❖The Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

There are many challenging issues a person with TM has to face on a regular basis; none is more difficult and demoralizing than bowel issues. I know, you would probably rather that I was writing about money.

I know that the dysfunctional bowel symptoms that accompany TM can create the most devastating impact on a person's quality of life. I know this, because I have observed these impacts and I have listened to people talk about these issues on numerous occasions. Keeping in mind that I am not a medical professional, I would like to make a distinction between persons who have a difficult time having a bowel movement and those persons who have a difficult time controlling their bowels. My comments are going to focus more on those of you who have difficulty in controlling your bowels, because of the loss of sphincter function.

I think that the medical profession has many more tools in the treatment kit for those who suffer from the former as compared to the latter malady. It is high on my priority list to have an article published on bowel maintenance programs; those for children and those for adults. It is my suspicion that the programs are going to be pretty well defined with a variety of options for a person who experiences difficulty having a bowel movement. For those who have no control of their sphincter muscles, I suspect that the options are going to be fairly limited. As a purely anthropological observation, I believe the medical community has a concern that the TM patient is evacuating; and I think a bowel maintenance program may be considered successful if the bowel movement is accomplished with anything less intense than a couple of sticks of dynamite. I'm not sure that a person who is pooping all over the neighborhood is considered to be having a bowel problem. Why? Because they are getting it out. I could be wrong; it is merely an observation. I will be looking forward to reading about this bowel maintenance program.

My greatest concerns and compassion go to those of you who are unable to control your bowels, because you have no or little control of your sphincter muscles. Some of you are unable to feel when you are about to have a bowel movement; some of you can't feel it until it is too late. Some of you can feel it, but have no way to control it. So, you have accidents in public and you pass gas in public. I'm sorry. I'm sorry, because I know how this issue has changed your lives. I see how it constrains your lives. I see how it has impacted the way you see yourself. And this all just makes me very sad.

There is not a single brilliant thing I have to say to any of you to improve upon this situation. I'm not a doctor, so there isn't much I can tell you beyond my common sense application to all of life's problems. But I do have lots of compassion and empathy, and your predicament does make me feel really horrible. So, what are you supposed to do about this? Well, hopefully, I am totally wrong and the bowel maintenance program article that I get published in the near future is going to be jam packed full of great ideas for you. I would imagine that routine and a regiment is very important for you. Making sure that you eat a balanced diet that is high in fiber is probably a good idea; and making sure that you consume lots of water. If you have little control of your bowel movements, controlling the consistency of your stools is probably really important.

Okay, regiment makes a great deal of sense, but, for most people, anything requiring discipline about food is not going to be easy. During a doctor appointment not too long ago, my doctor suggested that I take off some weight. Actually, what the doctor told me was that my weight was perfect, if I thought I was going to grow to about 6' 5". I'm certain my doctor learned this approach to weight loss during medical school in his Bedside Manner 201 class. "If you want your patients to follow a weight loss prescription, the highest rates of success are experienced by those with whom you are the most obnoxious and sarcastic."

A medical doctor is not going to help me lose weight. If eating was about ingesting nourishment, my weight would not be a problem. My weight loss issues might be better handled by a team of highly trained and experienced psychologists.

I'm not sure what the rest of you are doing around the world; in America,

we are doing really interesting things with food. Being regimented about food in America? We are super sizing it. We are camped out at all you can eat buffets. We are managing to put 5000 calories on a plate from a salad bar and feeling good about our healthy selections, because we are also using a low fat dressing. We are starving ourselves. We are binging and purging. We are living on diet pills and nutrition bars. We are wiring our mouths shut and having our stomachs stapled. We hold ourselves up to the most unrealistic models for appearance, become totally discouraged with the entire concept, and find solace in devouring the entire party-sized bag of peanut M&Ms while watching Richard Simmons sweat to bad disco music. So, just what consistency do you need for these stools to be? Hopefully, you're having a better time of stool consistency in France. I've heard cheese is very binding.

It takes every ounce of discipline in my being to make it through Yom Kippur. Most of us are just not very disciplined about food. So, all of this routine and regimentation is going to be extremely difficult. But that is where some of the answers lie for people with TM and bowel problems.

If you have a nervous stomach, you may be in trouble, even with a regimented diet, and fiber and water and routine. And the water thing, by the way, is really important. I am on a medication that is constipating. I try to include plenty of fiber in my diet and I take a fiber supplement. On one occasion I did not drink enough water with my fiber supplement. Later that day, I spent an hour giving birth to three small stones. Not a pleasant experience. You need to drink lots of water; if you are taking fiber supplements, you need to drink even more than lots of water.

I also have a nervous stomach. I used to go on kaopectate intravenous during final exams week. I did this through fourteen years of college. I can't even imagine how it would feel to have a nervous stomach and no sphincter control. You have a very difficult problem.

When you have a significant cause of stress in your life, you have some choices to make about the cause. You can start by looking at the circumstances that cause you stress and make some decisions about how you are going to change those in order to diminish or eliminate the stress. For those of you who have no sphincter control, there is only so much you are going to be able to do to change the circumstances. You can devote your life to forming the perfect stool; to developing a regimented diet and schedule that increases the probability that you are going to have a bowel movement at approximately the same time every day or every other day. But you are still going to have an occasional accident. The operative concept here is ***accident***. You just don't have control over all of the circumstances.

If you don't control the circumstances, your other choice to reduce or eliminate stress concerns how you feel and think about the circumstances that cause you stress. It is this simple – really. If you want the stress and emotional discomfort to diminish, and you cannot control your sphincter muscle, you are left with having to change how you feel and think about having accidents and passing gas among spectators. I know, easy for me to say. But whether easy or difficult to accept, those are the choices.

I perceive all of life about TM as a caregiver. I don't have TM. I started to learn about these issues very early on in Pauline's experience with TM.

We talk about everything. And we talk about her symptoms. Pauline complains to me. I listen. I tell her that I am sorry. We talk about pain and fatigue and we discuss strategies for managing these symptoms. We talk about all of her symptoms – and we talk about them a lot. We never ever talk about bowel problems and passing gas. Why? Cause there is just nothing to talk about. There is nothing she can do to change any of this. There is nothing I can do to change any of it. We just get on with life. My job in these situations is to keep life normal and moving forward. We make life normal as quickly as possible.

Making all of this normal is a big step in making this all less stressful for yourself. What else are you going to do? Allow me to suggest two things that you shouldn't do. Don't starve yourself. I know people who attempt control of uncontrolled bowel movements by starving themselves before a particular occasion. This is not a healthy approach. It is a dysfunctional method for many reasons, not the least of which is that it destroys any diet routine which is one of your better techniques for bowel maintenance. Some people stop going out in public where they might risk an accident. This is also not a healthy approach. In the end, this approach is only going to make you feel worse. You need to live your life, you need to continue to do the things that make you happy and bring meaning to your life. Isolating yourself from these things is not going to be satisfying over the long haul. Isolating yourself from people is not a good thing. Neither of these approaches is a satisfying or healthy resolution of the problem.

You should do what you can to help keep things normal. Bring a change of clothes, a few plastic baggies and a package of wipes when you go out.

If you have an accident, try to expend your energy moving on as opposed to feeling bad about it. I can tell you that none of your friends or family are ever going to decide that they don't want to spend time with you, because you have had or could have an accident. They are going to feel badly about it, but then they are going to take their cues from you. If you try to commit hari kari with the butter knife, they will likely attempt an intervention that will only elevate your discomfort. If you try a matter of fact let's deal with it and move on approach, that is what they are going to do also. They are going to admire you. Believe me, they will. I would.

I'm not suggesting to you that this is a small thing. I would have a really hard time with this. But I hope and I pray that I would be able to get to a place where my bowels did not control my life. It might gain control over my body, but I would hope that I would maintain control over my mind.

During the first TMA Symposium in Seattle, I led a discussion among people with TM and caregivers about symptom management issues. During the course of the discussion, a woman raised the issue of passing gas without control and in public. She talked about her embarrassment and she asked what other people were doing about it. There were various suggestions made; most of the advice concerned foods that cause gas and avoiding them. A hand went up in the back of the room – a sage philosopher from the TM community wanted to speak on the subject. I moved to the back of the room and handed the microphone to Mr. Boyle. His advice on the subject of passing gas in public, "I don't care." There was an immediate burst of laughter around the room, including from me. And to know Gunny is to only make his response funnier. But it was the best advice anyone provided on any subject during that discussion. In fact, it is the sanest and most reasonable advice I have heard on ***this*** subject – ***ever***.

The more you care, the worse you are going to feel. The more significance you place on this issue, the worse you are going to feel when it happens. And you have no control over when it is going to happen. The only aspect of this you have control over is how much significance you are going to ascribe to it and how you feel about it. Hey, let's try to get some perspective on this. You aren't stealing from the poor; you're farting in public. If you pass gas in the middle of the grocery check out line, your family should say "excuse me" in unison as a demonstration of solidarity.

As difficult as these issues are for adults with TM, these issues are much more difficult for children and young adults. Being different among one's peers is just really hard. Even being rebellious is defined by specific rules, including a uniform. You can't just do your hair in any pastel that strikes your fancy or deform just any body part. My heart aches for the children and young adults who have to deal with the bowel issues. But their decisions are the same as those of adults.

Children need to make the same decisions about changing the circumstances to the extent they have control over those circumstances, and they need to also find ways to deal with how they think and feel about the bowel issues. On the circumstances side, they need to understand what aspect of these issues they control and how much of it they do not control. You should probably help them understand that there is likely a relationship between a healthy diet, some schedule and regiment about eating and the avoidance of unhealthy dieting and the increased probability that they will have fewer accidents. That might be compelling motivation for them to make healthy decisions about food and eating behavior. An exercise program would probably also be a very good idea; for children and for adults with TM.

On the thinking and feeling side of the bowel issues, you could help your children with strategies for when they do have an accident. A change of clothes is a good idea for them, as well. I think children will often take cues from their parents in situations that could cause stress. If you react to an accident as though it is a major production and loaded with angst, you might be influencing your child to think of it in this manner, as well. If you deal with it in a more matter-of-fact manner and help them just move back to the flow of life, they might be helped to experience these accidents in a less stressful way.

It won't be easy for you. It sure would be difficult for me. But this is the situation, and you are all faced with limited options. Please work to find the healthy ones, the ones that will make these experiences as normal as possible. And that is also likely going to entail parents being good models for their children in the areas of nutrition and eating behavior.

Not having control of your bowels is a difficult challenge for many of you who have TM. I am asking you to ***please*** not make it any worse for yourself. You can't control what your sphincter muscles are up to, but you do have some control over what your brain is up to. You are such a wonderful person and we love being with you. We don't want you to

isolate yourself from us. We can handle this situation – please don't stay away from us, because you are embarrassed. We will help you move on. We won't tell you not to feel badly – you're allowed to feel badly. We're just not going to encourage you to dwell on it. And my team of psychologists tells me that food is so much more than the basic building blocks of life. The emotional, social and recreational aspects of food should be celebrated – every culture does. Please don't exclude yourself from this celebration.

Please take good care of yourselves and each other.

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.

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Fatigue in Transverse Myelitis

Joanne Lynn, MD

Medical Advisory Board of The Transverse Myelitis Association.

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

Fatigue is a common complaint of people with TM, but there have been very few investigations into this phenomenon. It is the most common and most disabling symptom for many people with Multiple Sclerosis. Despite many attempts to study fatigue in MS, we still do not completely understand its causes or how best to manage it. However, it is worth looking at what is understood about MS fatigue for clues about how to understand and handle fatigue in TM. We all use the term 'fatigue' to mean different things; and it is recognized that different types of fatigue exist in MS and, presumably, in TM. Fatigue in MS has been defined as "A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities."

Some of the causes of fatigue in patients with disease of the central nervous system include: 1) weakness, 2) disturbed sleep, 3) medications, 4) depression, 5) nerve fiber fatigue, and 6) infection. Any of these may occur simultaneously in the same person.

Weakness

Many people with TM have weakness of both legs ranging from complete paralysis to mild weakness with fatigability. An example of motor fatigue would be the person who starts out walking with a fairly normal gait. However, after they go a certain distance, fatigue kicks in and they start to have a foot drop or a limp. Those with cervical cord involvement may also have arm weakness. Fatigue may result from the extra energy required to compensate for this weakness in performance of daily activities. One approach to minimize this fatigue is to use energy conservation principles and labor saving devices (e.g., motorized scooters). Many people with TM can benefit from a therapy program of exercise to maximize physical conditioning. Physical and occupational therapists are the best resources to help an individual look for ways to conserve energy in daily activities and improve conditioning.

Disturbed Sleep

Many people with or without TM suffer from insomnia and otherwise disrupted sleep that may contribute to fatigue. Problems that are more common in people with spinal cord injury that may contribute to poor sleep include spasticity, urinary frequency or incontinence, neuropathic pain, restless legs syndrome, and depression.

Spasticity, or abnormal muscle tone, tightness and spasms due to injury of motor nerve fibers that descend in the spinal cord, may make it difficult to fall asleep or cause multiple awakenings at night. Symptoms of spasticity may be improved with daily stretching exercises and medications to relax muscles such as Lioresal

(Baclofen), Tizanidine (Xanaflex), Dantrolene (Dantrium), Diazepam (Valium) and Clonazepam (Klonopin). The benzodiazepine class of medications that includes Diazepam and Clonazepam may be too sedating for daytime use for some people, but are great for controlling spasms at night and promote sleep. Chronic benzodiazepine use is not recommended for simple insomnia, because it may have effects on the stages of sleep. However, the relatively mild deleterious effects on sleep are overweighed by benefits in many patients with spasticity.

