Christmas. I couldn't wait to see all my brothers and sisters and the Christmas tree in the living room and my dog, Heidi, the German Shepherd. I remember my Dad wheeling me into what used to be my sister's bedroom. But there was a surprise; it was filled with all kinds of

exercise equipment and tumbling mats. My Dad knew what lay ahead. He picked me up out of my wheelchair and placed me on the tumbling mats and started helping me stretch my legs. Then he lifted me up on my new exercise bike and I was able to turn the pedals a little. We looked at each other and I gave him a hug. I knew he was proud of me. Probably prouder than if I had scored the winning touchdown on that Monday that seemed like a lifetime ago.

Over the next few months, my strength was coming back. I began walking with the aide of my trusty walker. Then, after more months of rehab, I was able to start jogging with my Dad through the neighborhood. I remember the looks from the neighbors as I was jogging by. A miracle had happened.

As the years went by, I regained some of my lost physical prowess. I never completely recovered from TM, but I realized there was more to life than scoring touchdowns. I played organized baseball again and although I couldn't run (more like a slow jog), I tried to compensate with other things. I developed a nasty curveball and was a pretty decent pitcher. In high school, I earned three varsity letters in golf.

I went on to college and earned my CPA license. I met and married my beautiful wife,and we have three lovely daughters and a new son. Life has turned out good for me. I still suffer from TM. The strength in my left leg is not equal to my right leg, so I walk with a slight limp. A few years ago, I had to have a total left hip replacement probably as a result of the wear and tear resulting from TM.

There probably isn't a day that goes by that I don't say "why me," "why was I the one in a million" to contract TM. I still have dreams about scoring the winning touchdown and wonder what might have been had this not happened to me. But in retrospect, I consider myself the luckiest man in the world to have battled this terrible illness and won, at least a partial victory. I thank G-d, because without this experience, I probably wouldn't have met and had our beautiful children. If for some reason, it comes back, I am ready. I have beaten it once, and I will beat it again.

To my parents, siblings, friends and Dr. Moe, I say thank you for all the support and sacrifices you made over the years. They never allowed me to give up. From my sister who gave up her bedroom for my rehab equipment, to my Dad who used to lift me out of my wheelchair for my exercises and taking me jogging, to my Mom who used to wake up at 4 AM to take me to my rehab at the swimming pool, to my friends who stuck with me and remind me of the "glory days," and to my wife and children who allow me to be a part of their lives, I love you all.

My most frightening time of my life began on May 11, 1999. Everything had gone so normal all day and into the night, when around 9:45 PM, my fingers on my left hand started tingling and I thought they were just going to sleep and they would wake up. Then I just tried to go to sleep, and it was the weirdest feeling, the tingling went to my right fingers and then started up my arms. I started then to feel sick in my stomach and started to feel weak. I called my husband at work around 3 AM, and he immediately came home. We called the doctor and he told me to take some advil and call the office in the morning, if I did not feel better. Well I didn't sleep all night. Around 7 AM, we got ready to go to the doctor's. By then I was so weak, my husband almost had to carry me. As soon as the doctor saw me (not the one I talked to on the phone), he immediately told the nurse to call an ambulance. We got to the emergency room almost right away. I could not breathe on my own, so I was put on a respirator right away. After a few days, they decided to do a tracheotomy, or else the tube down my throat would ruin my vocal cords. I was effected at the C-2 level. I remained in the Hospital paralyzed

Bonnie Rebuck
Mt. Joy Pennsylvania
BGNSP37@aol.com

from the neck down and on a vent until June 1999. Then I was transferred to a Rehabilitation facility called HealthSouth, Mechanicsburg until September 1999. I went through extensive therapy and around July 25th I was able to wean myself off of the vent, which was very hard to do. The whole time I was hospitalized all the doctors were saying I had MS. Well, in November 1999 I went for a few more opinions and was re-dx with TM.

I keep getting better day by day. I use a wheelchair for long distances and a walker for short distances. I did get a little bit of foot drop while I was laid up and that is hindering my walking also. I just received Botox injections in my left leg on January 9, 2001 to try and get more movement in my ankle and I have a good feeling about it. As of right now, January 25, 2001 I am being serial casted and have already gained about 15 degrees in my ankle. So I know in time I WILL be walking on my own. I have gotten this far, and plan on getting the rest of the way better. I really don't know where I would be today if it weren't for my family and friends' support.

They were right by my side through this whole scary ordeal. I look back now and I can laugh at them trying to read my lips. They were not good at it, and it cracks me up today, but back then it was very frustrating. I have made some very good friends through all this. I know there was a reason for this happening to me. I may not ever know the reason, but I plan on keeping strong and keeping my great attitude, and I will get through this with GREAT results and with a smile on my face.

Why

As I sit here and wonder why,
tears fill up in my eyes.
One day full of life and vibrant,
next day flat on my back
and on a vent.
Next four months went very slow,
out of the hospital I did not go.
Therapy was my daily routine,
wanting to walk was my dream.
Day by Day I am getting stronger,
But days of therapy are no longer.
In my daughter's wedding I will be,
Matron of Honor,
and an honor that will be.
Walking on my own that day,
Is my dream that I pray.
So as I sit here and wonder why,
I hold back the tears that I might cry.

~ Bonnie Sue Rebuck

I am the mother of a child diagnosed with TRANSVERSE MYELITIS (TM) and I would like to share my experience with you and other parents of children with TM. I recently received my first newsletter from TMA by way of my father, who recently contacted you for some information on the association. I was touched by the stories shared by others and tearful over the suffering my baby endured during his ordeal.

You see, my son was 7 months old when he was diagnosed with TM. He could not tell me what hurt where or how much. I thank God for my "mother's instinct".

My son, Dillon Lee Richards, was born June 25, 1997. He was 7-½ weeks premature and weighed 5lbs 7 oz. He was healthy as a horse and slept through the night at 4 weeks of age. He only cried when hungry. He was smart, active and an angel!

On Thursday, February 5, 1998, we began our day like any other, only I noticed he was unusually fussy. He didn't seem to have any cold symptoms and he ate a good breakfast, so I chalked it up to a "bad mood". Throughout the day he became lethargic and extremely whiney. By dinnertime I was becoming increasingly concerned. His father, Darryl, came home from work and agreed that Dillon was "not right". We phoned our pediatrician who said that as long as he was eating and not running a fever, vomiting or having diarrhea, we shouldn't panic. He said Dillon could have an ear infection or is cutting teeth.

Dillon Lee Richards
Hilliard Florida

I remained by my son through the night, checking his temperature and basically worrying, as he cried out in his sleep. Darryl got up at 5:30 AM to go to work, at which point Dillon's temperature began to rise. I then called the pediatrician again, and was told to bring him at 8:00 AM that morning. I made him a bottle and immediately noticed that he was unable to hold it himself, a skill he'd mastered several months previous. He was moaning. I bent over him and begged him to "touch mommy's face" or "pull mommy's hair", as he so loved to do. He simply stared at me, his right arm drawn up to his chest, his left arm stiff at his side.

A wave of panic swept over me and I called "911". When the paramedics arrived, his temperature was 104° and his breathing labored. They life flighted Dillon to University Hospital in Jacksonville, Florida, a well known trauma hospital and home to many residents and doctors in training. I was forced to drive the 50-minute drive alone, as they refused to let me accompany Dillon on the helicopter.

My parents and Darryl arrived at the hospital before I did. When I saw my son lying on that emergency room table, I knew we were close to losing him. I had told the medics and the "911" operator that I suspected Spinal Meningitis, an illness I had experienced first hand at the age of 15. The doctors in the emergency room were milling about, most of them residents, trying to determine where to begin in reaching a diagnosis. By 12:00 PM Friday, February 6th, they had done a CT Scan and had taken him into x-ray twice. Dillon's breathing was becoming increasingly labored and he wasn't moving a muscle.

Frustrated and scared, I finally demanded they do a spinal tap because I knew he didn't have anything wrong with his bones. They agreed and then made arrangements for a room in ICU. Upon arriving at the room, I noticed that we were directly in front of the nurse's station and was somewhat thankful to have them so close. As we settled in the room, I also noticed that there were cameras in our room and that our room was the only room in ICU being monitored. I still didn't catch on.

That evening, the doctor arrived to give us what we had hoped would be a diagnosis. He began questioning Darryl and I about the previous day's

events, wanting to know if Dillon had been dropped, hit or picked up by his arms… and it hit me…they suspected abuse. I became angry and frightened all at once. I was an at-home mother who's life revolved around her child. I knew there had been no physical abuse. It also dawned on me that they had been running him back and forth to x-ray and doing every test possible to prove physical abuse instead of finding the source of the problem. I was fearful my son would die, and that if he didn't, HRS would step in and take him from me.