Some people with TM have a neurogenic bladder or abnormal bladder function from spinal cord injury that results in frequent need to get up and urinate during the night (nocturia) with disturbance of sleep. This problem requires evaluation by a physician and may require referral to a urologist. Several different bladder problems can occur with spinal cord injury. One is a "spastic bladder" or an irritable bladder that contracts with even small amounts of urine, giving an inappropriate message that voiding is needed. This increased urge to void can often be helped by medications such as Detrol and Ditropan. Another type of voiding problem is the "hypotonic bladder." This bladder is "lazy" and does not contract until it is very full. The person may get up and void only part of the bladder's contents, because of the incomplete contraction of the bladder wall. They then return to bed with a bladder that is already half full and have to repeat the voiding cycle several times during the night. People with this type of bladder dysfunction often benefit from learning how to perform self catheterization of the bladder before bed to empty it completely, which often allows them to sleep through the night.

It is often difficult for people with TM to know which type of bladder problem they have. Self-report of whether the bladder feels completely emptied is notoriously inaccurate in persons with spinal cord injury. One simple procedure is to check the post-void residual or amount of urine left in the bladder after urination by either catheterization or ultrasound to see if the bladder is emptying completely during voiding.

Some people with TM have trouble sleeping because of neuropathic pain such as burning, aching, stabbing or shock-like sensations often in the legs or trunk. These pains may become more distressing as the person lies down to attempt sleep and is no longer distracted by the activities of the day. There are medications that can be tried for various types of neuropathic pain and these have been discussed in a previous edition of this newsletter. Restless legs syndrome is a form of abnormal periodic limb movements that can disturb sleep. In this disorder, the person has an uncomfortable sensation in the legs which is transiently relieved by moving the legs. This disorder is common enough in the general population and appears to be increased in people with neurologic disorders such as MS. It can be helped with certain medications.

Medications

Many of the medications used to treat various symptoms experienced by people with TM may cause sedation and aggravate fatigue. These include antidepressants, antiepileptic drugs that may be used to combat neuropathic pain, anti-spasticity medications, antihistamines, some blood pressure medications, etc. It is reasonable to review your medication list with your physician for advice about medications that might contribute to fatigue and then have trials off or on reduced doses of suspect medications under physician guidance.

Stimulants such as amantadine (Symmetrel), Pemoline (Cylert) and Modafinil (Provigil) have been used to treat MS fatigue with some benefit. However, some would argue that pharmacologic treatment of fatigue may be more appropriate in MS because the brain is affected by this disease contributing to fatigue, whereas the brain is spared in TM. There is little research in the area of fatigue and TM to guide us. Amantadine is very cheap, but may cause confusion or nausea in some people. There is a risk of liver injury with pemoline. Modafinil is very effective in MS fatigue, but is still on patent and is very expensive.

Depression

Depression can also contribute to disturbed sleep by causing difficulties falling asleep – often due to a tendency to ruminate over worries – and by causing difficulty with staying asleep during the night, including a tendency to wake up earlier in the morning than desired. Depression is associated with the following symptoms: sad mood, tearfulness, sleep disturbance, appetite changes, lack of motivation and feelings of guilt and poor self-worth. Depression should be treated with antidepressants and/or psychotherapy. Some antidepressants are more "alerting" or stimulating than sedating. This should be discussed with a physician if fatigue is prominent and treatment with an antidepressant medication is considered.

Nerve Fiber Fatigue

This is an area of fatigue that we know about from studies of MS. Some of these observations may be extrapolated to TM. One of the primary types of tissue damage in MS

is demyelination (or removal of myelin, the insulation of the nerve fibers). When demyelination is present, the nerve fibers may conduct nerve impulses, but fatigue rapidly with heavy use and/or high body temperatures (from heavy activity, high environmental temperature such as a hot day or a hot factory, or fever). Many people with MS cannot tolerate heat very well because of this phenomenon of nerve conduction failure. In TM, there may be varying degrees of demyelination and/or injury to the underlying nerve fibers (axons) and it is not well documented what percentage of people with past TM have conduction failure typical of MS. People with MS and this type of heat intolerance use simple measures such as air conditioning, cool drinks, and avoiding overheating and sometimes use cooling vests to help improve function in the heat.

Infection

Common infections such as viral respiratory tract infections (e.g., common colds and sore throats) and urinary tract infections (which are more frequent in people with spinal cord injury) may cause an increase in fatigue.

The causes of fatigue in TM are complex and multifactorial. In addition, fatigue is a very common complaint in the general population without TM or MS. Consideration should be made of whether there could be other underlying illnesses that might contribute to fatigue such as hypothyroidism. The treatment approach to reduce fatigue in TM should be multifactorial with emphasis on physical therapy and home exercise programs to increase conditioning and stamina, evaluation of sleep and medications, and treatment of depression if present. There is no easy solution, but hopefully fatigue may be lessened by these approaches.

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Joanne Lynn, MD serves on the Medical Advisory Board of The Transverse Myelitis Association. If you have questions for Dr. Lynn regarding the Transverse Myelitis condition, please send those to Sandy Siegel; we will attempt to have your questions addressed in a future newsletter.

Member Questions and Answers from Joanne Lynn, MD

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 response is based on the information provided in a brief question and is without the benefit of a complete history or an examination. Any decisions regarding diagnosis or treatment should be made in consultation with your personal physician who is best suited to make appropriate medical recommendations for you.

Q. Why should a person with TM consider quitting smoking and what suggestions might you offer to help them quit?

Approximately 23% of US adults smoke cigarettes; tobacco use is the leading cause of preventable death in the US. More than 2/3 of current smokers state that they wish to quit. However, less than 10% of smokers who try to quit without treatment remain abstinent in the long term. Smoking is a problem for many people with Transverse Myelitis. There is little data about the effects of smoking on TM. In one study on Multiple Sclerosis, there were minor deleterious effects reported on motor function; however, this is relatively insignificant compared to the multiple other health problems caused by smoking. Some people with TM see their neurologist more frequently than they see their primary care provider, making it incumbent upon the neurologist to attempt to motivate patients to quit and to be familiar with potential treatments.

Barriers to quitting include tolerance and physical dependence on nicotine and psychological factors related to tobacco use. Two treatments have been shown to be helpful in smoking cessation: drug therapy and counseling. An approach that employs both of these treatments is most effective of all.

Counseling

Counseling for smoking cessation generally involves teaching about strategies to deal with stress and symptoms of nicotine withdrawal. Smokers often learn to associate

smoking with certain cues and times such as after meals, when relaxing, to unwind after an argument or other stressful event, during a work break, or with an alcoholic beverage. Cognitive counseling helps to teach smokers to break the links between these cues and smoking.

Drug Therapy

Nicotine replacement therapy provides nicotine to relieve cravings and symptoms of withdrawal. The use of nicotine replacement therapy is associated with significantly better rates of smoking cessation. Nicotine replacement is available in various forms: a skin patch, chewing gum, nasal spray and a vapor inhaler.

Other drugs besides nicotine are used in smoking cessation efforts. Buproprion (Zyban) has been shown to be helpful in combination with supportive counseling. Other medications which may be helpful include nortriptyline and clonidine.

Other Treatments

Hypnosis as a treatment for smoking cessation has been inadequately studied thus far. Studies of the use of acupuncture have failed to show effectiveness.

Approximately 50% of moderate or heavy smokers die prematurely due to illnesses related to tobacco abuse. Even if initial attempts to stop smoking result in relapse, many smokers eventually achieve long term abstinence after multiple attempts to quit. Smoking cessation increases life expectancy and reduces the risk of tobacco-related illness leading to a better quality of life for people trying to live well with their TM.

Reference: Rigotti N. Treatment of Tobacco Use and Dependence. NEJM. 346(7), Feb. 14, 2002, pp. 506-512.

Drs. Barnes, Kaplin, Morrison and Pidcock Join the TMA Medical Advisory Board

The Transverse Myelitis Association Medical Advisory Board was initiated by Dr. Charles Levy. Dr. Levy is a Physiatrist, a doctor of physical and rehabilitative medicine. We met Dr. Levy when Pauline was a patient at Dodd Hall, The Ohio State University. He was director of the wheelchair clinic at Dodd and he was responsible for getting Pauline fitted into her purple wheelchair in 1994. When Deanne and I were just getting the TMA off the ground, Dr. Levy created an opportunity for the officers of the TMA to come together in Columbus to learn about other rare disease organizations, and the great work being done by these groups. As Dr. Levy's guests at this conference, the officers of the TMA became sensitized to the importance of having guidance from the medical profession in our planning and our activities.

Following this conference, Dr. Levy graciously and generously offered to serve on The Transverse Myelitis Association Medical Advisory Board. Dr. Levy has been instrumental in guiding the TMA almost since our inception. Shortly after initiating the Medical Advisory Board, Dr. Levy recruited Dr. Joanne Lynn to serve on the TMA Medical Advisory Board. As a Neurologist and the Director of the MS Center at The Ohio State University, Dr. Lynn was a wonderful and significant addition to the Board. The Gilmurs next recruited Dr. James Bowen from the MS Center at the University of Washington to serve on the Board. Dr. Douglas Kerr joined the Medical Advisory Board during the First International TM Symposium in Seattle. Dr. Kerr established the Johns Hopkins Transverse Myelitis Center and has become the country's and the world's only specialist in the treatment and research on TM.

We have been incredibly blessed with a wonderful group of physicians to serve on our Medical Advisory Board. I am in contact with these doctors on a regular basis. They are contributors to the newsletters, they offer me advice about treatments and referrals which I pass onto people in the TM community, and they are participants in our meetings, conferences and symposia. They are engaged in TM research. They are intensively involved in disseminating information and educating about TM to both TM patients and doctors and they are publishing articles regarding various aspects of TM. As the TMA becomes involved in funding research, it is the Medical Advisory Board which will offer guidance in designing and participating in the review and selection process.

Perhaps most importantly, these physicians are offering patients with TM the best possible treatments and care. These doctors pretty much respond to whatever I ask – graciously, generously and none of them have any time for any of what I request. But it always gets done.

They are competent, exceptional, brilliant doctors and researchers, and they are quality human beings. I wonder often how it was that these four incredible people found their way into an association with our fledgling organization. It has been a blessing. I met Drs. Barnes, Pidcock, Morrison and Kaplin in Baltimore during the Second International TM Symposium. Drs. Morrison and Barnes are pediatric neurologists, Dr. Pidcock is a pediatric physiatist and Dr. Kaplin is a psychiatrist. They were all very interested in TM, were becoming very

involved in treating patients with TM, and were involved in research on TM. They were invited presenters in Baltimore, and they were all very much engaged by the people who came to Baltimore with TM and their caregivers. As pediatric specialists, I invited Drs. Barnes, Morrison and Pidcock to present and to participate in the TMA Children's and Family Workshop. All of the doctors who came to Columbus not only donated their time and expertise, they paid their own way to the workshop. And the doctors were not only in Columbus to present to the parents; they were in Columbus for the entire weekend to offer information and support to the parents throughout the entire workshop. Some of their family members also attended and served as companions to the children who needed assistance on the fieldtrips. Great doctors and awesome human beings!

I am thrilled to announce to our TMA members that Dr. Barnes, Dr. Kaplin, Dr. Morrison and Dr. Pidcock are the newest members of our Medical Advisory Board. These four doctors bring new areas of specialization to the TMA that are critical for our members and for furthering the goals of the Association. I am honored to introduce you to the newest members of our medical advisory board.

Gregory Neal Barnes, MD PhD

Dr. Barnes received his PhD in Biochemistry from the University of Kentucky Graduate School in 1990. He received his Medical Degree from the University of Kentucky College of Medicine in 1992. Dr. Barnes served as a Resident in Pediatrics at St. Louis Children's Hospital at Washington University School of Medicine from 1992 to 1994. He was a Clinical Fellow in Pediatrics and Neurology at Children's Hospital, Harvard Medical School in Boston from 1994 to 1997. He served as an Epilepsy Research Fellow at the Duke Center for the Advanced Post-doctoral Study of Epilepsy at the Duke University Medical School from 1997 to 2000.

Dr. Barnes is currently an Assistant Professor in the Departments of Neurology and Pediatrics at the University of Kentucky College of Medicine and in the Department of Molecular and Cellular Biochemistry of the University of Kentucky. He is the Director of the Developmental Neurobiology Laboratory in the Department of Neurology of the University of Kentucky College of Medicine. He is an Associate Member of the Spinal Cord and Brain Injury Research Center of the University of Kentucky College of Medicine. Dr. Barnes is an Attending Physician in the Departments of Neurology and Pediatrics, Division of Pediatric Neurology, University of Kentucky Children's Hospital in Lexington. He also serves as Medical Staff in Child Neurology, Kentucky Commission for Children with Special Needs in Louisville.

Dr. Barnes is a member of The Transverse Myelitis Consortium Working Group. He is very widely published and has preformed extensive research in the area of epilepsy.

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Adam I. Kaplin, MD PhD

Dr. Kaplin completed his undergraduate training at Yale University in 1988 where he graduated *magna cum laude* with a BS in Biology. He completed his MD and PhD training at the Johns Hopkins School of Medicine in 1996, where he was a Medical Science Training Program awardee. Dr. Kaplin completed an internship in internal medicine at Johns Hopkins Bayview Medical Center, followed by residency training in psychiatry at Johns Hopkins Hospital. In his final year of residency training, he was selected to be Chief Resident of Psychiatry. Dr. Kaplin was invited to join the faculty as an Instructor in the Department of Psychiatry at Johns Hopkins School of Medicine immediately following his residency training, and was awarded one of the two Pfizer Postdoctoral Fellowship Grants in Biological Psychiatry offered in this country. In his second year on the faculty, Dr. Kaplin was promoted to Assistant Professor of Psychiatry. Dr. Kaplin's research experience includes having been trained in the labs of two Nobel Laureates, and having completed his PhD training in the Lab of Solomon Snyder, MD, one of the preeminent leaders in the field of Neuroscience. Dr. Kaplin has been an author on nine papers and four abstracts in scientific or medical journals. His research has focused on mechanisms of neuronal stimulation and communication. Additional awards that Dr. Kaplin has received include being selected as the NIH/NIMH Outstanding Resident of the year in 1998, and a Future Leader in Psychiatry by Emory University in 2002.