The doctor said Dillon had "nurse-maid's" elbow and that they thought an infection had set in as a result, causing high fever and paralysis. I became irate and told the doctor that I knew he was wrong, that I suspected meningitis.

That night, our first night in the hospital, I held my son in my arms and rocked him, all the while being watched closely by the nurses and cameras. I was afraid, tired and frustrated at the obvious steady decline of my son's health. At some point a nurse came in and told me that the spinal tap had not revealed meningitis, however the protein levels in the fluid were suggestive of some other problem. They had a neurologist arriving at 8:00 AM the following morning from the local children's hospital.

When the neurologist, Dr. William Turk, arrived, he began examining Dillon. He seemed worried, and after 10 minutes of thoroughly examining Dillon, he told me to begin gathering our belongings because he would have an ambulance arriving to take Dillon and I to the ICU at Wolfson's Children's Hospital just down the road. He told me that Dillon did not have "nurse-maid's" elbow and that he was scheduling Dillon for a MRI.

As promised, we were taken to Wolfson's Children's Hospital where we waited several hours for the MRI, as it was Saturday and a radiologist had to be called in. They put Dillon on a feeding tube, a breathing tube, antibiotics and other monitoring equipment.

I was exhausted and petrified, but at least I felt as if my son was getting the treatment that he needed. About 10:30 PM that night, Dr Turk arrived and told us that the MRI confirmed Transverse Myelitis (TM). We had never heard of it. He gave Dillon a 30% chance of surviving the next 72 hours because the disease had paralyzed him from the chin down and there was already some brain swelling. He said that if Dillon did survive, there was only a 40% chance he'd recover use of his arms and legs. His breathing was labored, but they wanted to keep him off of a respirator, if possible. They began steroid treatment to combat the swelling and hoped the steroids would work before he was unable to breathe on his own.

That night was the worst night of my life. The doctors told me to go home and get myself some belongings. They told me to get things of Dillon's that would make him feel more comfortable, as he would be staying in the hospital a while. He said it would be a "biblical event" if Dillon were out of ICU in less than two weeks. I didn't want to leave him, but Dr. Turk insisted that he wouldn't let me stay in the room with Dillon because I had already been up with him for two days. Walking out of that room and leaving my son with my sister and mother in that hospital was the hardest thing I ever had to do.

We went home and gathered my things and Dillon's and tried to get a couple of hours sleep. We were up again at 5:00 AM and ready to get back to our son. I walked out of Dillon's nursery with a bag full of toys and clothes and pictures…when I saw a plaque hanging from the wall that I'd received as a shower gift. It read:

Now I lay me down to sleep, I pray the Lord my soul to keep, watch me safely through the night and wake me with the morning light.

That plaque remained above Dillon's hospital bed for the duration of our visit.

Dillon's recovery was underway. Within five days he was released from ICU and moved to a regular room where he remained for eight days. He was released from the hospital one day shy of two weeks and he had already begun to move his arms and head.

Dillon will be three years old June 25th. At 2 ½ years old, he is still unable to walk, however, he attends two sessions each of speech, physical and occupational therapy per week, in addition to his specialist's appointments. He has recently tested at age level in his fine motor skills, with some problems, but some advanced skills. He has an above average vocabulary with his only speech problem being the inability to pronounce certain sounds properly due to a weakness in his tongue. He is "socially" advanced for his age and has a delightful and determined personality. He has recently taken his first steps with the use of a walker and has become good enough at it that we were able to get approval to order one for home use.

The opthamologist said there were no long-term effects on his eyes, although the disease could cause gradual blindness. The urologist says he'll be able to control his bladder and

bowels normally. Dr. Turk has warned me to be "cautiously optimistic" and that Dillon is writing his "own book" in his recovery.

In two years time we have been told Dillon would never walk; then he'd never walk fast; that he'd never run; and now they are shrugging their shoulders and letting **him** decide what he's going to do.

The past two years have been emotionally draining and rewarding. I am so proud of my son's determination and I feel so lucky that the right doctor was able to make the correct diagnosis.

We have a long way to go in his recovery, however we feel blessed to have come this far. Since the ordeal, I have often wondered what would have happened had Dillon's neurologist not been well informed of TM and I wonder how many children have been mis-diagnosed as a result of uninformed physicians. How many parents have been blamed for symptoms related to this little-known disease? What can I do to educate people?

I would be interested to hear from any parents of children with TM, as I have never spoken to anyone who has the disease or is even remotely familiar with it. I would also be curious to know how many children this disease affects each year and what the youngest known age of onset is.

I can be contacted at:
(904) 845-1196. Correspondence can be sent to:
Candace Courson
RR1 Box 1895
Hilliard, FL 32046
As one of the minority of TM sufferers who experiences recurring episodes, I hope my story helps others.

I had been in the Parachute Regiment for eight years prior to working as a deep-sea fisherman and suffered from back problems as a result of a parachuting accident in 1968. But nothing prepared me for the devastating effects of TM.

It was 3 June 1988 and I was painting the cabin of the fishing boat on which I worked, when I suddenly felt a pain in my right leg and it began to feel numb. I had visited my doctor a week earlier complaining of cramp-like pain in my right leg, which he thought was caused by circulatory problems. But the cramps had gone and on that particular Friday morning, there had been no pain at all. The numb feeling in my leg got so bad that I knew I had to get off the boat quickly. I found someone to drive me home. By this time my right leg was completely useless and I literally crawled upstairs on my hands and knees to bed and called my doctor. Within three hours the numbness had spread throughout the whole of my lower half. My doctor couldn't find a pulse in my right foot and I was rushed to hospital by ambulance. By now the pain in my right side was so bad, I was punching the sides of the ambulance (and to think a doctor had once told me I had an exceptionally high pain threshold!).

The following day, I was transferred to a more specialised hospital in Edinburgh for tests, which included a lumbar puncture, two myelograms,

Sandy Smith
Scotland UK
mmsmith@freenet.co.uk

and a CT scan but the doctors could find nothing wrong. I was given steroids for the first week, which is still a bit hazy. During that first week, I had absolutely no control over my lower half. My right leg was totally paralysed but my left leg was liable to shoot out and kick whoever sat on that side of my bed. My wife and sons bullied me into concentrating every ounce of energy into making my toes move and when my big toe finally moved about a ½ inch, I had to be propped up to see it move as I couldn't feel anything and wouldn't believe them. From then on we were all determined I would walk again.

The next few months were spent doing intensive physiotherapy. As movement gradually returned to my legs, I had muscle spasms so fierce I was yanked out of bed at three o'clock one morning, pins and needles in my legs, and then several months of the weirdest sensations imaginable. For days on end my legs would feel like wet concrete setting, then for no reason my whole bottom half felt like it was encased in broken glass. There were times when any movement made the inside of my legs feel like a wet cloth being very tightly twisted or my feet felt like big sponges. Sounds crazy, I know, but I felt these sensations even though I was completely numb. It was extremely uncomfortable.

I think that during this period, all my energy was taken up with coping with what was happening to my body so I had no interest in anything or anybody. Fits of depression were common place and I would slink off to my room and talk to no one for possibly a week at a stretch. Then came what was probably the worst time of all when I was hit with bouts of white hot pain, mostly in my right side and leg, lasting for up to 20/25 minutes and which caused me to black out. The strange thing was, when I regained consciousness, the pain had always gone. This was when my Physiotherapists refused to treat me as 'they couldn't cope with the pain I was having' so it was back to hospital for an-

other month but still no answers. Electrical tests showed that the nerves from my brain to my feet were intact but something appeared to be stopping the messages getting through. No one could explain why.
It was around this time (six months later) that the words Transverse Myelitis appeared on a Medical Insurance Certificate. We asked what it was and were told it meant nothing really. It was simply an expression used by doctors when there was inflammation in the spinal column and no one knew why. We were to spend the next eleven years thinking this!

By February 1989 I was able to drag myself along with elbow crutches. A consultant then told me I would probably never walk and would always have to live with that pain. I went home and cried but I hadn't reckoned on my wife's stubborn determination. She decided that if there was something there that was bad enough to stop me walking, the doctors should have found it and if they didn't, she was determined I would walk again and nothing was going to alter that. We decided not to tell our family but just to say that the doctors hadn't painted a rosy picture. We didn't go into detail and thankfully they didn't ask.

We found a private clinic and mercifully acupuncture reduced the pain levels to a more manageable level so that I no longer passed out. I still had no feeling in my lower half but with endless exercise, I slowly began to walk. I spent hours trying to walk to the beat of singing nursery rhymes and this helped improve my co-ordination. I progressed to using a personal cassette player thinking that while I attempted to walk in time to the beat, the music would take my mind off my legs. It helped. Not content with walking indoors, my wife insisted on taking me out for a walk every single day. Sometimes I could only manage to the bottom of the garden path but we both felt it was important to walk outside as this helped my confidence as well as my ability to walk. There were still times when I found it difficult to make my legs work and was forced to lie in bed for several days at a time.