Dr. Kaplin's involvement in Transverse Myelitis (TM) began when he was recruited by Dr. Douglas Kerr to serve as the Chief Psychiatric consultant to the Johns Hopkins Transverse Myelopathy Center (JHTMC) in 2000. In addition to his clinical involvement in the Center through his work as a consultant and outpatient psychiatrist for patients with TM, Dr. Kaplin has initiated a collaborative research project with Dr. Kerr to investigate

the psychiatric sequela of TM. To date, no other clinician or researcher has investigated the psychiatric effects of TM. This work has already revealed an astonishingly high rate of clinical depression in patients with TM, and promises to not only elucidate optimal ways to treat this sequela, but may shed light on the pathophysiologic mechanisms of how TM involves the central nervous system. Dr. Kaplin was a presenter and one of the members of the planning committee for the Second International Transverse Myelitis Symposium in Baltimore, MD in 2001. He also participated in the Cody Unser, Reeve-Irvine Research Center/UCI California TM Conference in 2002, where he, Dr. Doug Kerr and Ms. Chitra Krishnan spoke about their experience in the JHTMC working with patients affected by TM.

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Leslie Morrison, MD

Leslie Morrison, MD is an Associate Professor and Division Chief of Child Neurology at the University of New Mexico School of Medicine. Dr. Morrison has been involved in research on Transverse Myelitis and is extensively involved in educational efforts which support the TM community and which disseminate information about TM to the medical community. Dr. Morrison represents her institution as a member of the Johns Hopkins Transverse Myelitis Consortium since March 2000. She was an invited speaker at the Second International TM Symposium in Baltimore in July 2001 and the First California TM Conference held in June 2002. Dr. Morrison attended the first TMA Children's and Family Workshop in July 2002 in Columbus. In addition to her two formal presentations to the parents, she was available throughout the workshop weekend to answer parent's questions and to offer support to the families. She is currently engaged in a research project focused on matrix metalloproteinases in the cerebrospinal fluid of Transverse Myelitis, expecting completion by July 2003 and funded by the Cody Unser First Step Foundation.

Dr. Morrison brings a very unique perspective and exceptional qualifications to her care of children with Transverse Myelitis. She received her education from the University of New Mexico as a physical therapist and has five years of experience in pediatric PT. She then received her education and training as a Child Neurologist.

Dr. Morrison's other research interests and experience include the study of inherited neurological disorders that disproportionately affect New Mexican families. This work has earned her recognition from the Dean of the UNM School of Medicine, and has resulted in research funding and new clinic development. Dr. Morrison has particular enthusiasm for mentorship of students from middle school through faculty, to further career development in the Clinical Neurosciences. She is nationally recognized for her service as an examiner for the American Board of Psychiatry and Neurology, and has recently been appointed to the Neurology Recertification Committee, the Child Neurology Society Practice Parameter Committee, the Board of Directors for the Child Neurology Foundation, and as a counselor for the Society of Clinical Neurologists. At the University of New Mexico, she serves as the Chief of Clinical Operations for the Department of Neurology, is an elected member of the Medical Executive Council and is on an ethics advisory team for the Health Sciences Center.

Dr. Morrison enjoys time with her family in music, outdoor sports and travel.

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Frank S. Pidcock, MD

Dr. Frank Pidcock is a clinical research scientist at Kennedy Krieger Institute. He is the Associate Director of Pediatric Rehabilitation at Kennedy Krieger Institute. He is an Assistant Professor of Physical Medicine and Rehabilitation and Pediatrics at the Johns Hopkins University School of Medicine.

Dr. Pidcock attended the Johns Hopkins University before going on to medical school at the Hahnemann Medical College in Philadelphia, Pennsylvania, from which he graduated in 1977. His postdoctoral training includes pediatric residency at Hahnemann University Hospital from 1979 to 1981, developmental pediatrics fellowship at St. Christopher's Hospital for Children from 1979 to 1981, and rehabilitation medicine residency at Thomas Jefferson University Hospital from 1991 to 1994. Dr. Pidcock was the Director of the Pediatrics Program at Children's Rehabilitation Hospital in Philadelphia from 1987 until 1991. After completing a residency in rehabilitation medicine in 1994, Dr. Pidcock joined the medical staff at the Kennedy Krieger Institute as the Associate Director of the Pediatric

Rehabilitation Program. Dr. Pidcock is an attending physician at both Johns Hopkins Hospital and Kennedy Krieger Children's Hospital. He is board certified in pediatrics and physical medicine and rehabilitation.

Dr. Pidcock's clinical research focuses on developing treatment protocols and quantitative measurements for the use of therapeutic botulinum toxin injections in the treatment of children with spasticity from cerebral palsy, traumatic brain injury, or other processes that affect motor control. Indications for giving therapeutic botulinum toxin include improving mobility, preventing deformity, and improving quality of life. Measurement techniques that Dr. Pidcock is studying include functional brain imaging (fMRI) to look at the effects of peripheral botulinum toxin injections on cortical activation and a spasticity measurement system designed to quantitatively measure the effects of spasticity reduction at the wrist.

Other areas of interest for Dr. Pidcock include the rehabilitation of children with pediatric transverse myelitis and musculo-skeletal manifestations of chronic graft vs. host disease. He is also involved with the development of outcome measurement tools for children with burns.

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The Transverse Myelitis Association to Fund the Johns Hopkins Transverse Myelopathy Center for 2002-2003

The Transverse Myelitis Association is pleased to announce the award of a $50,000 grant to the Johns Hopkins Transverse Myelopathy Center for the 2002-2003 fiscal year. The grant will fund the Research Program Coordinator position at the JHTMC. The Johns Hopkins Transverse Myelopathy Center was established in October 1999 as a multidisciplinary center dedicated to the diagnosis and treatment of Acute Transverse Myelitis (ATM) and to better understanding of the pathophysiology and natural course of the disease. The Center of Excellence has several explicit goals:

- To provide expert care and treatment for patients in the acute phase of ATM;
- To extend the spectrum of care through collaborative management of the disease condition by health care providers from multiple disciplines: neurology, urology, physical medicine and rehabilitation, rheumatology, physical and occupational therapy, neuroradiology, and neurosurgery;
- To develop standard diagnostic criteria and work-up for patients based on clinical research to understand the natural course of the disease;
- To perform clinical and basic science research in order to comprehend the pathophysiology of ATM;
- To devise novel therapeutic interventions for patients in the acute and convalescent stages of ATM;
- To coordinate international symposia as platforms for both physicians and patients to interact and share theories and advances in research and management of ATM; and
- To publish and disseminate the knowledge gained through clinical practice, research and international symposia to community physicians to target recognition of the disease in the community.

The JHTMC is the only medical center in the world focused on the treatment of ATM and research on ATM. Since its inception, Dr. Kerr, the Director of the JHTMC, has cared for hundreds of adult and pediatric ATM patients. In addition to his own practice at Johns Hopkins, Dr. Kerr also consults with physicians from all over the world to offer care for ATM patients. The experience and expertise he is acquiring about ATM is invaluable to our community. As the goals of the JHTMC identify, Dr. Kerr is also committed to disseminating the information he develops at the TM Center through publications, through symposia with other physicians and in educational meetings with ATM patients and their caregivers.

In addition to caring for ATM patients, the JHTMC is committed to basic and clinical research on Acute Transverse Myelitis. Dr. Kerr is involved in numerous ATM research projects. He is also coordinating a large number of projects involving other physicians at Johns Hopkins and employing a multidisciplinary approach. Dr. Kerr is also engaged in

a large-scale project to encourage ATM research in a consortium of physicians and scientists who will share data and information about the condition.

The existence of the JHTMC has changed the future for the TM community. What were hopes for our community just a short time ago are now becoming realities. There is a focused and organized effort to develop the best possible treatments for ATM symptoms. There is a focused effort to perform research to better understand ATM. There is a community of physicians and scientists who are energized to find the answers to the many questions that surround ATM. These physicians and scientists work for institutions around the country and around the world. The TM Center at Johns Hopkins provides the initiative and the coordination for much of this activity.

Meeting the TMA goals of education, awareness, and advocacy for ATM research have all been intensified and accelerated by the establishment and growth of the JHTMC. It is absolutely imperative that the Johns Hopkins Transverse Myelopathy Center continue to thrive and expand. The TMA is committed to that purpose. The TMA will continue to work closely with Dr. Douglas Kerr and Chitra Krishnan to find funding sources for the JHTMC. The TMA remains committed to raising funds for the important research projects of physicians and scientists from across the country and around the world that are central to the needs and the hopes of the TM community.

Centers of Excellence dedicated to the study of rare diseases provide a common platform for patients from all over the world in search of sophisticated treatment and understanding of their disease condition. Patients benefit from an interdisciplinary approach to providing state-of-the-art care that is constantly challenged and enhanced by ongoing research. Further, these centers aid the advancement of research to better understand the disease condition and to develop novel and effective therapies by bringing together interested physicians and patients. Study of rare diseases is very challenging because of the need for standard diagnostic criteria and acceptable protocols of care that need to be developed based on research and the experience of physicians and scientists and their understanding of the natural course of the disease.

Research at the Johns Hopkins Transverse Myelopathy Center

Chitra Krishnan

Acute transverse myelitis (ATM) is a very rare disease that affects people of all ages regardless of gender. To date, there have been two incidence studies published that establish an incidence rate of 1-4 new cases per million per year with peak incidences between the ages of 10-19 and 30-39 years [1;2]. There is no single etiology for ATM. In many cases, the clinical syndrome with a sudden and acute onset may be the result of damage to neural tissue by an infectious agent or by the immune system or both. Studies to date that have characterized acute transverse myelitis have suggested that rapid progression of symptoms, the presence of back pain, signs of spinal shock, areflexia, flaccidity, abnormal somatosensory evoked potentials, abnormal imaging, and high deficit score at onset may serve as indicators of poor prognosis for ultimate recovery [3-8]. Approximately a third of the patients have been reported to recover with little to no sequelae following the initial attack, one-third are left with a moderate degree of permanent disability, and one-third have virtually no recovery and are left severely functionally disabled [1;8;9].

The Johns Hopkins Transverse Myelopathy Center was established in October 1999 as a multidisciplinary center dedicated to the diagnosis and treatment of acute transverse myelitis (ATM) and to better understanding of the pathophysiology and natural course of the disease.

During the second International TM Symposium in July 2001, we formally established a network of regional centers of excellence in transverse myelitis. Institutions affiliated with the Consortium include Johns Hopkins University (Baltimore, MD), Mayo Clinic (Rochester, MN), Mayo Clinic (Scottsdale, AZ), Yale University (New Haven, CT), Washington University (St. Louis, MO), University of Miami (Miami Project to Cure Paralysis (Miami, FL), University of New Mexico (Albuquerque, NM), University of Kentucky (Lexington, KY), University Hospital of Antwerp (Belgium), Cleveland Clinic Foundation (Cleveland, OH), The Ohio State University (Columbus, OH), University of Washington (Seattle, WA), Tuft's University (Boston, MA), The George Washington University (Washington, DC), Children's Medical Center, University of Texas Southwestern Medical Center (Dallas, TX), University of Florida, North Florida/ South Georgia Veterans Health System (Gainesville, FL), Barrow Neurological Institute (Phoenix, AZ), Indiana University School of Medicine (Indianapolis, IN).

One of the first collaborative efforts of the consortium was the

establishment of uniform diagnostic criteria and nosology of acute transverse myelitis (ATM) to ensure a common language of classification, to reduce diagnostic uncertainties and to lay the groundwork necessary for multi-center clinical trials. These criteria were developed using the existing review of the literature and the vast experience of the medical providers in the Consortium with patients who presented as ATM. Distinguishing the presentation of ATM as either idiopathic or disease-associated needs to be determined early in the acute phase as timely and accurate diagnosis and identification of the etiology is very critical to the management of the disease. We developed a diagnostic algorithm as a first uniform step to improved care by detailing a possible complete work-up to ensure timely and accurate diagnosis. The paper was recently published: Transverse Myelitis Consortium Working Group. Proposed diagnostic criteria and nosology of acute transverse myelitis. N*eurology* 2002; 59: 499-505.

In order to gain an understanding of the disease, it is critical to determine what the various triggers of the inflammation are that induce neural injury in the spinal cord. It is also important to understand the cellular and humoral factors that play a role in the process. Finally, it is imperative that we discover ways to modulate the inflammatory response in order to improve patient outcome. Dr. Douglas Kerr, the Director of the Center and Harold Ayetey from the University of London, have recently published a paper on the "Immunopathogenesis of acute transverse myelitis." The paper is a review of the potential immunopathogenic mechanisms in ATM summarizing all of the recent discoveries relying, when necessary, on data from related diseases such as ADEM, GBS and NMO. This review was recently published: Kerr, DA and Ayetey, H. Immunopathogenesis of acute transverse myelitis. *Current Opinion in Neurology* 2002; 15: 339-347.

The JHTMC has established an ongoing extensive clinical database where we currently have more than 250 patients. All patients referred to the Center are given a questionnaire to complete during their initial visit. Data related to their illness, antecedent factors, clinical symptoms during the acute phase, radiologic characteristics and treatments received is gathered and entered into the database. They are then followed over time and their progress is charted and recorded. We currently are exploring the dataset to understand the demographics, natural course of the disease, characterize it further based on similarities, understand prognostic variables, and validate our diagnostic criteria. This database also serves as a clinical repository for future clinical studies and trials.

In collaboration with Dr. Frank Pidcock and Dr. Melissa Trovato in the Department of Physical Medicine and Rehabilitation, we are currently analyzing our dataset to study any differences in pediatric and adult idiopathic ATM. Is pediatric ATM a clearly different entity? Can we predict the outcome of a child? To date, we have about 30 pediatric cases of idiopathic ATM referred to us from all over the world and about 100 adult patients that meet our diagnostic criteria. To our knowledge, this is the largest database of idiopathic cases. Disease-associated ATM has a known etiology enabling a better characterization of the disease and consequent therapies. Idiopathic ATM, on the other hand, is a challenge to identify and manage. We hope to be able to capture the characteristics that distinguish idiopathic ATM patients that eventually completely recover from those who do not.

To further assist this study, we have a clinical repository of blood and CSF of patients both in the acute and convalescent phase. Some of the ongoing studies include identification of serologic markers that define and characterize transverse myelitis both from a diagnostic and prognostic point of view. We work closely with the Department of Rheumatology (Dr. Laura Hummers and Dr. Fred Wigley) in an effort to understanding the mechanisms of ATM in patients with serologic or clinical evidence of connective tissue disease such as sarcoidosis, Behcet's disease, Sjogren's syndrome, SLE and mixed connective tissue disorder.

In partnership with Dr. Neal Halsey and the Center for Immunization Safety Assessment, we are presently working on developing a case assessment/retrospective case-control study to determine whether there is any association between vaccination as a preceding event and idiopathic transverse myelitis.

A subset of our patients with ATM (N=40) have been found to have recurrent transverse myelitis. We have defined recurrence as the presence of more than one episode meeting the criteria for ATM with intervening improvement and excluding the presence of MS. More than half of these recurrent cases are idiopathic in etiology. We are currently analyzing the serum of these patients for specific markers, such as antibodies to the SSA antigen (also known as Ro antigen) seen in patients with primary Sjogren's syndrome, SLE, connective tissue diseases and in babies with neonatal lupus erythematosus that may be associated with recurrent events.

Douglas Kerr, MD/PhD and David Irani, MD, Co-Director of the JHTMC, published a paper on the presence of 14-3-3, a neuronal protein, in the CSF as an indicator for poor prognosis in the Lancet 2000 Mar 11;355(9207):901. This is an ongoing study; we have analyzed the CSF of more than 50 patients with idiopathic ATM and are currently studying the association of the 14-3-3 with outcomes such as ambulation. We are also looking for various cytokines and other markers in order to correlate them with clinical outcome. Other studies include characterization of lymphocytes present in the CSF during the acute phase of ATM, and examination of the capacity of CSF from the acute phase of ATM patients to cause morphologic alterations and apoptosis of human cultures neurons.

The JHTMC is considering the use of magnetic resonance spectroscopy to further define the spinal cord lesions in ATM patients. This would better enable us to characterize and follow recovery of patients with ATM.

In order to further our research efforts, we are currently developing an internet-based ATM database on a secure server. We hope to include information from all of the patients who present with features of ATM at all of the Centers in the Consortium. This would further enable us to study clinical features and natural history of the disease, while assessing our diagnostic criteria and algorithm. By including more Centers, the data will tend to have less referral bias.

Jointly with Dr. Adam Kaplin, MD/ PhD in the Department of Psychiatry and Neuroscience, we are currently studying depression and cognitive function in ATM. ATM patients seen at the Center are given a questionnaire called the SCL-90 to assess the presence of depression and its severity. Depression is quite common among ATM patients. It often leads to decreased compliance with physical therapy regimens and adversely affects ultimate outcome. We also administer four neuro-cognitive tests to ATM patients. These tests look for subtle cortical and sub-cortical changes that might be reflective of neurocognitive deficits.

Rehabilitation is a very integral part of the recovery and treatment of ATM patients. We work closely with the Physical Medicine and Rehabilitation team (Drs. Ling-Ling Cheng, Rosemarie Filart, R. Sam Mayer) constantly assessing and seeking effective rehabilitation measures and management. Patients are often left with permanent weakness following ATM and spasticity which limits the extent of recovery. Patients report stiffness, tightness, or painful spasms often in the buttocks and legs. Ongoing projects include spasticity evaluation and treatment with new drugs, such as tiagabine and use of a tone assessment device for formal functional gait assessment, intervention spasticity management with the Baclofen pump and use of 4-AP (fampridine) in the functional improvement of ATM patients.

Bowel-bladder and sexual dysfunction are common problems in ATM patients. Current investigations are underway to characterize the extent of autonomic dysfunction and recovery, along with new therapies, such as sacral nerve stimulation that could allow patients to have reduced or eliminated need for intermittent catheterization. Using data from these preliminary studies, we hope to elicit recovery patterns in bladder and sexual dysfunction and provide the basis for clinical trials and other future interventions.

Basic science studies are focused in two areas: neuro-regeneration and developing an understanding of neural injury in ATM through the creation of an animal model. Specifically, we have created a focal inflammatory mouse model which replicates many of the clinical and pathologic features seen in humans with ATM. We hope to utilize this to further understand how the immune system injures the nervous system. We are also exploring the clinical potential of embryonic stem cells, Schwann cells and olfactory ensheathing cells (OECs), which seem to show great promise in the near future.

The JHTMC has a long-term and intensive commitment to both basic science and clinical research. We are focused on better understanding the disease process so that we can find effective treatments for the patient at the onset ATM. We are also dedicated to finding more effective treatments for patients who suffer from the chronic symptoms of ATM. Finally, we are committed to finding approaches to neuro-regeneration, in order to stimulate functional improvements for all short-term and long-term patients with ATM.

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If we can motivate 3000 TMA members to raise $1000 per year, we will have $3 million per year to fund TM research!

The TM research that is being performed at the Johns Hopkins Transverse Myelitis Center is very exciting. That we have one of the premier medical centers in the country and the world interested in TM is the most hopeful development to occur for all of us in the TM community. There is so much potential in what can be accomplished from basic and clinical TM research at the JHTMC. There are other doctors interested in TM research from other medical centers around the country. Most of the physicians on our medical advisory board are doing research in TM or in areas related to TM. If we were funding this research, it would be research **directly** on TM. There are physicians and scientists doing a great deal of research on areas that are related to TM, both in the areas of improved treatments for symptoms and in cure research; this can be seen in a review of the program agenda from the 2001 International TM Symposium in Baltimore. If the TMA were funding TM research, these are the physicians and scientists who would be interested in pursuing this funding for basic and clinical research. Outside of the federal government, which has yet to make a commitment to fund TM research, it is going to be the TMA that makes the long-term and sustained commitment to funding TM research, and **only** TM research.

This has been a watershed year for me in regards to my work with The Transverse Myelitis Association. I have learned so much. It has certainly been my busiest year doing work for the Association. So busy, in fact, that I never had a chance to publish the second newsletter this year. And for that I am so sorry. Honestly, I deeply apologize for missing this newsletter. I know just how important these communications are for our membership. This is one of the lessons I learned this year; I am not allowed to become so busy on one project that other projects do not get completed. I was busy planning the TMA Children's and Family Workshop. From July 10th 2001 until the workshop started on July 18th 2002, I spent every single day raising money. And I do mean every single day. The good news is that I was able to raise over $70,000. The bad news is that I was only able to raise $70,000. From my background and perspective, this is a lot of money. From the perspective of effort and the time I committed to this endeavor, it is not a lot of money. And I was raising this money for children. It should be easy to raise money for children who have Transverse Myelitis. It was not easy.

Oh, the lessons learned. First, I want to thank all of the TMA members who made generous contributions to the Children's Workshop. We could not have done this without you. And what we did for these children and their families was just awesome beyond words to describe. The parents learned so much and the children had a great time. The children met others with TM that they will stay in touch with for the rest of their lives. These kids really bonded during the workshop. The parents were able to spend a weekend together sharing and learning. They needed this time with each other.

I was so touched by the generosity of our membership; please go to the Children's and Family Workshop page on our web site and review the list of contributors. We received tremendous support from our TM community. A group of parents really made an exceptional effort to raise the dollars for the workshop: Jack and Joanne Callahan (the Claddagh Foundation); Cody and Shelley Unser (the Cody Unser Firststep Foundation); Maureen and Walter Hallagan; Steve and Colleen Blandford; Cathy and Dan Dorocak; Tom and Jeanne Hamilton; Gail Hirsch; Morgan and Pam Hoge; and Rickey and Jenita Woods. Thank you so much to **everyone** who helped to make this happen.

I committed to everyone who made a donation that every penny above our costs for the workshop would go into our TM research fund. We are completing the final bills for the workshop, but because we begged and borrowed so many of the goods and services for the workshop, close to $40,000 from this fundraising is going to be added to our TM research fund.

This is all great news. So, what's with the lessons?

When I first became involved in the Association work, I told Pauline that I would do anything to help people and to help the TMA. But I did not want to get involved in the money part of this thing – not at all. It was not that I didn't have an interest in it; I was allergic to the idea of being involved with the money side of the work. And I avoided it for a long time. We have never had membership fees. We weren't raising much money, and it was easier to pay for everything out of pocket than it was to start asking people for money. We operated this way for a long time; this is all evident from the financial statements we publish each year. The costs finally became greater than we could afford to cover, and out of necessity, we began seeking contributions from our members with some earnestness; okay, with outright desperation. Thus the remittance envelope appeared.

The Association was growing. The membership was certainly growing quickly. Dr. Levy initiated our medical advisory board. Dr. Kerr established the Johns Hopkins Transverse Myelitis Center. The activities of our small organization began to become much more complex and the work intensified. But more than anything, the potential for what we could accomplish began to explode. With the focus on TM at Johns Hopkins, doing TM research was no longer a hoped for goal; it was a reality. And my not being involved with money issues was no longer realistic. If I was going to do my job; if I wanted to see the goals of the TMA accomplished; if I wanted to see the people I love benefit from the results of TM research, I was going to need to become very involved in fundraising.

So, I have become involved. For the past year, I was involved every day. Where do I focus my energy now – **on getting you involved!** I have to get you involved. I cannot do this alone. That was another lesson learned this year. In 365 days I raised $70,000; that is not enough money for our operational needs and our research needs.

Here are some additional lessons….

The pharmaceutical companies are not going to fund TM research. If there are 34,000 people in the United States with TM, we are never going to look like a market to these companies. They do research and they develop medications that benefit TM patients, but they are not going to be directly involved in funding TM research. I spoke with representatives from all of the companies who manufacture the medicines that all of you are taking. In almost every case, the conversation began with my having to describe and explain Transverse Myelitis. Most had never heard of it. Those who had did not know anything about it. Do not count on TM research being done by pharmaceutical companies.

Foundations are not falling all over themselves anxiously waiting to fund TM research. I could wallpaper my kitchen with the rejection letters I received from foundations that fund health-related organizations. Again, I was applying for money to help children. Many of these grant applications went to foundations that specifically fund health-related education and some are focused on spinal cord injuries and diseases. From all of the foundation applications, we received only one foundation grant; and that grant was facilitated by a physiatrist on their board who understood TM.

Medical supply companies and adaptive equipment manufacturers were great. We received grants from many of the local companies that work with TM patients and from national manufacturing and distribution companies. Most are not in the same league as the pharmaceutical companies. Their grants were small, and they are not ordinarily involved in funding basic research.

These were all difficult lessons for me, because I take all of these issues so personally. The failures are painful. I would receive an envelope from one of these companies and foundations in the mail, and Pauline would hide under the couch while I opened it. Almost all of the time I had the opportunity to become

outraged; almost all of them were rejections. "How could they reject us? The quality of this program is outstanding; just look at the quality of our presenters. We are helping children who really need this help. Who could be doing something more worthy with these dollars? This stinks!" Then Pauline would get out from under the couch and ask me to please not have a heart attack. How can you not take this personally?

The most important lesson … far and away the greatest support I received for the workshop came from other people who have TM and from my family and friends who understand what TM has done to Pauline's life and from the family and friends of the people in the TM community.

As I have written before, and as I will write many more times in the future, if we are going to raise money for TM research, we are going to have to be the people who do it. Do not look to anyone else to accomplish this task; no one else is going to do it. So, I have to raise money, and I have to convince you that you have to raise money. And then I have to motivate you to raise money. And that is a lot of work about money from someone who does not want to be involved with the money part of this job.

I know American culture. In fact, I'm a cultural anthropologist, so I am supposed to understand American culture really well. I think I do. And I think we're fascinating.

I want to share with you some of what I believe gives the TMA credibility in asking you to get involved with fundraising and also in asking you for donations.

No one who works for the TMA gets paid. We spend hundreds and hundreds of hours of our time and do so entirely on a voluntary basis. The TMA has no employees whatsoever. We have almost no overhead. The officers of the Association pay for their own computer equipment and supplies, office equipment, office supplies, internet access, phone bills, including long-distance phone bills and we all work out of our homes. All of the funds we receive go directly to offering services to our members. The vast majority of our operating costs are for the printing of information that is distributed to our members and for postage.