My first major relapse came in 1994. I just couldn't move my legs at all and my back felt like a block of wood. My doctor couldn't believe it when he ran his pen across the sole of my left foot and instead of my toes reacting, my hip joint rotated and my foot turned inwards; something he'd never seen or heard of before. Back to the hospital again but this time a very high dose of steroids had me on my feet within a week. I continue to have periods where, for several days, my back seizes up which prevents my legs from working but steroids and bed rest usually gets me mobile again. I attend a chronic pain management clinic and acupuncture helps keep the pain at a manageable level. And like other TM sufferers, I endure problems with bowel and bladder. There is still no feeling in my lower half, except for pain, which means when I sit in a chair, my top half feels like it is floating. But no feeling doesn't mean no movement, so I can walk for short distances.

I was back in the hospital after a fairly major relapse in October 1999 when a young doctor asked me to be his 'test' case. Because this condition is so rare, I appeared before about 30 senior consultants. A chance remark by this young doctor resulted in us finding the TM Association on the Internet and for the first time in 11 ½ years, I realised that TM is a recognised condition and that other people suffer from it. The relief is indescribable. I have had a long telephone conversation with another sufferer in Scotland so have proved your statement 'we are not alone'.

My consultants don't think that my parachuting accident had anything to do with my TM but I do, and nothing will sway me from that thought. I feel as if I have been to hell and back, especially during the first year, but the important word is back. I came back from hell and with the help and support of my family, I live an active life. Our sense of humour helped us through the 'black' times and I now drive a car with hand controls and do voluntary work helping other disabled people. The best advice I can give is to concentrate on what you ***can*** do and try not to think of what you can't. If you're lucky like me, you might find you have abilities you would never have known about.

My son once said, 'If you're doing a jigsaw puzzle and there's a piece missing, you won't complete the puzzle. TM is a puzzle, and the doctors need to have all the information available if they're to have any chance of solving the puzzle'. I would like to wish the TMA continued success, so please keep the information coming. Before I sign off, I would like to say to my fellow sufferers, if you look around, you will always find someone in a worse condition than you. You will laugh and you will cry, but if you persevere, you will get there in the end.

One afternoon in 1972, when I was 11, while playing in the backyard, a pain began in my right side/back. I thought I had just pulled a muscle, but as the pain intensified, I came inside. When my mom got home from work and saw how much pain I was in, we both assumed I had pulled a muscle in my back. So she called our chiropractor. By the time we got there (about an hour later), I was completely paralyzed from the waist down. He

tried to take a few x-rays, but needless to say, he wasn't going to touch me with such symptoms! An ambulance took me to a hospital that my parents did not care for, but they had no choice in the matter. At the emergency room, they performed a few simple tests (reflexes, temperature, sticking me with a pin, etc.) but could find nothing abnormal. They began questioning my parents as to whether they beat me a lot. One nurse realized I really couldn't feel anything below the waist and tried to convince the doctor to look at me again, but they sent me home.

So off my parents go with a paralyzed child! They had to get the next door neighbor to carry me upstairs to my room! My parents knew the diagnosis was ridiculous, but weren't sure what to do. The next morning they contacted my pediatrician and he sent us to a different hospital. The doctors at that emergency room assured my parents that they would get to the bottom of things and find out what was wrong. They did more extensive tests, a spinal tap and mylogram. Again, everything was normal. They reported back, "Well, we might just have to consider the possibility that her paralysis is psychosomatic." Even the nurses thought I was pretending since sometimes my foot would jump as an involuntary reflex, for example. They didn't send me home, but for about four days I just laid in the hospital bed. Finally, five days into the ordeal, a neurologist made the "assumed" diagnosis of TM; this being based on my symptoms and not on any given test. They didn't have MRI's in 1972.

Janice A. Yoder
Lusby Maryland

The doctors told my parents they had no idea as to how much recovery, if any, I would have, and that very likely I might never walk again. The neurologist felt it best that I be "institutionalized" since he felt there was no way my parents could care for me. No rehab was suggested. The doctor said all they could do was give me nursing care. My mother insisted that she could do that at home, and eventually arrangements were made for a hospital bed, wheelchair, etc. About a week later, I came home.

Our small living room was turned into a makeshift bedroom for me. The chiropractor began visiting almost immediately and we really believe his manipulations helped. He was such a kind man. I think that in his heart he believed I could be completely cured. That didn't happen, but I did make excellent progress (considering I might never walk again). I give my mother credit for teaching me to cope with my changed circumstances. She taught me not to give in to self-pity, but to get out and about with people and lead as normal a life as possible. Around the home, as I was able, I was expected to do small chores. A year after the onset of TM, I was back in public school, although at first in a wheelchair. Each year as I became stronger I used it less and less, until eventually I walked around all day on crutches. I was never teased at school. I don't know if it's because the children knew me from before TM or what, but I got along fine with everyone.

Today, I get around with the aid of one forearm crutch. There is permanent nerve damage to the legs and, of course, the usual bladder and bowel difficulties that come with this illness. Interestingly, except for the initial onset, I've never been in any pain as a direct result of TM. A few years ago, however, the mild scoliosis I'd had for years turned severe, and that created some lower back pain. However, I've had success using magnetic therapy and chiropractic treatments to manage the symptoms associated with the scoliosis and to date have kept surgery at bay.

I lead a very active life – I drive, swim, horseback ride, etc. I often say I do most things other folks do, it just takes me a little longer. And I'd say I'm mentally well adjusted (although some may question that!) In 1991 I married Carl, my loving and supportive husband. By choice we have no children, but our lives are active and rewarding. My faith in my heavenly Father and His promises have been a tremendous source of comfort and strength to me through the years. I am in no way bitter. Sometimes we say, "Why me?" My feeling is, "Why not me?"

I have found it interesting to watch how people react to my disability. When they first meet me they notice my crutch, and they're very conscious to offer assistance when needed. But after a while they kind of lose sight of that. I'm just another person – not a *disabled* person. How many times I've pulled into a handicapped parking space and a friend will say, "We can't park here. This is for the disabled." And then after a brief pause, "Oh, I forgot!" That truly warms my heart and I consider it a compliment.

I recently asked my husband to check the Internet to see if there was any information on it about TM. What a surprise to find there's an Association! This is the first time I've heard anyone else's experiences with TM. I don't know how much assistance I can be to anyone since my illness occurred so many years ago, but I'm happy to help in any way I can. I'd like to extend my thanks and

appreciation to all the hard-working individuals working with the Association. You're making a valuable contribution to the lives of many.

Hi, my name is Pamela Schechter and I have undertaken the role as coordinator of local TM support groups on the national and international level. In that capacity, I have been asked to write a column for the newsletter which will assist members in starting support groups in their communities and will provide suggestions for ways to increase participation and offer support to people with TM.

I consider my role as coordinator of local TM support groups a natural progression of all the volunteer work that I have done for the past thirteen years in my local community. I have always believed that volunteering and volunteers play a vital and viable role in maintaining the quality and character of the areas in which we live. I have discovered that volunteering can act as an antidote to stress and depression. About thirteen years ago, imperceptibly and steadily, the desire to do community work for these reasons, became a reality for me. I joined a newly formed substance abuse community organization. I would see the advantage of devoting my spare time and energy to a group with a common purpose. I eventually became Outreach Manager for the agency. During this time, I attended Queens College in Flushing, NY where I received an undergraduate degree and later a Master's degree in Public Administration.

In 1996, my life changed irrevocably when I was diagnosed with TM, and in my case, caused by Lupus. Lupus is an auto-immune condition which can attack any organ, cell or system of the body. Because of motor and sensory loss, I could no longer walk

TM Support Groups

A Message About Support Groups
Pamela Schechter

in a normal fashion. I now had to rely on a cane to balance myself when walking or even standing. With prolonged and proper treatment, I have regained some balance and a more normal walking gait. Since then, I have joined The Transverse Myelitis Association and the Lupus Foundation of America [Long Island /Queens Chapter]. I have expanded my volunteer work to include both these organizations. At the time of my diagnosis, Lupus was a well-known disease, recognized by most people. But when I disclosed to those concerned about my condition, including family, friends, neighbors, etc., it was unanimous, not one of them had ever heard of TM. I encountered a wall of total ignorance about the disorder.

At first I was dismayed and a little hesitant about explaining TM, because I did not know too much about it. After several visits to my local library's computer site, I became familiar with most of the information and details about TM. This proved to be therapeutic for me because I could now adequately explain the syndrome to all and sundry. The knowledge eased my own fears and anxiety about my condition. It was also at this time that I recognized within myself some important needs and desires. As noted, I have a strong commitment to volunteer work. I had a desire to bring education and awareness about TM to the public's attention. I had an interest in meeting others who have been diagnosed with TM, and wanted to create the opportunity for people with TM to meet each other and to facilitate the exchange of information about symptoms and treatments, medical referrals, and coping mechanisms. I decided in several ways to achieve these goals.