We are frugal about every penny we spend. If we can get it donated, we try to get it donated. If doing it ourselves will save a few dollars, we do it ourselves. I was at a meeting recently and was explaining the process I use to publish and mail the TMA newsletters and directories to thousands of people in more than 60 countries. When I completed my description, a person in the audience remarked that she was also involved in mailing a newsletter and it sure sounded as though I was doing this the hard way. Believe me, I know I am doing this the hard way. The easy way would be for me to pay a company to do all of the collating, stuffing, sealing, labeling, sorting and mailing. Unfortunately, there is a cost associated with every one of these steps. The more steps I do, the less the total cost of the job. So, I manually sort the zip codes for a bulk mailing. My eighty year old father and twenty year old mother go through the more than 3600 labels and systematically put them onto all of the envelopes. I have already put return labels on each of these envelopes and have stamped the postage on them. Then I invite family and friends over to my house for a weekend to collate, stuff and seal. Finally, I take a day off of work, borrow my ex-wife's truck, and take a truckload of sacks to the post office. It sounds gruesome, it is gruesome, but it saves us a lot of money. Money that we would rather see go to TM research.

We have not used TMA resources to pay for travel. When the TMA board members travel to a symposium, they pay their own travel, hotel and food expenses. The board members pay their own registration fees. Board members pay their own way to Board meetings. When the Johns Hopkins TM Center opened, we thought it was important to have the Board represented at this auspicious occasion. Our representative, Dick Gilmur, paid his own expenses to get to Baltimore for this event.

Beyond the printing of our remittance envelope, we do not use TMA operating funds for the purpose of fundraising.

Americans want their organizations honest, open, frugal, and smart about how they spend money and invest money. What Americans want from non-profit organizations is all of these qualities to the tenth power. We have worked very hard since 1994 to build your trust in the TMA and to build our credibility. You should emphasize all of these characteristics of the TMA when you are fundraising among your family and friends. We are very proud of the TMA; you should be also.

Why do we need TM research and why should you care about it? We need TM research because TM is not MS, it is not Devics, it is not a traumatic spinal cord injury. We need for the doctors to figure out what the disease process is for TM. What is TM? What causes TM? As you read in the JHTMC research article, the doctors are just now beginning to search for the answers to these most basic questions. TM research will result in a better understanding of the disease, and it will result in better

approaches to treating people at the onset. Will that research help Pauline or Cody or Jim or Rachel or Kevin or Stephen or Maureen? Probably not. But I would never want for another person to go through what our loved ones have experienced. If we can help them, we should. **No one else is going to help them. It is us or no one.** Are we getting the picture yet?

You should be interested in supporting TM research because this research is going to result in improved approaches for treating TM symptoms. Symptom management research is one of the important areas of concern at the JHTMC. TM research at the JHTMC is also focused on cure research. One of the most exciting discoveries in this research is that only small increments of physical improvement can result in significant functional gains for a person with spinal cord injury or disease, such as TM. I am so hopeful for this exciting future. And I want this future to arrive as quickly as possible.

There is another very important reason to consider funding TM research. It is the case that the research being performed on traumatic spinal cord injury and myelin regeneration, as well as in other areas of medicine has a positive benefit for TM patients. When it comes time for clinical trials, however, I am not at all certain where TM patients are going to fit into the schemes of some of these institutions. It may be that those institutions that have been heavily funded by families who have been impacted by traumatic spinal cord injury only want clinical trials focused on those patients. It may also be that there are considerations about the characteristics of the trial population which would discourage the inclusion of TM patients. I had a discussion about this issue with Dr. Kerr. This is the information he shared with me about research and clinical trials:

*There are significant similarities and parallels between traumatic and non-traumatic spinal cord injury (SCI). It is important to understand this and draw knowledge from fields related to Acute Transverse Myelitis. Fundamentally, there are common pathways of neuronal death even if the initial injury is distinct and varied. However, there are basic differences both in the acute phase and long after initial injury between traumatic and non-traumatic SCI. The extent of scar tissue is much more in traumatic SCI, the distribution of injury in the spinal cord is different, cellular glial reaction to injury is different between the two. It is, therefore, at least probable that the fundamental mechanism of regeneration will also differ. Thus, to fund traumatic SCI centers will beget clinical trials in traumatic SCI only. No trial will enroll patients with both. The only way to conduct clinical trial research in ATM is to generate a better understanding of this and only this disease process (*Dr. Kerr, personal communication).

When the time comes that there are clinical trials available at the Johns Hopkins Transverse Myelitis Center, only TM patients will be included in these clinical trials. And as you have read in the previous article, the clinical trials will concern both improved treatments for TM symptoms and procedures to restore myelin and nerve cells.

I have been asked over the years how much it would cost to fund TM research projects. The following information should help you understand something of the scope and costs associated with medical research. There is basic science research and then there are clinical trials. I have categorized each class of research into small, medium and large project categories.

In regards to basic science research, the total cost of a small project might be from between $15,000 to $30,000 per year for three years. The costs would cover such expenses as 50% of a technician's salary and supplies, such as equipment and reagents. A medium grant might be for about $100,000 per year for three to five years and very often involves salary support for the principal investigator, as well as salary support for a graduate student, a technician and a post doctoral student with about $40,000 of costs associated with equipment and reagents. A large basic science grant would focus on one broad research subject with different sub-projects and goals. Typically, the costs of large projects would be from $250,000 to $300,000 per year for three to five years. The costs would include approximately 30% of the principal investigator's salary support, the support of two technicians, a graduate student and a post doctoral student and about $150,000 for reagents and supplies.

A small grant for clinical research could cost anywhere from $50,000 to more than $100,000 per year. The money is typically used to provide salary support so that a researcher's time may be used to carry out clinical research. Small projects do not involve clinical trials.

Medium to large clinical trials are driven by those who will profit from them. These are projects with costs that are typically between $500,000 and $1.5 million per year. Very rarely are these projects supported by private foundations; they are generally funded by such entities as pharmaceutical companies and stem cell companies. The grants cover the

salaries for a principal investigator, a nurse, a clinical coordinator, and a center coordinator, as well as other equipment and supplies.

So, here is the challenge for you and me. First, we need to keep The Transverse Myelitis Association operating. If you are in a financial position to help us, please use the remittance envelope and send us a donation to help us with our operating expenses. Please keep in mind that the only support we receive comes from those of you in the TM community.

And the second and bigger challenge is that we need to hold ourselves accountable for raising money for research. You do not need to be wealthy to do this fundraising. You do not need wealthy friends and family to do this fundraising. You only need to be motivated. Please read the articles about how people are raising money for the TMA; hopping, shooting hoops, reading books, playing golf, having dinner parties, holding raffles. There are so many different ways to raise money. How you do it is really not the primary issue. The focus of the activity is to approach those people who are closest to you; your family, your friends, your neighbors, your co-workers. These are the people who have the most intimate knowledge of how TM has impacted your life and these are also the people who care about you the most. These are the people who will offer you the greatest financial help. You ask them to sponsor you for the number of books you read or the number of times you hop or the number of hoops you make; what you do to raise the money should be motivated by your interests. The important focus should be to get these people involved and to keep them involved.

Our challenge is not to do a fundraiser; our challenge is to do this fundraiser every year. We will not succeed at our goals if we raise money for TM research one year and then take a nap on the couch for a couple of years. Once we begin to fund TM research, we will not be taken seriously by the medical and scientific community unless we are able to sustain TM research on a regular basis.

Here's what I am going to do to meet my end of the bargain. I am going to have a golf outing every year. I love the game of golf, so this is an activity that I can do every year. If I chose an activity that I do not have a passion for, I know I will not be able to do it every year. I am going to approach my family and my closest friends and also the people with TM in my community, and their family and friends and I am going to invite them to get involved in the planning of the golf outing. I will be able to raise much more than my $1000 share from this fundraiser and I know that I can create a social opportunity for people in my community with TM, and I know that I can also create some awareness about TM in my community. Pauline is meeting her commitment to fundraising by participating in the Reading for Rachel Program in her school and in all of the elementary schools in her district. Pauline will also be available to tell me everything I am doing wrong while conducting the golf outing.

Are we going to have to raise this money for research forever and ever? I hope not. I do eventually want to go lie down on the couch, eat a sandwich, and give a Browns game my undivided attention. It is my great hope that the NIH will eventually focus on and fund TM research. But I have no control over the NIH, so I have no idea if and when they are going to do the right thing. I only have control over me. So, I need to do what I can.

Funding TM research should not be an American issue. Over the years I have come to feel a close kinship with our TM community around the world. I have gone from offering information and support to people in need to experiencing friendships with people for whom I deeply care and love. We are an international TM community. So, Steve and Ali, and Errol, and Ulrika, and Ursula, and Tanishka, Yvonne, Geoff, Ann, Ian, Mary-Jo, Mette and Thomas, Roland, Netta this research is for you also. What the JHTMC learns about treating TM patients and curing TM patients, will be shared with your doctors in your countries. Dr. Kerr is already working with physicians from all over the world. He will consult with doctors from all over the world and he will share research results with doctors all over the world. We need your help. Please get involved in fundraising for TM research! And please encourage the members from the TM communities in your countries to get involved, as well.

So, when is the TMA going to begin funding TM research? I don't know. Here is what I do know. We cannot raise $100,000, fund three small basic science projects, and then have to wait three years before we raise enough money to make available the next request for research proposals. In the three years the TMA is absent from the scene, physicians and scientists will find new hobbies. We have to be able to make a commitment to fundraising that is sufficient for the scientists to be willing to make a commitment to TM research. I think that is the bargain. We will begin to fund research when there is a steady and fairly predictable stream of funds being generated for TM research.

This is going to happen as soon as I

can figure out how to motivate all of you to get involved and raise TM research dollars. If it takes a year, I will be delighted. If it takes ten years, I will be less delighted, but I will be satisfied. I am not going to get discouraged about how long this takes; but we are going to do this. We have to do this. We owe this to those of you who have suffered with TM for decades; we owe this to those of you who have suffered with TM for the past couple of weeks. We owe this to the people who are going to contract TM tomorrow. We owe this to the children with TM who are just beginning their lives.

I remain allergic to the money thing. But you have all changed me. I know what is possible for you. I know what needs to be done for you … days without pain, days with control over your bowels and bladder, being able to share a totally and mutually satisfying physical sexual experience with your companion, being able to carry the trash to the curb. I will remain committed to this goal, however long it takes. We are going to raise this money; we have to make this research happen.

One final point, we have a wonderful, incredibly competent, committed medical advisory board. The physicians on our board are researchers and scientists, as well as physicians. They are going to help us design the research program and the process for requesting, reviewing and awarding grants. We are going to rely on their wealth of experience and expertise in this area. The TMA board is going to be well-guided by the medical advisory board in developing a program that will attract the best researchers and the best research projects.

I can remember talking about funding TM research before I knew Dr. Kerr and before there was a JHTMC. I knew this was something we should do and that we needed to do. But my notion of this research was almost ephemeral; I did not know anyone who was doing anything that looked remotely like TM research. Well, that situation has certainly changed. TM research is being done, and we have a group of brilliant doctors who are doing all kinds of research related to TM. Given the money, we will attract them to doing TM research. An ephemeral notion has evolved into a sense of urgency about not losing an opportunity.

Please get involved. Please make a commitment to raising research dollars. Please make the commitment to raising these dollars from your family and friends every year. We can make a difference for ourselves and for those in the future who are going to suffer with these same horrible symptoms. Please help me help them! Please help me help you!

Chronic Pain Control Using A Spinal Cord Stimulator: A Patient's Perspective

Rick Steele
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Coping with chronic pain can be one of the most difficult challenges the Transverse Myelitis patient will face. Over time, the pain can become overwhelming, leading to sleep disturbances, immobility, and major depression. Quality of life is significantly decreased. This pain will gradually become more difficult to control, interfering with daily activities, family-life, and the ability to function productively at the job. The increase overtime of the intensity and duration of the pain commonly results in heightened distress, as well as other psychological and psychiatric disturbances. This pain can so severely compromise the quality of life that some patients will do anything to alleviate the pain. All hope of any recovery is lost.

As a Transverse Myelitis patient with chronic neuropathic pain since my initial insult in August 1996, this is exactly how I was starting to feel. All hope for any relief was gone. For many years I believed that my pain was just a part of my condition, something that I would have to learn to live with for the rest of my life. Finally, after five years, I hit a wall of no longer being able to tolerate the constant daily pain. I was having a burning sensation diffused throughout my legs, feet, toes, thighs and buttocks. I quickly developed depression and very low self-esteem. I did not want to live any longer, if each and every day of my life I had to wake up to more intolerable and debilitating pain. I was using over-the-counter pain medications such as aspirin, extra-strength Tylenol, and ibuprofen, combined with physical therapy, biofeedback, self-hypnosis, and ice wraps. Eventually, overtime, all became useless in controlling my pain.

My doctor informed me that I did not have to live with severe chronic pain; there were available treatment options. However, it would be necessary to work me through a list of these options, using a combination of drugs before analgesia (pain relief) might be achieved. My doctor cautioned that pharmacological management can produce the desired analgesia in some patients but not all. He also informed me that any relief produced might be tempered by the drug's associated side effects. Our therapeutic goal became improvement of the quality of life by pain reduction, mood elevation, increased mobility, and better sleep with minimal side effects.

Neuropathic pain can be very resistant to treatment. I was immediately started on Lidocaine patches (topical

anesthesia agent), Topamax, Neurontin (anticonvulsants) and Wellbutrin (antidepressant). With a medical condition like Transverse Myelitis, nerve messages traveling through the spinal cord may become scrambled and misinterpreted in the brain as pain. Therefore, medications that work directly in the brain, such as anticonvulsants and antidepressants, have been successful in treating neuropathic pain in some patients. Trying to identify the "right" dose and combination of each drug is a trial-and-error process. After several months of close monitoring while titrating my drugs, I was ingesting up to 4800 mg. of Neurontin, 400 mg. of Topamax and 300 mg. of Wellbutrin daily. This combination of drugs was starting to relieve my pain; however, major side effects appeared abruptly. These side effects, which were starting to interfere with my general good health and ability to have an improved quality of life, were blurred vision, double vision, somnolence, dizziness, ataxia, loss of ability to concentrate, loss of appetite and nausea. Severe diarrhea necessitated a quick tapering of all drug therapies. And with that, intolerable pain had returned. My only option was to start narcotics in a high dosage. I took up to 120 mg of oxycontin every six hours, yet with only minimal relief.