I successfully lobbied my local assemblyman, Brian McLaughlin, who had the state legislature of New York declare June 6th 1999 the first **Transverse Myelitis Awareness Day**. To celebrate that occasion, I thought it would be a splendid idea for TM members in New York to hold a luncheon/support group meeting. I contacted my local diner, a place I go to bi-monthly for my lupus support group meetings, and reserved space in a private room. This undertaking was a very informal effort on my part as I sent out hand-written invitations and directions to the diner. The response to the invitations was most gratifying as 25 people came to the luncheon, far exceeding my initial expectations. The favorable comments from members about the luncheon spurred my determination to plan further meetings. I had the pleasure of writing about the first luncheon/ support group meeting that appeared in the TMA newsletter. I have hopes that this article prompted interest by other members in other states to start their own groups if they have not already done so.

There is a vital need for TM support groups. After four successful meetings, I am convinced that members who attend experience a more hopeful and positive attitude about their illness. There is a mutual sharing of life with TM, fostered by a

common purpose and group bonding that may not occur anywhere else. Briefly, support groups serve many important purposes. Through the support groups people can assist each other by offering information about doctors, medical facilities, and therapists in their vicinity who have some experience with TM. They can share and exchange information about services and entitlements that state or local government agencies may offer to those disabled by the disease. Support group participants can share information they have become aware of regarding current research and new treatments. Support groups provide a forum for members to share their own personal experiences with their condition and how they cope with TM; and to offer support and help to caregivers and family members who have questions and concerns about TM. In future articles in the newsletter, I will use this column to offer suggestions and strategies for these many important purposes of support groups.

I wish to help and encourage others to start their own support groups; to offer assistance in deciding what they hope to accomplish; how to run a support group, to offer information and literature about support groups and to act as a conduit for new ideas and suggestions from members. If you are interested in starting your own local and regional support group and need help in getting started, please call me at area code 1-718-762-8463 or write to: Pam Schechter, Coordinator, TM Support Groups, 41-10 Bowne Street , Apt.7m, Flushing, NY 11355. My e-mail address is PamIam6@Juno.Com.

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.

Beginning in September, a race car driver by the name of Ken Smith contacted the TMA after seeing the CBS 48 Hours show featuring young Cody Unser and her struggles after her diagnosis of TM. Ken felt compelled to get involved in some way to promote awareness of TM and with his connections in the racing community was able to set up racing events throughout the country. The first of these events was going to be held at Irwindale Raceway in Irwindale, California on Thanksgiving Day.

Through the communications with Ken, the people at Irwindale Raceway graciously offered a substantial discount admission to all TMA members who wished to attend this event, making it a great opportunity to meet others with TM. There was a small group of us that attended the races, and it was really exciting to watch. The sports cable channel, ESPN, taped the race, and Cody Unser and her mother, Shelley, were there to make sure that the public learned about TM. We all had the opportunity to meet this adorable, happy girl with such a contagious upbeat attitude. Shelley is backing up Cody with her wishes to dedicate her life to raising research funding along with awareness of TM through Cody's First Step Foundation. We all know what Cody is living with day to day, and to see the energy that she is putting forth is inspiring.

The most rewarding part of the day, for me, was being able to meet with the small group of TMA members that came for the races. Our personal sharing of experiences, both humorous and emotional, brought us close together. Thanksgiving has always been a time that our entire family gets together and has a big turkey dinner with all the trimmings. This year we had the opportunity to get together with our **TM family**, thanks to the people at Irwindale Raceway and to Ken Smith.

California TM Support: Irwindale Raceway, Thanksgiving Day, 2000
Deborah Capen

A big thank you goes to all of you who came and shared that day with my husband, Michael, and myself.

*And a very special **thank you** to Debbie and Michael who sacrificed their Thanksgiving with their family to organize the meeting of the Southern California TMA members.*

I attended a Disability Federation of Ireland (DFI) meeting, hoping to hear some good news from the budget that the Government had resolved December 6th. Nothing much has changed; we did get allowed £6 million to be shared between all the disabilities, physical and sensory. These funds also have to cover Home Care Attendants, Day Care Centres, Personal Assistants, and Home Helps. So, by the time it is shared, there will not be much for each section. This will all be coming through the Health Boards, at their discretion. The money for the Independent Living Centres has come from the Government through the Health Boards throughout Southern Ireland. The money is made available through the Independent Living Centres around Ireland to facilitate the continued work of providing Personal Assistants for all people with disabilities.
I am in the process of trying to secure funding from the Independent Living Group to cover the costs of postage and telephone. I have nothing secure on that yet. I have also applied to our

local Health Board for the same funding; we have to apply through the Health Boards. I received a letter from them late last year to say that I was not able to avail of this funding last year, but to apply again this year. We do have a meeting planned for early February. But I will not know the outcome for a few months.

We have secured an amount of £45,000 to perform a detailed study and implementation plan for Transport in Rural Areas for ours and one other county. The study and planning period is from last October up until next June. We have to establish a service and put it into place. We are looking to both the private and public sector to be involved. While doing this work, it will also help to create awareness of disability and the services that are not currently available to the disability community.

TM Support Group of Ireland
Ann Moran
annmoran99@yahoo.com

I have been in touch with many of the people who contacted me about the TM Support Group of Ireland. I am trying to arrange a meeting for us this year.

I made a wonderful trip to California this year. I would like to say a huge **thank you** to Debbie and Michael, and Lori and John for having me. It was really interesting meeting them. Also meeting with Kris and Kaycie and Mary Ellen. We had a great dinner in Los Angles the evening I was returning to Ireland. It was great to talk to everyone; a little Seattle Symposium - LOL! Debbie was so good; she showed me many of the surrounding interesting sights, and introduced me to her family. I will remember it all for a long, long time. My family was amused when I told them, it was so **hot** the day we were to have a barbecue, we had to have it inside. In Ireland we have to have them inside, because it's **raining**! Yes, even in the summer. I also met up with Cindy Mcleroy at Debbie's. I was sorry that I was not able to meet up with Jane and Mike Hammond in Seattle. After the fun I had trying to get into Debbie and Michael's van at the Los Angeles airport, it might have been a good idea that I didn't try to get into your van. Hopefully, next time.

Finally, a note on **The Quilt** for those who are interested in how it's coming along. Well, it's at the quilting stage. I am working on it as often as I can. I have a problem with one of my eyes. We suspect the start of cataracts, which means I can only sew during the daylight hours. It is very difficult for me so see clearly at nighttime in artificial light. But I do hope to have the quilt finished very soon. Then we must sort out how to auction it or raffle it. I will have it photographed and put on the TMA site for all to see.

On November 11th, 2000, we assembled again at Ben's Deli and Restaurant at the Bay Terrace Shopping Mall in Bayside, Queens for the fourth luncheon and support group meeting for the members of the New York TM Support Group. Twenty-six persons, including members, their families and friends from various parts of New York State and New Jersey, attended. As before, I had reserved use of a private room available to us from 12 noon until 4 PM. For this occasion, the restaurant provided us with individually served meals, which consisted of soup, sandwich and desert.

After we finished the eating, I made some important introductory remarks including information about the upcoming Transverse Myelitis Symposium to be held on July 12 - 15th, 2001, at the Holiday Inn, at the Inner Harbor in downtown Baltimore, Maryland. I also discussed the possibility of starting a TM satellite clinic in New York City, staffed by doctors from Johns Hopkins, who would commute from Baltimore to New York City about every 10-12 weeks. This proposal elicited an enthusiastic response from the members, because the clinic would be conveniently located for most of the tri-state members.

Hope Klopchin, who is a fifth year Ph.D. candidate in counseling psychology, led the support group discussion. She is currently interning at Long Island Jewish Medical Center. Ms. Klopchin opened the discussion by telling us something about her background, including her academic credentials. Most significant was that she has TM, contracted when she was 12 years old. She explained about her ordeal with the disorder and that it took her approximately six years to fully recover. After her recovery, she assiduously pursued an academic and then professional career and now is completing her doctorate at the State University at Buffalo, NY.

Fourth Meeting of the New York Transverse Myletitis Support Group
Pam Schechter

One of her main themes focused on the physical and emotional reclaiming of yourself after a serious illness. At some point, members joined in the general discussion with personal observations and experiences with TM. One member told of her trip to the Johns Hopkins Transverse

Myelopathy Center where she was examined and evaluated by the doctors at the clinic. Dr. Douglas Kerr is personally supervising her treatment in collaboration with her local doctor. Another member cautioned about taking new drugs without thoroughly researching its effects on TM. She told us about taking Zocor, a drug used to lower her cholesterol, and how it caused extreme muscle weakness. Her doctor, at one point, diagnosed her with Multiple Sclerosis. When she stopped taking the drug, the weakness abated and she felt much better.

Another member spoke of how depressed and helpless she felt after her diagnosis. It was suggested that she seek professional counseling to alleviate her depression and anxiety. Many members discussed the effects of having Transverse Myelitis on their families and how encouraging it has been to receive the support and help from their children and spouses. Ms. Klopchin ended the meeting by discussing the possibility that TM, like all chronic diseases, can lead to moderate or severe neurological deficits. These deficits may cause depression and anxiety, but if recognized [she listed common symptoms associated with depression] can be effectively treated by mental health providers.

The general consensus from the members was that the discussions were productive, informative and helpful in coping with Transverse Myelitis. All the members and I wish to thank Ms. Klopchin for the thoughtful and professional manner in which she conducted the support group meeting. We wish her well in her career plans and hope she will come back to lead a future luncheon and support group meeting.

Molweni! Greetings from vibrant South Africa; the lively hub of Africa! My name is Tanishka du Plessis and I am a 26-year-old female residing in East London in the Eastern Cape province of South Africa. I was diagnosed with TM in March 1999 after developing paralysis at T8 level within approximately ten hours of the onset of excruciating backache and stomach pains. My health has had its ups and downs during the past ten years. In 1991 I contracted Crohn's disease (an auto-immune disease affecting the bowel area) that led to a resection of my ascending colon, ileum and sections of small intestine. Last year, aside from being diagnosed with TM, I was also informed that I have anti-phoslipid syndrome and osteo-arthritis.

My story of recovery from TM is similar to that of many others: after 4 months of painful and intense therapy, I gained enough strength in my legs to start walking with the aid of crutches. Today I walk with the aid of just one crutch, as I tend to unexpectedly lose my balance and have difficulty walking on uneven surfaces. I do not have 'normal' feeling in my legs, have constant backache, poor bladder and bowel control and yet despite all this, I find so many reasons to smile and continue smiling. My life has been blessed over and over!

Anyone living with TM or any other debilitating illness, can give an account of the numerous physical and emotional challenges faced on a daily basis. There are often days when depression rears its ugly head, yet by the grace of G-d I sustain enough strength to prevent depression overshadowing my life. My friends have told me that they consider me to be so strong to have coped as well as I have. I truly believe that I am no stronger or

TM Support Group of South Africa
Tanishka du Plessis
tanishkaduplessis@hotmail.com

wiser than anyone else I have met! I believe that inner strength is a unique human
quality that can be found within everyone. It is a strength that forms part of the core of any human being and is a force that prevails, regardless of how bleak the situation might appear to be! I thank G-d that I am aware of the power of my inner strength and that I have been able to continue using it in a positive manner. TM is part of my life – there is no denying that! It affects my body and limits my physical ability, but in no way has it affected or limited my soul or spirit. It has, in fact, enriched my life, by allowing me to focus on the many positive aspects of my life. I have life, I have a good life – and I am eternally grateful for that!

My life experiences have helped to shape my positive mindset. I grew up in a childrens' home where I had to learn at an early age not only how to fend for myself, but also to understand that life is about facing challenges head-on and using such challenges in a positive manner. The reality of life is that every single one of us will have to face difficult challenges throughout our lives. The onus lies on us to realize and understand that every challenge can teach us a valuable lesson. I know that it is my attitude towards life that will ultimately determine the quality of my life.

Last year while in the hospital, I made the following four promises to myself: (a) that I would never give up during the physiotherapy sessions, (b) that I would go back to work if I recovered, (c) that I would get my driver's license and (d) that I would create awareness about TM and be there for

others who had TM. I have by the grace of G-d managed to do the first three and am currently working on establishing a support group in South Africa. I contacted Sandy Siegel a couple of months ago with the idea of establishing a support group in SA. Through his encouragement and wonderful help, I have made contact with four dynamic fellow South Africans living with TM. The response that I have received from these South Africans has been incredibly encouraging. We are all so keen to kick-start a support group and be of help to others living with TM.

The South African support group will uphold the vision of TMA by providing support and creating awareness about TM and the TMA. There is a general consensus among us that there is definitely not enough information available about TM in South Africa.

To get the ball rolling, I wrote letters to relevant South African medical research units, neurologists and medical departments of universities to inform these stakeholders of TMA (especially regarding the symposium in Baltimore) and the aim of the South African support group. I was also requested by Sandy to assist in establishing a network between neurologists in SA and Dr. Kerr from the John Hopkins Centre. So far, the responses are slowly filtering in, but the important thing is that there are medical experts who have shown an interest in getting involved. There is still a great deal of work that lies ahead of the South African support group. I am trying to compile information about South Africans living with TM and am looking at ways to raise funds to send at least one representative to the symposium.

There is so much that we can do if we commit ourselves to becoming actively involved and stand together to make a concrete difference in someone else's life. My TM experience has made me aware of the many dilemmas faced by disabled people including problems gaining access to buildings. In South Africa, there are many hardworking organisations such as the Rehabilitation for Persons with Disabilities who have access committees to investigate and advise companies/organisations on how to make their buildings more accessible to disabled people. I recently started a petition against my employer (the provincial legislature) to make the building more accessible as there are three levels with no lift facility or wheelchair ramps. The current structure of the Legislature makes it impossible for the disabled (and extremely difficult for the elderly) to access the public galleries and venues for committee meetings. I circulated the petition to many organisations for the disabled and was completely overwhelmed with the support it received. Every single signature penned on the petition contributed to creating a sense of awareness and the Legislature has since started obtaining quotations to have the building revamped. So, every little bit we contribute, no matter how small, can be the catalyst for bringing about change.

We should never underestimate the power of love and the power of giving. During my illness, my fiancée and his family, my close friends and colleagues showered me with incredible support and love. It spurred me on to live and to strive to be of help to those in need. As the saying goes: "We are not here to see through each other, but to see each other through." So, lastly, watch out world… the South African support group is here to stay!

The following section of the newsletter presents a number of important fundraising activities that are currently underway or are being introduced with this publication of the TMA Newsletter. As you will read, our members and our friends are finding some very interesting ways to raise funds for TM research and for the TMA. We are really excited about all of the activity going on which also raises awareness in the public about TM. We hope that you will take this great opportunity to become involved in one or more of these efforts.

With this presentation of the fundraising events, it offers me the opportunity to share some information about the TMA's involvement in these projects, as well as some additional information about contributions to the Association. There have been families who have approached the TMA and have asked to make donations which they would like to have support the Johns Hopkins Transverse Myelopathy Center. When a donation is made to the TMA specifying that these contributions be sent to the JHTMC; we make that contribution to Johns Hopkins in the name of the person or family who has made the donation. If a donation is made to the TMA for the purpose of TM research, those funds are deposited into the TMA Endowment Fund; the purpose of this fund is exclusively to support TM research. When a donation is made to the TMA without a specification, those funds are deposited into our operating account; the account which pays the TMA's operating expenses, the major portion of which covers the costs of education and outreach (the printing and mailing costs for our educational materials, membership directories and newsletters). We greatly appreciate your contributions to the TMA, and our great hope is that we will be able to expand our

Raising Funds and Awareness

Raising Money for TM Research and the TMA
Paula Lazzeri

services as we continue to grow, based on your very generous support. All of the donations described above are fully tax deductible.

Cathy Dorocak is the Chair of the Reading for Rachel Program. Cathy works with the board of the TMA to conduct the program. There are no TMA operating funds being used to implement or promote Reading for Rachel. All of the printing, mailing, and supply costs, as well as long distance bills associated with Reading for Rachel are being covered as out of pocket expenses by the people who believe in the program (to fund research to find a cure for TM). All of the Reading for Rachel donations are deposited into the TMA endowment fund. As noted, this fund has been set up for the exclusive purpose of funding TM research.

The TMA is regularly approached about fund raising ideas. We encourage people to get involved and to act on their ideas; and many have. The TMA does not have the resources to assist all of these efforts -- either financially or with manpower. What we can do is serve to solicit help for you and to get lots of people involved. You will see from the fundraising articles that this is precisely what we have been doing. We will write letters of support, we will facilitate networking, we will help you put promotional materials together, and we will provide you with information. And we will assist you by promoting your program in the newsletter.

People are raising funds for Cody's Firststep Foundation, for the Johns Hopkins Transverse Myelopathy Center and for the TMA. The TMA completely supports all of these efforts; we are a team working for the same goals. We all want to find a cure for TM! We want to share in Cody's first step, and Jim's and Rachel's. And until we find that cure; we want to find better treatments for the symptoms of TM, we want better education for physicians and healthcare workers who treat us, we want better information and education for ourselves, we want support and networking opportunities, and we want to bring greater awareness of TM to the general public. All of these efforts are worthy of your support. For those of you who contribute to the TMA and its goals, we are so humbly appreciative of that support.