Medications are used to treat chronic neuropathic pain, if the benefits of the drugs are greater than the possible side effects. For me, whose pain therapy was no longer effective and caused serious side effects, my treating neurologist referred me to a pain specialist for evaluation of Advanced Pain Therapy Neurostimulation.

Advanced Pain Therapy Neurostimulation is a revolutionary treatment for chronic pain and is a proven alternative to medications and other therapies for pain control. Advanced Pain Therapy Neurostimulation uses a small surgically placed neurostimulator that sends electrical impulses directly to the spinal cord or peripheral nerves. These electrical impulses block the pain signal from reaching the brain. Having the diagnoses of both Transverse Myelitis and diffuse pain throughout my legs, feet, toes, thighs and buttocks, the area of treatment and stimulation would need to be directly on my spinal cord. Spinal cord stimulation has been proven beneficial in treating chronic pain of the trunk and lower extremities.

The Spinal Cord Stimulator (SCS), also known as a Dorsal Column Stimulator is the particular neurostimulator used directly on the spine for the treatment of severe chronic pain. This device consists of a surgically implanted pulse generator producing low-level electrical impulses delivered directly to the spinal cord via leads surgically inserted in the epidural space. These electrical impulses interfere with the direct transmission of any pain signals traveling along the spinal cord to the brain. Painful stimulation is then replaced with a more pleasing tingling sensation in the areas where pain is usually felt. This sensation is referred to as parasthesia.

After the pain control specialist indicated that I would be an appropriate candidate for the Spinal Cord Stimulator, I investigated the different companies that manufactured the various available simulators and their different components. Company representatives were both willing and eager to meet with me, answer my questions, and to provide me with the names of other patients who recently had Spinal Cord Stimulators implanted. In addition, knowing that a Spinal Cord Stimulator requires an invasive surgical procedure with potential risk factors, I decided to seek second opinions regarding the appropriateness of a Spinal Cord Stimulator for a Transverse Myelitis patient. The Spinal Cord Stimulator is considered an advanced pain treatment modality; it is not a treatment option for everyone. In general, all conservative pain management approaches should have been tried and failed in adequately controlling pain before the use of a Spinal Cord Stimulator.

There are two companies in the United States that currently market the Spinal Cord Stimulator, Advanced Neuromodulation Systems, Inc. (ANS), and Medtronic. You may visit the ANS website at www.ans-medical.com or speak directly with a representative at their headquarters in Plano, Texas by calling (972)309-8000 or (800)727-7846. Medtronic's website is www.medtronicpain.com or they can be reached at their Minneapolis, Minnesota location by calling (612)574-4000 or (800)328-2518.

Each company offers two different types of Spinal Cord Stimulator systems: a fully implanted system with an internal power source, and an implanted system with an external power source. The major difference between these two systems is, of course, the location of the battery. Where as the internally-powered system uses a battery implanted beneath the skin, the externally-powered system uses a battery worn outside the body.

This fully implanted system's battery source is an Implantable Pulse Generator (IPG) consisting of the battery and related mechanics. Housed in a single metal container that is completely implanted under the skin, it is usually placed in the area of the buttocks or abdomen. The IPG, about 2 and 1/2 inches by 2 inches and 1/2 inch thick, creates and sends the electrical impulse to the spinal cord via wire leads that run from it to electrodes positioned in the epidural space of the spinal cord. This system requires additional simple surgical procedures from time to time to replace

the battery when it becomes depleted. Batteries usually last about three years. However, actual battery life is further dependent upon the particular settings and frequency programmed to treat your pain. This system can remain on 24-hours per day even while one showers, bathes or swims.

The externally-powered system has a similar IPG device known as a receiver that is much smaller in size, containing electronic circuits, but no battery. Like the IPG, this receiver is positioned under the skin in the abdomen or buttocks area. The receiver functions similarly to the IPG by sending mild electrical impulses to the spinal cord. It operates via radio-frequency signals that are passed through the skin from a transmitter worn externally on the belt. A replaceable taped patch with an antenna wire, which runs to the transmitter, is placed on the skin directly over the site of the implanted receiver. For the system to operate, this patch and antenna connected to the transmitter must be in place. Patients whose pain requires high energy levels to control their pain are good candidates for this system because no surgery is required for battery replacement. However, this system cannot be used while showering, bathing or swimming, and the external component can be difficult to carry as well as sleep with.

A Spinal Cord Stimulator company representative and the treating physician will assist the patient in selecting which of the two systems is better suited for the patient's type of pain. Generally, the internally-powered system (IPG) is the one to choose for simple pain patterns, which require less energy and therefore fewer battery replacements. The externally-powered system is better suited for the more complex pain patterns, because the battery is contained in the external transmitter and can easily be recharged.

An important fact to note is that the implantation of the stimulator is a two-staged surgical process. It involves a trial implantation of the spinal cord leads on a temporary basis to help determine if the therapy will be effective in the patient's pain control. A trial period may last anywhere from one to ten days. If the trial proves to be successful (pain is decreased by 50 percent or more), the patient will return to the operating room to have the complete system permanently implanted. Surgical pain from the incision site on the back will last for several days, but it heals quickly. However, pain at the IPG or receiver site on the buttocks can last up to six weeks as scar tissue is formed. Once the scar tissue is formed, this pain will disappear.

I have had the Advanced Neuromodulation System IPG (the internally-powered system) Spinal Cord Stimulator in place since April 2002 and have had a significant decrease in my pain. I'm currently only taking 10 to 20 mg. of oxycontin per day. A good outcome with the Spinal Cord Stimulator is defined as a decrease in pain by 50 percent or more. I'm experiencing about a 75 percent reduction in the debilitating pain that had been occurring prior to the implantation of the stimulator. This reduction in pain has provided me with the ability to start daily rehabilitation and to actively participate in a structured physical therapy program. As I become more familiar with the stimulator and when to utilize its various programs specifically programmed for my needs, I'm becoming more successful in taking control of my pain. After a prolonged investigation process, I chose the ANS neurostimulator. My decision was based on the fact that the ANS product is currently more technically advanced then the Medtronic system. However, both companies are aggressively pursuing more advanced spinal cord pain control technology and in no time at all Medtronic could have the better product. More importantly, I valued ANS for the professionalism, the responsiveness, and the genuine caring attitude demonstrated by the company's field service representative.

The treating physician and a field service representative will teach each patient about the use and care of the implanted stimulator. The patient will learn how to adjust the level of stimulation to control their pain throughout the day. Gradually, the patient will begin to take control of their chronic pain and do more of the things they were wanting to do. I have discovered that living with the spinal cord stimulator requires no extra time or effort on my part. However, I must take extra precautions around department store theft detectors, airport security, high-voltage power lines, and power generators as their magnetic power devices may cause an increase or decrease in the stimulation effect. Additionally, MRI (magnetic resonance imaging), ultrasounds and diathermy procedures should be avoided. All patients are provided with an identification card that contains important information about their implant. It should be used to alert medical personnel and others, such as airport security officers, that you have an implanted medical device.

It's over! What a great experience! What am I talking about? The two day conference on Transverse Myelitis that was held June 19-20, 2002 at the Sutton Place Hotel in Newport Beach, California. A conference made possible by a grant that the Cody Unser First Step Foundation received from the California Endowment fund for California residents. It was co-sponsored by the Cody Unser First Step Foundation and the Reeve-Irvine Research Center at the University of California, Irvine. What an exciting

time everyone had. We made new friends, learned a lot of new information from the speakers and from each other. We bonded, we cried, we got excited at some new ideas, some of us came away with a determination to start the ground work to build a network of support groups in the state.

Cody Unser First Step Foundation California TM Conference June, 2002
Cindy McLeroy

One of the attendees had been diagnosed with TM in 1964. Until this conference, he had never met another person with TM. We received first-hand information about the latest spinal cord research from the members of the research team at Reeve-Irvine Center. We met and heard from Dr. Kerr, Dr. Kaplin and Chitra Krishnan, MHS, all from the John Hopkins TM Center. We met Cody Unser, the founder of the Cody Unser First Step Foundation, who has a contagious upbeat attitude with so much energy directed towards raising research funding and awareness of TM.

Those of us who had never had the opportunity to meet Sandy and Pauline Siegel finally did so and wished we had been able to do so earlier. Looking back at those two days I am in awe of the people I met and their commitment to research, awareness and the support of each other with TM.

Over 100 folks attended the free event. There was a great mix of people in attendance. There were those of us with Transverse Myelitis, caregivers, physical therapists, clinicians, and doctors. It was great to see people that I have met through the years as well as to make new friends and to put faces with names of others with whom I have corresponded over the years. People were bubbling with excitement and anticipation of the programs ahead for the next two days and the opportunities to make new friends.

The first morning we heard from members of the Reeve-Irvine Research Center who each spoke about topics related to mechanisms of neural injury in the spinal cord. Oswald Steward, Ph.D, Director, Reeve-Irvine Research Center talked to us about the body's response to CNS injury. He described how our understanding of how the body reacts after an injury and what can be done to repair the damage is growing at a fantastic pace and the body's response to CNS injury. Hans Keirstead, Ph.D. spoke about potential treatments and clinical trials. The Reeve-Irvine Research Center currently has several potential treatments in the preclinical phase, on the verge of moving to phase I clinical trial. Aileen Anderson, Ph.D. spoke about inflammation. She described how the processes of degeneration and regeneration are intertwined in both their impact on, and potential benefits to, the goal of improved functional outcome in the injured spinal cord.

Another member of the Reeve-Irvine Research Center team is Maura Hofstadter, Ph.D., Director of Education and Scientific Liaison. She was a critical component of putting the event together and was an instant friend to many of us.

The morning session was followed by lunch. There was so much ebullience in the room as everyone was trying to meet as many other people as they could and to discuss the roads everyone has traveled with TM. Food was great too!

The afternoon session started with Dr. Doug Kerr. Dr. Kerr discussed the clinical features and prognostic factors of Acute Transverse Myelitis. Chitra Krishnan, MHS, spoke about Acute Transverse Myelitis being a group of disorders characterized by focal inflammation of the spinal cord and resultant neural injury. After our break we heard about symptom management in Acute TM. Leslie Morrison, M.D. from the University of New Mexico talked about Acute TM special issues, specifically pediatric Acute TM. Adam Kaplin, M.D., Ph.D. talked about the psychological impact of TM on a person. He addressed how the impact on individuals can be profound as they adjust to TM. The results can be prolonged sadness and demoralization. Other events can result in depression.

We had a group dinner. Great fun, friends and talk. Many of us talked with Cody Unser during the evening and are so impressed with her commitment to TM. She also is a regular teen-ager. We so appreciate her involvement with TM.

The next morning, after a continental breakfast, we heard Dr. Morrison discuss symptom management in Acute TM, including spasticity and gait. Dr. Kaplin spoke about urologic/sexual function and Dr. Kerr talked about Neurorestorative therapies. Sandy Siegel, Ph.D. and President of The Transverse Myelitis Association talked about quality of life assessments and caregiver issues. There was also a lot of great discussion on personal issues of the folks attending the conference. We learned a great deal from each other.

After lunch, another great meal, we had TM networking and breakout sessions. I participated in a group that had so much energy towards support

group activity. We brain-stormed some of the things we would be interested in seeing done in a support group. At the end of the day it was difficult to leave. Debbie Capen and I have agreed to co-coordinate initiating support groups in California. If you are interested, you can contact me using my email address at cindymcleroy@sbcglobal.net or calling me at (714)638-5493.

I sincerely hope that this conference was just the "FIRST" annual TM conference for California.

Cody wrote a really wonderful essay for a school assignment. She read it at the California TM Conference this summer. I thought it was great and asked her if she would let me publish her essay in the newsletter. Thank you, Cody, for allowing me to share your inspiring words with the TM community.

I had become quite comfortable with all of my friends, and since I had known most of them from my childhood, I could honestly say I knew their good and bad sides like the back of my hand. When my mom took me to meet Jade on that bitter, cold December day, I wasn't looking for any new friend. The day tasted like a stinging, rotten sour apple jolly rancher that would not go away. The first thing I noticed about her was how pale and rigid she seemed. Everything about her was mechanical, the way she moved and showed off. She had no color in her wardrobe. She

The Friend I Never Asked For
Cody Unser

dressed in nauseating metallic green. She definitely had a very high and strong opinion about herself for someone who was very ugly. She was relentless in trying to get to know me, which made me furious.

So, when my mom told me she was moving in with us, I was determined to get rid of her. She had to go everywhere with me, to the doctor's office, the mall, even with me to be with my true friends who I really cared about. It was so embarrassing to go out in public places with her. She was clumsy, awkward and didn't know how to act. She got in everyone's face and tripped everyone up. I even kicked her one time out of annoyance. So, finally, one day I decided to confront her.

"What do you want from me," I asked?

"I just want you to like me and let me be a part of your life. If you would just give our friendship a chance, I know we can do amazing things together," Jade replied.

So, I made her a deal. For one week I would include her in everything I did and I wouldn't judge her, as I would learn to become her friend.