The Reading for Rachel Program for the year 2001 is well underway. We have every hope that this year will be a really successful year for the program given our broader geographic appeal, improved web site, logo etc. We have been promoting the program in the months of January and February and the children will be reading their books for Rachel in March. It is not too late to get involved. If you are interested in participating in the program, you can download all of the materials you will need at our beautifully designed web site:

www.myelitis.org/ readingforrachel

You can also obtain the materials by contacting one of our regional coordinators:

Richard J. Boyle
4843 Westchester Drive 207
Youngstown OH 44515
(330) 797-9465
gunny0011@aol.com

Gayle Peltier
494 E Parkside
Hayden ID 83835
(208) 762-9381
npeltier@email.msn.com

If you are unable to participate this year, we would hope that you will consider getting involved next year. The Reading for Rachel Program Team spent most of the summer and fall preparing the materials, including our beautiful Reading for Rachel logo and bookmark. Now that this work is behind us, we plan on rolling out the program during the late summer months in coming years. Our plan is to approach schools either before the school year begins or shortly thereafter each year. We want to be certain that they consider the program before they have finalized their schedules/fundraisers for the school year.

Reading for Rachel
Cathy Dorocak

If you know teachers, principals, school administrators, PTA officers and members, librarians, or school board members, it is not too early to talk to them about the Reading for Rachel Program. Share with them your own experiences with TM, and help to educate them about the importance of finding a cure for this condition. *Every single dollar earned from the Reading for Rachel Program will be used for TM research*. The program is fun for children, and it creates a wonderful opportunity for children to be encouraged to read, and to spend time with their parents reading! Children can also learn some very important lessons about

disabilities and helping others. The Reading for Rachel Program is very easy to implement and administer. It is also an opportunity for children to work on the Internet by navigating, downloading and printing documents. They will also be able to see a video of Rachel in a variety of therapy settings so they can see whom they are helping! We encourage everyone to watch the 7-minute video, which can be found on the main page of our web site.

We are also hoping for worldwide involvement in the Reading for Rachel Program. We have learned very rapidly that TM knows no ethnic, racial or geopolitical boundaries. Since the very beginnings of The Transverse Myelitis Association, we have been making friends from every continent and country around the globe. It is our most fervent hope that treatment and cure research would benefit everyone who has TM, regardless of where they live. We encourage our members from everywhere in the world to get involved in Reading for Rachel.

Richard, Gayle and my husband Dan and I would like to thank Matthew and Kevin for being such wonderful brothers to Rachel and for thinking of such a great way to celebrate Rachel's birthday each year. We would like to thank everyone who has taken the time to promote the Reading for Rachel Program - every effort, both big and small is very appreciated. We would also like to thank Nic Niland for designing the wonderful logo and bookmark for the program. Finally, we would like to thank Jim Lubin for creating such a great web site for the Reading for Rachel Program. We have created a super Reading for Rachel Team, and we are hopeful for even bigger and better results in the future. Thank you all so much for your support!

Cathy Dorocak
Rachel's Mom
And National and International Chair of the Reading for Rachel Program
DMDOROCAK@msn.com
(440) 572-5574

Perseverance gives power to weakness, and opens to poverty the world's wealth. It spreads fertility over the barren landscape, and bids the choicest fruits and flowers spring up and flourish in the desert abode of thorns and briers.

~S. G. Goodrich

First, Learning About TM through A Friend

In the spring of 2000 I received a letter from Alica, a friend of mine from childhood, saying that she had been diagnosed with transverse myelitis. I had never heard of TM before, so I went online to see if I might learn more. That's when I found the TMIC list and realized, to my complete surprise, how TM often affects people -- and more people than I cared to comprehend. Immediately my heart was broken for Alica and anyone who might suffer the affects of TM in their lives.

My heart was not simply broken, however -- it was stolen. Immediately after writing to the list, people came forward and offered their encouragement for Alica. She has long since received everyone's best wishes and help, but I remained on the forum namely because of everyone's remarkable tenacity, perseverance, knowledge, friendliness, moral support and hope -- all of which are richly displayed in their lives. Unbeknownst to most, perhaps, I am simply grateful for how much my own life has been enriched ever since.

Inspired by TM Talent

Within this same time frame and after reading the last edition of the TMA newsletter, I was inspired by Netta Ganor's "Clouds" and "Seagulls" pictures that were printed with Sam Melville's poem, "A Thief In The Night." I thought there must surely be enough talent within the TM community to create greeting cards. I had hoped by doing so that we could generate funds for medical research at the Johns Hopkins Transverse Myelopathy Center. Sure enough, there is tremendous talent among those with TM. Thus, it is my privilege to introduce here the Transverse Myelitis Greeting and Note Cards.

Transverse Myelitis Greeting and Note Cards
(And A Request for Your Art Designs)
Karen Becker

TM Greeting and Note Cards

As I write this, the creation of the cards is still underway. However, for those of you who are not yet aware of this project, what we have asked others online, we are also asking you, TMA's readership: If you, a family member or close friend want to submit any number of original and quality artwork, photography, graphics, or verses, we are still accepting your submissions until June 1, 2001. We do have a printer for your original work, thanks to Jenna Stentz's father,

Duane Hamilton. All we ask is that you give us written permission to use them as greeting cards designs. We will accept your designs either on a zip disk, CD, or in the highest quality copy. Original designs are also accepted; however, anyone involved in the creation of the cards is not liable for damage to original work. We will return your designs upon request. To submit your work, along with a brief bio, please refer to the address listed at the end of this article. Feel free to send questions or comments also.

Card Quality

At this time, it is the printer's intention to print the cards in a four-color process, using standard fold, no foil. We are expecting to provide a brief bio of each person contributing his or her design. Also on the backs of the cards will be our greeting card logo. The cards will be pictured and orderable via a brochure, which is also designed to inform the public about TM and Dr. Kerr's medical research.

Our Goal and Logo

Graphic artist Karrie Bernhard designed the greeting card logo and brochure layout. Karrie quickly picked up on the original drawing of a blue flower sent to me several years ago by Alica. While the logo holds personal sentiment for a dear friend whose own TM eventually led to this endeavor, the blue flower conveys our hope that medical research and all attempts to fund those efforts, blossom and flourish beyond our greatest expectations -- all for the sake of finding a cure for those suffering TM and other spinal cord injuries.

All the proceeds from the card sales will go directly to the Johns Hopkins Transverse Myelopathy Center in support of Dr. Kerr's medical research. No one is compensated or reimbursed for their designs or efforts in this project.

Marketing

We have asked others online to help us distribute the card brochure and to refer people to our website where the cards may be viewed. A number of TM supporters are also going to link their website to ours, and vice versa. There are several people hoping to establish bulk sales of the cards within their own communities. In essence, while we are striving mightily to create quality cards, it will be a success insofar as we can sell them and in high quantities. For that reason, we are asking you also to consider distributing our brochures and establishing bulk sales in your area.

Contacting TM Greeting and Note Cards

You may contact me by writing or sending an e-mail to:

TM Greeting and Note Cards
P. O. Box 682
Arnold, MO 63010

E-mail: **tmcards@email.ky**

We also have a website for the cards which is currently under construction. At this time we are not able to take orders online; however, people may view the cards and send their order to the postal address listed above. Our cards online will, at the least, receive greater recognition, and hopefully that in itself will extend our funding efforts and encourage other TM supporters. Our website address is:

http://tmcards.freeyellow.com

The process of selecting the art and printing the cards will take approximately three to four months. We are anticipating that the cards will be available early this winter 2001.

Finally, thanks to everyone's talent, interest, expertise and support, the Transverse Myelitis Greeting and Note Cards is a unique hallmark for everyone with TM. Educating the public about transverse myelitis is as much a part of this endeavor as anything. These cards can make a strong statement for you in the public realm, and in a very practical way, besides.

Thank you in advance for your submissions and support in this endeavor!

The TMA is working with Dr. Kerr to conduct an auction fund-raiser. Richard Boyle (Gunny) and I are going to be coordinating this activity. The auction is going to raise funds for a clinical assistant to work for The Johns Hopkins Transverse Myelopathy Center and Dr. Kerr. This person, (a physician's assistant or nurse practitioner) would have

several roles. One, he or she would see patients with Dr. Kerr, thus increasing the care that would be given to patients. Two, this person would be a coordinator of TM care given to patients throughout the country. Once the TM network (Consortium) is established, the clinical assistant will coordinate care in the various centers, and will coordinate the collection of clinical, serologic and CSF data. This person will also field all calls; thus enhancing the ability to get back to patients more effectively. Finally, as the JHTMC begins clinical trials for TM patients, the clinical assistance would be responsible for getting this program off the ground and running smoothly. As you can see, the clinical assistant fills a critical need for the JHTMC that will enhance care to TM patients. This position also represents movement toward a cure for TM by facilitating the important research process.

Filling a position of this nature will take a serious commitment of dollars and a long-term commitment of the TMA to assist in raising funds to help in filling this position. We believe it is important and we have made a commitment to Dr. Kerr to assist in whatever way we can.

When we conduct the auction is going to depend on the response we get from our members to this important activity. We are counting on you to collect and donate the items we will auction. We would consider having part of this fund-raiser take place at the symposium.

We are asking TMA members to approach their famous celebrities/ sports stars in their area and ask them to donate an item to be auctioned off to the highest bidder. Such items might include an autographed baseball from a major league ballplayer, a signed portrait (be

TMA Auction: Raising Funds for A Clinical Assistant to *Help Us Help Ourselves!*
Lori Biehler

creative!) or other memorabilia (people would pay good money for a dimpled chad ballot from Palm Beach County, I bet). That item would then be placed on the auction block.

If there are others interested in working with me to organize the auction, please get in touch. This would mean promoting the auction, encouraging people to make donations of items, getting information about what has been collected, obtaining an auctioneer, and organizing the actual auction. We would open up the auction to the general public via E-bay or other Internet auctions.

If you are interested in getting involved in the Johns Hopkins/TMA auction, please get in touch:

You can reach me through email at **lostinwoods@earthlink.net** or my phone at (973) 726-5991.

Any funds that are donated to the Johns Hopkins Transverse Myelopathy Center are fully tax deductible.

Pauline and I are going to write a cookbook. My sons who have fond memories of my hot dog casserole will be rolling on the floor in wild hysteria when they read that line. *Okay, get up off of the floor, you two, and let me finish.* Actually, we are going to be asking all of **you**, the members of the TMA, to write this cookbook. And we want this to be so much more than a cookbook!

First, we would like for you to send us your favorite recipe. We would like for the recipes to reflect the wonderful diversity that exists in our TMA membership. Our members come from every one of the fifty United States, as well as from Puerto Rico and other territories. If your favorite recipe reflects the culture from your region of the country, please identify that for us. If your favorite recipe reflects your ethnic and/or racial heritage and traditions, please include that background for us. We also have members from all over the world and reflecting enormous cultural diversity. We need for you to send us your favorite recipes from your cultural traditions! Please be creative in writing your recipes. You may have specific ideas about how your dish should be served; include that information. We are all proud of who we are and the traditions in which we have been raised. Please feel free to embellish these recipes with your pride and your personalities.

If you make your favorite dishes as I make mine, we are going to ask you to make your recipe before you submit it to us, and really measure what you are putting into that bowl. Please use the traditional recipe style in your submission. Provide us the name of the dish and identify its origins (the regional and or ethnic or cultural source). Specify the ingredients and the proper amounts (provide it in the form of a list); and be sure to identify how many portions are served from this recipe. Then tell us what to do to prepare the dish. If your dish contains an ingredient that is indigenous to your region or country, and you think it might not be available everywhere, please describe the ingredient and suggest what you believe to be a more widely available substitute. Use whatever standards of measure are customary for your country; we will have to create a conversion chart.

TMA Cookbook: A Request for Your Recipes and Your Stories

Pauline R. Habib and
Sandy Siegel

We are going to ask you to submit only one recipe. We have many members and we want for every person in our membership with TM to submit a recipe. If your child has TM and they have not yet prepared a meal, please have your family submit the recipe for your child. If they have a favorite dish, that would be a great recipe to submit on their behalf. If they do not, or if it comes from the corner pizza parlor, have the whole family make the decision.

We would also like for you to send us a picture of you and your dish. You may also include all of the other members of your family in the picture. If you allow everyone into your picture, be sure to identify who **you** are among your clan. If the picture is going to be of sufficient quality to be published in a book, be sure Dad has his glasses on when he focuses the camera, make sure the flash really goes off, and please take the cover off of the pot, so we can see what you've actually made. If you need to send more than one picture, that is fine.

We want for this cookbook to be about so much more than your favorite foods; we want for this cookbook to be about you. We want you to tell your story and we want to tell the world about how TM has effected your life. Along with your recipe, we want you to submit a short biography. You are going to need to keep this to a few pages. You are all fascinating people, really. Everyone has a story. Where were you born, where do you live. Describe your family. Tell us about yourself. And then tell us about your experiences with TM. When did you contract TM, how old were you, how were you effected, did you have a recovery, and if so, how much, and how has this experience changed your life. Okay, write as much as you want and Pauline and I will just have to do some editing where needed.

We want for the recipes to be provided by persons with TM (or by the family on behalf of a child with TM), because we want to tell the world our story. We are going to offer them a very interesting and incredibly diverse selection of the world's great dishes; and we are going to tell them about how such a diverse group of people has come together as a community. What has brought us all together is TM; we are going to tell them that story also.

Your submissions are going to have to be written in English. If you need a translator to assist you, please let us know. We have volunteers who will help you translate your recipes and stories into English.

This book will not be written tomorrow. This is going to take Pauline and myself a long time to compile and write. But we are going to do it; and we are going to do it with sufficient quality that we can attract a publisher to print and promote it. It is certainly a story worthy of telling; and it will have readers interested in reading it. Be patient with us; this is not going to happen overnight.

We need for you to make this happen. We will allow you a little time to get your information together. If we are not receiving your recipes, your stories, and your photographs by the summer, we are going to come looking for you.

All of the money raised from the sale of the cookbook will be used to support The Transverse Myelitis Association. Please mail your submissions to:

Pauline Habib and Sandy Siegel
1787 Sutter Parkway
Powell, OH 43065-8806
USA

Feel free to send the submissions electronically to:

Sandy Siegel: **srulyosef@aol.com**

If you send the photographs as scanned electronic images, please keep copies of the photographs in the event the publisher requires the actual photo image in the publication and printing process.

We would like to thank TMA member Phil Burcham for sharing the wonderful idea of a cookbook written by our membership! Pauline and I are very excited about learning about all of you from your stories. We are also thrilled about the idea of trying out all of these recipes. Thank you for your contributions. Together we are going to make a difference in our fight against TM!

We would like to recognize and thank Nic Niland for performing some important graphics work for the Association. Nic graduated from Bentworth High School in Bentleyville, Pennsylvania in 1998. Upon graduating, he started college at the Columbus College of Art and Design. He is a junior and is majoring in Advertising/Graphic Design. Nic works as an intern at Kingston where he rebuilds logos, creates fliers and catalogues and performs other graphics work. Nic recently designed a T-shirt concept for the Columbus

Landsharks, a professional lacrosse team. Nic hopes to study in Europe sometime during his college education and also plans to study and work in London, England for a period of time upon graduating from college.

We had been searching for a graphic artist to assist us in improving some of the designs of our literature. After a lengthy search, Nic was recommended to me by a professor at the Columbus College of Art and Design. I asked Nic to design a logo for the Reading for Rachel Program. The logo printed in the newsletter does not do justice to the creativity and skill reflected in Nic's work. You can view the color logo on our web site, and we also invite you to go to the Reading for Rachel web site at www.myelitis.org/readingforrachel. You can see the logo and also a wonderful bookmark that Nic created for the children to use to keep track of all of the books they are reading for Rachel. We know that the great work he has performed on this project will only enhance our ability to draw attention to our cause and encourage people to participate in the program.

Nic has been great to work with on this project. He has listened to me talk for hours and hours about Transverse Myelitis, about our members, about the children with TM, and about the work of our Association. He has been very patient with me; and he has developed a very good understanding of and appreciation for the work we are trying to accomplish. He is very supportive of our efforts. Nic has donated his time, energy, talent, creativity and skill to the Association on this important project and others. He has also expressed a willingness to assist the Association in other work that we might need to have performed in the future. We could never afford to pay for this work to be done. We have been blessed to have a

The Reading for Rachel Logo and Bookmark: Thank You, Nic!

professional come forward to meet our needs so generously. We are very grateful to Nic and appreciate his very kind support of the Association and its members. Thank you, Nic.

If you are searching for information about TM, a tremendous resource has been made available to you by Jim
Lubin. All of the presentations and workshops from the TMA Seattle Symposium were videotaped. The complete agenda of the symposium is available on our web site, and Jim has converted all of the video so that you can watch the workshops and medical presentations at home from your computer. If a presenter handed out materials, Jim has posted most of these in pdf format. You can access the Seattle page through a link on the main page of the TMA web site.