That was three years ago. I now can say that Jade is the sexiest, most active, willful, out going, courageous, fun loving companion I have ever met. She lights up a room wherever we go. She understands me when I'm down. She lifts me up and takes me places I thought I would never be able to see. She pushes me out on the dance floor and shows me how to jive in my own atmosphere and paint the swift mood of the moment in slow motion. She taught me that even though our friendship was crucial, I could be an individual separate from her. She also taught me to never be afraid of whom you are and to never let it escape from your heart. Jade was more than just a stranger on the street; our friendship became more personal than just your regular hello. It was like she was inseparable from me and I was inseparable from her.

For some odd reason I became lifelong friends with this once ill faced immature girl. Or was it me that I was staring at, I didn't know? Now, everything she wore was a beautiful vibrant silk outfit of a purple lime. Her daily outfits I appreciated through expression of our true beauty and what it meant to both of us. I know when she disappears in my life she will always be in my heart as my friend I had never asked for.

So you would understand why I was upset when my mom brought home Tony, my second wheelchair.

Alet Uys has TM and is a member of the TMA. She is a 13 year old living in Pretoria South Africa. Alet has conducted research and wrote a case study which has been published by MedPharm's journal, The Medical Journal. Douw Greeff, MD, the Managing Editor of Geneeskunde/The Medicine Journal, has granted us permission to publish Alet's paper about TM. According to Dr. Greeff, Alet is the youngest person to ever publish in The Medical Journal.

Alet's research and paper were exhibited at the Gauteng Provincial Exposition. She received a gold medal for her work and received an invitation to participate in the National Science Exposition. She also received a certificate of achievement from The Centre for Schools of Quality AFRICA for excellence in Medical Research. The Centre has trustees in the United States, Turkey, China and South Africa. Alet has received the AVENTIS First Prize, for outstanding achievement in medical science.

Gevallestudie: Transvers Miëlitis
Alet Uys' Case Study as Published by Geneeskunde/The Medicine Journal, South Africa

No less than seven doctors in various branches of medicine visited her stand during the Gauteng Provincial Exposition. The doctors asked her many questions about her research and paper. She dealt with the learned men in a very calm and confident manner, as she was so sure of her facts.

The National Exposition, held in October 2002, is a Youth Science Competition and the most prestigious competition of its kind in Africa. No less than 400 schools participated in the Provincial Exposition; whilst 450 schools participated with 700 projects at the National Exposition. Alet received the gold medal at the National Exposition for the best project in the category, "primary school medical sciences." Alet will have the opportunity to exhibit her project in Moscow next year.

Alet's ultimate goal is to go to medical school and to become a neurologist.

Alet Uys's article has been published in Afrikaans in the 2002 July issue of Geneeskunde/The Medicine Journal: Uys A. Transverse Myelitis. Case Study. (Afr) Geneeskunde 2002;43 (July)(6):47-50 (ISSN 0016-643X) The article is also available on the Geneeskunde/The Medicine Journal website www.medpharm.co.za.

The following article is a direct translation of the Afrikaans article as published.

I am a 13 year old, grade seven pupil and currently headgirl at Lynnwood Primary school (an Afrikaans school in Pretoria, South Africa). My experience with Transverse myelitis at the age of 11 motivated me to do research on this topic for our school's grade 6 and 7 science expo.

My goal with this research is to improve awareness about Transverse myelitis, especially among medical students and qualified doctors, as the disease is very rare, information in medical literature does not always provide all the answers and the disease can only be cured if it is diagnosed and treated very early.

Two thirds of all Transverse myelitis sufferers do not recover completely; I am very fortunate and grateful to be one of the patients in the world who recovered completely from this disease because of early diagnosis. My research is a way through which I also want to reflect my appreciation for regaining my health.

My work is dedicated to dr Joe Terblanche (Neurologist at Unitas hospital, Centurion, South Africa) who helped me and motivated me to progress, step by step, to where I am today.

My experience with Transverse myelitis started on 2 October 2000. I felt pain from deep within my upper legs and the sensation of a tight band around my waist. The constant and terrible pain kept me awake at night and I felt very sick.

Tuesday October 03: I went to see my family doctor. He drew some blood and suggested that my condition was caused by growing pains. When we phoned him the following day for the results, we were told that the blood got 'lost' and again the doctor said that my condition was only caused by growing pains.

Thursday October 05: My parents decided to take me to an orthopedic surgeon who confirmed that my condition was probably due to 'growing pains' and he prescribed Voltaren gel, which he believed would help to relieve the pain. I was also told to go for an isotope scan the following day in order to confirm the diagnosis.

Friday October 06: The Voltaren gel did not relieve my pain. I went for the isotope scan and the results indicated that everything was fine. My parents and I found it hard to believe that growing pains could be so constant and bad, causing me to wake up time and again during the night.

Sunday evening October 08: I fell out of bed when I tried to get up to go to the bathroom. My parents phoned the orthopedic surgeon at his home and informed him about the weakening condition of my legs. We were told to visit his rooms the following day; when he realized that my problem was not of an orthopedic nature, but neurological, I was immediately referred to a neurologist for a complete neurological examination.

Monday morning October 09: I was finally admitted to hospital with the diagnosis of acute Transverse myelitis and accompanying minor bladder complaints.

Transverse myelitis is a very rare neurological disease that affects one out of a million people each year. The patient's autoimmune system mistakes the myelin sheath of the spinal cord for intruders and attack the sheaths, causing inflammation of the spinal cord.

Autoimmune diseases are the result of antibodies or T cells that attack molecules, cells, or tissues of the

organism that produce them; the following process occurs:

When a germ enters a person's bloodstream, white blood cells are activated to arrest (via phagocytosis) and transport the germ to the closest lymph node. The lymph node then produces T cells and antibodies to attack and destroy the germ. The antibodies attack the person's tissues by mistake, because certain proteins of the person's tissues resemble the protein covers of the germ.
In the case of Transverse myelitis, the antibodies attack the nerve tissues located in the person's spinal cord. The person's own antibodies become a greater danger than the original germ itself, because the antibodies do not only attack and destroy the original germ, but also the person's own tissues (spinal cord nerves). Messages between central and peripheral nerves are interrupted because of myelin damage caused by the antibodies and the person becomes sick. The condition may deteriorate and progress to paralysis if the disease is not treated promptly, because the antibodies will damage the nerve cells permanently and the person will lose complete function of the bodily areas supplied by these nerves e.g., loss of function of legs and bladder.

Speedy and timely administration of high intravenous doses of cortisone decrease inflammation and swelling of the spinal cord by suppressing the patient's immune response, providing the possibility of less structural tissue damage incurred to nerve cells and a greater chance for recovery.

Autoimmune disease in itself is not rare; Multiple sclerosis, rheumatoid arthritis, SLE, rheumatic fever and nephritis in children are all examples of autoimmune diseases. Transverse myelitis is however a rare way in which autoimmune disease presents. In this instance the antibodies specifically attack the spinal cord tissues.

The myelin sheaths of the nerves become damaged or destroyed at the point of inflammation. This prevents communication between peripheral and central nerves, causing various degrees of motoric and sensoric dysfunction.

Characteristically, the clinical picture presents on both sides of the body, below the spinal cord area affected by the disease. This occurs because the disease process involves the complete width of the spinal cord.

Transverse myelitis may be acute or sub-acute. During an acute attack, the disease develops over a period of a few hours or days. The clinical picture of a sub-acute attack may develop over a period of 1 to 2 weeks.

Early symptoms may include sudden low back pain, loss of muscle power, paresthesia in the toes and feet (within the first few hours up to several weeks), pain in the legs and sensoric loss with partial or total motoric paralysis. Loss of sphincter function may also occur (loss of bladder control is common).

Other symptoms and signs include muscle spasms, poor appetite, headache, fever, a general feeling of discomfort and hyperesthesia during changing weather conditions. Some patients may also experience respiratory problems, depending on the level of spinal cord damage.

Most people only experience one episode of *Transverse myelitis in a lifetime.*

Children and adults, both male and female, may present with *Transverse myelitis*. At present, there is no proof of any hereditary predisposition. All races and families are therefore vulnerable. The highest incidence is found amongst age groups 10 to 19 and 30 to 39 years.

The four classic characteristics of *Transverse myelitis are*

- Varying degrees of motoric loss in arms and legs
- Pain (the most prominent symptom), especially in the lower back, as well as sharp shooting pains in the legs
- Sensoric changes
- Loss of bladder control

Most patients experience various degrees of weakness in their legs. Patients may stumble or drag one foot when they try to walk. They may also experience a sensation where one or both legs feel heavier than normal. Total motoric paralysis may follow as the disease progresses, confining the patient to a wheelchair.

Although some patients recover completely, the majority suffer permanent damage to their spinal cords, causing considerable morbidity in their daily lives.

The extent of pathological dysfunction to areas of the body relates directly to the level of the segment affected in the spinal cord.

The results of my tests indicated that I had an absolute motoric level at T10 and a strength grading of 1/5 in my left leg and 2/5 in my right leg. Other tests included a MRI scan and later that week a Lumbar puncture. Both investigations were indicative of problems.

The diagnosis for *Transverse myelitis* is reached by obtaining a complete medical history and performing a complete neurological examination.

Special investigations that are valuable in assisting to make the diagnosis include, MRI (magnetic resonance imaging) scan of the spinal cord; Myelography (contrast medium is injected into the subarachnoid space and X-rays are then obtained); Hematological (blood) tests for HIV status and vitamin B_{12} levels; CSF (cerebrospinal fluid) analysis to exclude high protein levels and a high white cell count.

Spinal cord injuries caused by trauma, tumors or abscesses and shortages of vitamin B_{12} need to be excluded as possible causes for the symptoms.

Idiopathic *Transverse myelitis* is diagnosed when no specific cause can be identified.

I was started on treatment with Soli-Medrol, 500mg per day for 5 days, and my condition improved dramatically.

The treatment focus is mainly geared towards providing the patient with symptomatic relief (the degree of neurological dysfunction may have an effect on the severity of symptoms experienced by the patient);
Treatment includes

- Corticosteroid therapy, which is the primary form of treatment during the first weeks of the disease. It decreases inflammation and swelling of the spinal cord and it also suppresses the patient's immune response, but it does not alter the course of the disease
- Relief of pain, on an 'as needed' basis
- Bed rest during the initial phase of the disease
- The monitoring of vital signs, especially in patients with respiratory problems
- Expectant observation
- A multi-disciplinary approach by a team consisting of a neurologist, specialist physician, hematologist, microbiologist and nursing staff
- Physiotherapy, which plays a very important role during the recovery phase, should focus on strengthening of muscles and improvement of coordination and general movement. *After my treatment, I received physiotherapy for about 2 months. I had to learn to walk again and had to do exercises to develop and regain my balance and strength. The sensation in my body and limbs also started to return and I made very good progress.*

Sunday, October 15: The cortisone treatment was stopped and that morning, the same pain of the previous week returned. I was re-admitted to hospital at about 7am and treated with a three-day course of cortisone.

At this stage the doctor decided to start treatment for Bilharzia (a chronic condition that I was diagnosed with during all the special investigations that occurred) for which I received Biltricide, 1200mg once that evening and 600mg the following morning.

October 19: I felt healthy in general and was discharged from hospital. I continued treatment with Prednisone 60mg per day for four days, which was reduced by 5mg every day thereafter, Slow K 1 to 2 times per day, Calcium Sandoz 1 per day and Losec.

The neurologist explained that my autoimmune system over-reacted against another type of infection or virus, and attacked my own spinal cord. No other causes could be found.
Because of all this I could not attend the last quarter of school or write my exams.

At present there is little known about the possible etiological factors that may cause Transverse myelitits to occur. The condition mostly results after viral infections, followed by an abnormal immune reaction or it may also occur as a result of insufficient blood supply to certain segments of the spinal cord. Infective agents that may play a role include chicken-pox (*Varicella*), shingles (*Herpes simplex*), flu virus, rubella (German measles) Hepatitis A and rubeola (Measles). Other causes may include bacterial infections of the skin, middle ear and respiratory tract.
It may also occur as a complication of vaccination against e.g., rabies or chicken-pox.

When *Transverse myelitis* follows an infection, the secondary immune response causes more damage to the spinal cord than the primary viral or bacterial infection. The secondary immune response (autoimmune reaction) is considered to be the main cause of the symptoms, resulting in the clinical picture of *Transverse myelitis*.

Recovery from *Transverse myelitis* starts within 2 to 12 weeks after the onset of the disease. It may however prevail for up to two years. It is very unlikely that a patient will recover if there is no improvement within the first 3 to 6 months. One third of patients with *Transverse myelitis* recover completely or partially i.e., they can walk again and are able to maintain bladder control. Another third show moderate recovery with permanent areas of sensoric deficit on the skin, have problems with bladder control and present with spastic movements. The last third do not recover and remain paralyzed and confined to a wheelchair.

Early diagnosis and treatment with corticosteroids mean less damage to the myelin, an improved prognosis

and a better chance of recovery.

It is my wish that more people in the medical profession (especially family doctors) will in future be able to recognize Transverse myelitis in its early stages so that the patient can be referred to a neurologist as soon as possible for immediate treatment.