The Transverse Myelitis Association 2000 Statement of Financial Activities (in US Dollars)

Paula Lazzeri

The following tables present The Transverse Myelitis Association Annual Report for 2000. 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 2000. 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.

Total Donations and Expenses to Income TMA Funds Benefit TMA

G

e n e r a l C h a r i t a b l e D o n a t i o n s

Seattle Symposium: A Valuable Source of Information about TM

	27,499	27,499
iGive.com Donations	462	462
amazon.com Donations	147	147
Ireachout.com Donations	219	219
onGiving.com Donations	146	146
T-shirt Sales	30	30
Symposium Video Sales	1,090	1,090
Endowment Fund	7,922	7,922
Interest Income	227	227
Donations made by Board of Directors	0	5,552
Total Income	**37,741**	**43,293**
Expenses		
Board Meeting Expenses	0	981
Computer Software	0	106
Domain Address Subscription/Website	898	948
Internet Access	0	1,045
Mileage and Parking	0	84
Office Supplies	197	548
Postage and Shipping	5,811	6,932
Printing and Copying	9,590	10,022
Secretary of State Fees	10	10
Symposium Video Production	790	790
Telephone and Fax	0	1,382
Total Expenses	17,295	22,847
Net Income	**$ 20,446**	**$ 20,446**

Transverse Myelitis Association 2000 Statement of TMA General Fund Account Balance

1999 End Balance	20,737
Add 2000 Deposits	29,736
Less 2000 Expenses	17,295
2000 End Balance	**$ 33,178**

Transverse Myelitis Association 2000 Statement of TMA Endowment Fund Account Balance

1999 End Balance	0
Add 2000 Deposits	7,922
Add Interest Income	83
2000 End Balance	**$8,005**

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.*** We know there is a need for this information, because it is frequently requested from both parents and children. Please take the time to send us the following directory information:

Parents' Names
Street Address
City, State/Province

The TMA Children's and Family Network Directory

Country, Zip or Postal Code
Home & Work Phone & Fax
Parents' Email Address

Child's Name
Child's Email Address
Child's Age at Onset of TM
Year of Onset of TM
Spinal Cord Level of Effect

Thus far, only 26 families have responded for inclusion in the Children's Directory. I have been waiting for a response that reflects more closely the numbers of children in our membership that have TM. In waiting for so long to increase the value of this directory by including more networking opportunities, I have

been withholding this resource from those who need it. For that, I am truly sorry. The publication of this directory is of the highest priority for the TMA. After waiting for a short time for a reply from this newsletter request, the children's directory will be published and mailed to those families who have provided us with their child's information. We sincerely apologize for the delay.

You can send the information to Sandy Siegel either through the postal service or the Internet.

It is never going to be too late to complete and return the TMA survey. The survey was sent to you in the first mailing of the TMA Newsletter in 1997. It continues to be sent to new members as a part of their initial packet from the TMA. Thus far, there have been more than 530 members who have completed and returned their surveys. All of these responses have been entered into the database representing thousands of pages of critical information. After the completion of the survey analysis and publication of the results, we will continue to update our database of information and will continue to generate updated results from subsequent respondent survey additions.

We are about to begin the coding of the information, and upon completion of the coding process, we will begin our analysis. As we have stated previously, the results of this work will be shared with our members and with the medical community.

If you have not completed and returned your survey, please do so as soon as possible. You hold one of the

TMA Survey

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.

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; it will never be too late to complete and mail me this information. Thank you!

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

Or send it to me via email at:
ssiegel@myelitis.org

Please Help Us With Our TMA Database

It used to be fairly easy to find an error in the TMA database; it does not take much time or energy to look through 180 names. Our membership today is about 2800 people! The task of finding duplications has become a more difficult proposition. If you receive more than one mailing from the TMA, please let us know so that we can correct our database. This simple gesture can save the Association a great deal of money in printing and postage costs.

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:

The TMA on the Internet

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

The following are some of the TMA web pages:

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

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

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

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

The TMA Officers' e-mail addresses:

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

The Transverse Myelitis Association Medical Advisory Board

Thank You, Errol and Geoff and a Call for International Volunteers!

Twice a year the TMA publishes a newsletter that is sent to all of our US and international members. Once a year, the membership directory is published and mailed. Errol White, one of our Australian members, has taken responsibility for the printing and mailing of the newsletters and directories to our TMA members in Australia and
New Zealand. Geoff Treglown is a TMA member from England. Geoff has volunteered to perform the printing and mailing responsibilities for all of our European members.

The TMA would like to thank Errol and Geoff for performing these critical tasks for the Association. We are so appreciative of your generosity and support.

Volunteering to handle these tasks has been very important for the Association in the past; and this assistance has become even more significant for the TMA.

As all of you in the United States are aware, the US Postal Service increased its rates in January. There were increases for domestic rates, and there were increases that have impacted our bulk mailing rates as a not-for-profit.

The most serious increases, however, were experienced for our international mailings. The rate class we were using for the mailing of our newsletters and membership directories was eliminated by the postal service. The old rate was a fairly reasonable rate that allowed us to send printed matter via air; and thus, in a relatively short period of time.

With the elimination of this rate, the TMA simply cannot afford to send the international mailings via the air rate; we do not have the funds to cover these costs as our international membership continues to grow. We are going to have to mail to our international members using a surface rate, which means that our materials will take approximately a month or two to be delivered.

The vast majority of the TMA's expenses consist of printing and postage costs. To the extent the Association is able to save on some of these costs, the more we can consider supporting other efforts and activities. Additionally, since the Association does not require membership fees, our operating budget depends on the support of voluntary contributions which are extremely difficult to predict. Our ability to expand our services very much depends on the Association's ability to find ways to save, and to further develop our fundraising efforts. And as should be apparent from this newsletter, we are intensifying both approaches.

As you review the latest membership directory, please consider assisting the TMA by printing and mailing the newsletter and directory to your national TMA members. If you are in the process of establishing a national TM support group, this would be a great activity to share with your members. The TMA has a large membership in Canada; we would be most appreciative of a Canadian member coming forward to take on this responsibility. Likewise, our Indian membership continues to grow.

In order to perform this job, you will need Internet access. Errol, Geoff and I make all of our arrangements via e-mail messages, and have found it to be a very effective and efficient way to handle our communications.

A big thank you to Errol and Geoff for saving the TMA substantial funds! We greatly appreciate your generosity. And we are looking forward to other international TMA members coming forward to assist us in this important effort. Thank you.
I would like to thank Claudia

Thank you, Claudia!

Maynard, a good friend, who has been assisting me with the publication of the membership directory. Claudia is proficient in designing and working with databases. When I first began the publication of the directory, I performed most of the work manually, because I am not smart enough to figure out how all of this software works. Claudia has been able to save me a tremendous amount of time and stress in this process. Claudia, thank you so much for helping out your technologically challenged friend!

I would like to thank my Mom and Dad for proofreading the newsletters;

Thank you, Bubby and Zadie!

they have been performing this task for me since the first publication in January 1997. This is no small task due to the complexity of the medical jargon, and I never give them very much time to get the job done. They perform this task with such great love and care; just as they do everything in life for their children. They learn and cry as they proof the articles and stories just as we all do. **Thank you!** Growing up, we never had to look in a dictionary; "hey, Ma, how do you spell suprapubic?"

Registration Forms: Second International TM Symposium

Two registration forms have been included with this mailing. Johns Hopkins has asked that a separate form be filled out for each person in your family (or a friend) who is registering to attend the symposium. If you are going to be registering through the mail, please use these forms. You may also register on-line. Complete details for the registration process are included in the newsletter. We are looking forward to seeing you in Baltimore!

The Transverse Myelitis Association Officers

Sanford J. Siegel
President & Newsletter Editor
1787 Sutter Parkway
Powell, Ohio 43065
(614) 766-1806
ssiegel@myelitis.org

Deborah Capen
Secretary
PO Box 2084
Hemet, CA 92546
(909) 658-2689
dcapen@myelitis.org

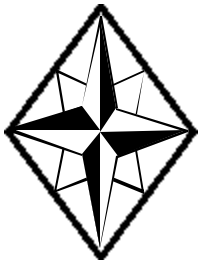
Paula Lazzeri
Treasurer
10105 167th Place NE
Redmond, WA 98052
(425) 883-7914
plazzeri@myelitis.org

Jim Lubin
Information Technology Director
PO Box 82433
Kenmore, WA 98028-0433
fax: (425) 483-0215
jlubin@myelitis.org

Deanne Gilmur
Founder & Board Member
3548 Tahoma Place W
Tacoma, WA 98466
(253) 565-8156
dgilmur@myelitis.org

The Transverse Myelitis Association

Sanford J. Siegel
1787 Sutter Parkway
Powell, Ohio 43065



Second International TM Symposium; July 12-15 in Baltimore, Maryland