I would like to thank

Dr Joe Terblanche (Neurologist)
Dr Izelle Smuts (Pediatric Neurologist)
Dr Andre Nel (Prometheus Healthcare)
Prof. Suzanne Delport (Pediatrician)
Dr Douw Greeff (Editor : Medical Science)
Mr At Meyer (Menlopark Science Academy)
Me Saartjie Roos (Science teacher, Lynnwood Primary School)

Alet Uys (13)
Headgirl 2002, Lynnwood Primary School

Web links :

Google.com TRANSVERSE MYELITIS FACT SHEET

www.paralysis.org

www.spinalvictory.org

www.themiamiproject.org

www.myelitis.org

www.naric.com

Areas of research include :

- To determine the role of the immune system in the destruction of myelin
- The development of strategies to facilitate the regeneration and repair of damaged myelin

Cody's Scuba Adventure

Paula Lazzeri and Pauline Siegel

Sandy received a letter from Cody Unser in January 2002. Cody explained that her foundation was sponsoring Cody's Scuba Adventure at Treasure Island Resort in Grand Cayman, the British West Indies. Cody said that her physical therapist, Stacey Minton, was also a scuba instructor, and had encouraged Cody to learn to scuba dive. In the summer of 2000, Cody received her Open Water Scuba Certification during a diving trip in Florida. She explained that it was one of the most important and liberating experiences she had ever had, and she wanted to share this experience with other paraplegics. In her letter to Sandy she said,

The reason I am writing to you is that this is a quality of life project for my foundation, and you have had a deep impact on the quality of my life. We are asking 10 people who have been very important to me to each make a selection from their hospital, rehab facility, foundation or geographic region. Therefore I am asking you to select someone you deem worthy and qualified – a medically sound paraplegic of any age (over 12) and a partner to join me for this awesome adventure. All expenses – air, lodging, food and scuba certification – will be covered by my foundation.

The day after receiving the letter, Sandy called Shelley Unser to make a special request. He told Shelley that he wanted to ask for permission to have the two of us go on the trip. This was a very special favor to ask of Cody and Shelley for a number of reasons. First, since both of us have TM, we were going to require special instruction in different cities. We were going to be traveling from different cities. We would not be able to help each other, since we both had TM; we would not be able to handle all of the physical needs a partner without TM would be able to do, such as carrying luggage and our scuba equipment. Allowing the two of us to go on Cody's Scuba Adventure, represented an additional cost and more logistics complications for Cody, Shelly, and the organizers. And the situation was further complicated by the medical requirements. In order to receive medical permission to train and attend the scuba adventure, the level of spinal cord effect had to be such that upper body and lung involvement was not a problem. This was not the case for Paula who had both upper body involvement and some lung issues. Shelley never flinched when Sandy presented her with his great plan, and she immediately said that she and Cody would love to have us on the trip and they would make everything work.

Pauline: Sandy called me at school after he talked to Shelley. I love the water. My family owned a boat when I was a child and we spent many wonderful hours on the water during the summer time. I have been on snorkeling trips many times. I even took Sandy on a snorkeling trip on our honeymoon, and Sandy does not like the water. He is always telling me that Jewish people only swim with fish that have fins and scales. Becoming a scuba diver has been a lifelong dream for me and when I got TM I really thought that this dream would just never come true. Sandy told me that I was going on the scuba adventure. I screamed with excitement and had a permanent smile fixed on my face for

weeks.

Paula: Sandy called me and explained that he had received this wonderful honor from Cody and was being asked to select a paraplegic and a partner to go on a scuba trip. He said that he wanted for me to go with Pauline. I accepted this gracious offer and then had immediate reservations. Sandy and I began an email exchange that lasted for a couple days. As I am impacted higher on my spinal cord, I am not comfortable around the water. Sandy assured me that I would be in the water with twenty-seven guys who looked like the Chippendales. I told Sandy that it would be very difficult for me to travel across the country on my own and to go through all of the airports and flight changes. Sandy explained to me how he arranges flights for Pauline, and assured me that I could be accommodated; that traveling would be okay. And I had concerns about the bowel and bladder issues; how was I going to handle that in the ocean? Sandy responded that the good news was that they probably wouldn't ask everyone to get out of the ocean to clean up an accident and that it would probably keep all of the sharks away. It all seemed overwhelming and a little frightening, but it was all too exciting not to try. So, I decided that I would go.

The first step was for us to receive medical permission to get the scuba training and to go on the open water dives. Pauline received permission. Paula was only given permission to participate in snorkeling. Stacey Minton, Cody's scuba instructor and the adventure organizer, arranged for us to start instruction with teachers in Seattle and Columbus. Cody's foundation was able to get all of the scuba gear donated and it was distributed to all of the participants from all over the country. Each participant began working with their instructors in their respective cities.

Paula: My instructor's name was Craig Willemsen. He owns a scuba shop in Bellevue, WA not far from work and home. We began snorkeling lessons about two months prior to the trip. We worked in a local pool that was warmer than the average indoor pool. It was gradual progress with each time floating around the pool a little longer each lesson. I went from holding onto my instructor's hand in the shallow end in fear to floating around the deep end by myself for 30 minutes at a time. I also learned how to clear water from my mask and signals to flag an instructor.

Pauline: Stacy found a scuba school that was fairly close to my home and was able to arrange a wonderful instructor who worked with me, Joey Jacques. All of the instructors were required to be certified to work with and teach people from the disability community. We went through weeks of intensive training. I had to learn how to use all of the equipment and I had to learn how to perform various procedures under water. I was taken through a check-list of requirements in order to receive my certification. Then I had to pass a written exam. The purpose of the training was that we were going to be taken through all of the requirements for scuba certification before we left for the Caymans. We would perform our open water dives in the Caymans to complete our certification. I had as my goal to receive the full scuba certification. In order to do so, I was going to have to swim twenty-five laps in the pool. This seemed the most daunting of the requirements. I trained for months in order to build up the stamina to complete twenty-five laps. During one of my classes, Joey decided that I was ready to try, and he asked me to do the laps. I wasn't sure I was ready, but I went ahead and tried. I completed my twenty-five laps in the pool!

Cody's scuba adventure began on August 8th and ran through August 12th.

It was the most incredible time. We met the most wonderful people. There were eleven paraplegics on the trip with their companions and their scuba instructors and they came from all over the country. We were the only people with TM – and Cody. The other paraplegics had a myriad of spinal cord injuries and diseases. Each of the participants had the most incredible stories; and their participation in Cody's Adventure was so inspirational for everyone.

Pauline: Cody's adventure was the most amazing experience. I met such incredible people; the participants and the instructors were such awesome people. The dives were really beyond description. Our first dive was off one of the beaches near our hotel. The next dive was in 100 feet of water off of a boat. We also had a dive around a sunken ship. The last dive was in sting ray city. This was a dream come true for me. And to watch Paula's transformation was really great. When she first went into the water, she was really cautious. By the end of the trip, she had become a fish. Paula was amazing.

Paula: Pauline and I had the BEST time. Pauline is quite the diver. I was inspired by every person there. There were 11 disabled participants. I was the only snorkeler and all the others were divers. After watching them scuba dive I really wanted to try. I am hoping to have a respiratory evaluation soon to see if I can dive. If I get a green light, I've been told I could be a participant again next year; as a diver. That would be great. The participants, volunteers, and instructors were all wonderful people. They had tons of media folks there to

capture the whole event. Bob Martin is a reporter from the CBS affiliate in Albuquerque. Bob was on this adventure taking video footage of our every move both above and below the water. We were all sent a 30 minute video of our awesome trip. Bob also created a four-minute segment of the experience that ended up on American Stories on CNN and Speed Week. He made mention of TM several times. This was a perfect way to raise awareness about TM.

We ate and drank well. The marine life and water was amazing. On Sunday we got to swim with sting rays. They are the most graceful and friendly marine animal there. I watched Pauline feed squid to a very large sting ray. We saw a ship wreck at the bottom of one reef, too.

Pauline and I missed one of our connecting flights on the way home. Pauline had to spend the night in Chicago. I was on a plane with Cody, her siblings, and Bob Martin the videographer. We spent the night in Dallas. Pauline and I would like to thank Bob for helping us with the flight arrangements on the way home. We greatly appreciated your help and concern.

Paula: Cody's foundation has tried to focus on quality of life issues. She has impacted the quality of life of so many people. She has certainly impacted the quality of my life. I can only hope that I pass my respiratory exam with flying colors. To be able to dive like Pauline and all my new friends would be a dream come true. Thank you, Cody!

Pauline: I will never forget my first scuba trip. Cody is such an amazing person. She has her own life and her own challenges to deal with; she could be focused on herself and her own needs. And no one would judge her for just taking care of herself. She has chosen not to focus on herself. Cody has an amazing sensitivity, compassion and maturity. She wants to help others. She wants to share her passion for life. She had a great idea and she had the energy and enthusiasm to transform her great idea into a reality. Paula and I were the grateful recipients of her efforts. What an incredible experience. Thank you, Cody.

This article first appeared in The Union newspaper. The Nevada County Publishing Company has granted The Transverse Myelitis Association the right to reprint this wonderful article about Mary Woods in our Newsletter.

SPD Postal Worker Unsinkable
The Union, Western Nevada County California
February 11, 2002
Grace Karpa

Mary Woods enlivens the days of postal customers at Grass Valley's SPD Market. And she only had to leave retirement, fight cancer and recover from a paralyzing illness to do it.

Woods, 58, came back from retirement from the U.S. Post Office to work at the contract station in the grocery store.

"I love the work. I love the customers," Woods said.

The feeling's mutual, if you stop people waiting in line.

"She's a worker," said customer Ruth Smith of Alta Sierra. "On the ball always."

Sue Martin of Grass Valley said she comes to the contract station in the popular market because "it's friendlier and faster."

Woods wears an Independent Grocers Association name tag that declares SPD employees to be "Hometown Proud."

And proud she is to work both for the post office and in SPD Market, particularly since they've seen her through tough times.

Four years ago – "Dec. 2, 1996. I'll never forget it," Woods says - she arrived to work at 8:30 a.m. at her post office job. By 2 p.m., Woods was paralyzed from the rib cage down. Supervisors at work drove her home.

Doctors discovered Woods had been stricken with transverse myelitis, a first cousin to multiple sclerosis. The disease is a neurological syndrome caused by inflammation of the spinal cord, and often leaves people paralyzed.

Woods was confined to a wheelchair at one point and was offered disability compensation, which she declined.

She recalls sitting on her back deck overlooking Highway 49, thinking "how fortunate people were to be able to get in a car and drive."

"I thought, I'm gonna do that someday," Woods said.

With the help of physical therapy, Woods went back to work gradually in March the following year, starting back at two hours a day. Within nine months, Woods was back to working an eight-hour day.

"The post office was really cool," Woods recalled. "SPD was good to me during my recovery. SPD's just been awesome."

Although she's back at work and out of a wheelchair, Woods doesn't want to raise hopes for sufferers that

recovery is ever 100 percent.

Doctors don't have a clue how much you''l recover, Woods warns. "But it's not a death sentence," she said.

"I look back on it now, I did pretty damn good, but I fatigue easily," she said philosophically. "I'll probably never be a rock climber."

Woods moved to Grass Valley in July 1996 to join her children, Margie Leatherman, 40, of Grass Valley; Michelle Woods, 39, of Roseville; Don Woods, 37, of Grass Valley, another cancer survivor, and Dan Woods, 33, of Grass Valley. Her eight grandchildren range in age from nine months to 23 years old.

Most of her 30 years with the post office were spent in Southern California towns of San Gabriel, Upland, Ontario and Claremont. She misses the restaurants and beaches, but said she didn't know "places like Grass Valley existed."

"I'm really happy here," Woods said.

Translations

Providing Assistance for our International Members

The TMA has members from more than sixty countries around the world. Most of the people who find us from our web site speak some English. Many are quite fluent in English. Due to the volume of information we have offered on our web site and the frequent changes we make to the content, we are not going to be able to offer translations of the entire site in different languages. We do, however, believe that we can assist people who are not entirely fluent in English, if we can offer them a few important pages of information in their native language.

Yvonne Lugo has translated the TMA brochure into Spanish and we have posted it on the web site. Ursula Mauro has translated the membership form on the web site into German. If you can perform translations for us, we would be grateful for your help. We are interested in having the main page of the web site translated into languages that are not currently represented. If you would like to check the text that is being translated, just click on one of the flags located on the main page.

We would also like to have the brochure translated. Again, you can click on the brochure from our web site to find the text that needs to be translated. Finally, if you can provide us with the text for the membership form in your native language, that would be a tremendous help for those people who find us and do not speak fluent English.

So much of what we do in the TMA is focused on helping people to not feel so isolated by their experiences with TM. By offering this information to a new TMA member in their native language, we believe that we are going to help them to feel more significantly welcomed into our community. Please send your text translations to Jim Lubin: jlubin@myelitis.org

Thank you for your help on this important project.

This past July I was privileged to attend The Transverse Myelitis Association's first Children's and Family Workshop. This opportunity allowed for parents, children and young adults living with Transverse Myelitis to learn more about many issues ranging from medical, to educational, to emotional. During the program young children were able to listen to stories and participate in arts and crafts. However, the part of the workshop that impacted me personally the most was the chance to meet other teenagers and young adults with similar experiences.

Through discussions and activities we learned how each of our experiences with Transverse Myelitis was different, as well as the similarities we shared. Despite the fact that TM had impacted each of us differently we all shared a common bond. The idea that I was not the only one going through this reassured me. Additionally, as one of the teenagers with TM, it gave me a chance to see the effect the disease and its aftermath have on siblings.

The workshop allowed the parents to attend presentations by expert physicians, educators, and adults who had contracted TM as children. Young children went to a science museum and to the Columbus Zoo, listened to stories, watched movies, and enjoyed arts and crafts while the presentations were in session. The teenagers, including me, spent the days enjoying sailing, kayaking, swimming, and other activities while getting to know each other. In defiance of the lack of wind, we were able to sail and I can say without hesitation that it was my favorite recreational activity. The feeling I had while being on the water, away from my wheelchair and without limitations, was incomparable.

Although the activities we participated in gave us a chance to have fun while learning about one another, the discussion amongst the teens left the

The TMA Children's and Family Workshop

The Workshop: A Teen's Perspective

Eve Hampton

most lasting impression on me. Those of us with TM were able to share our adventures in the world of paralysis, including how we felt initially and how our feelings have changed since. For me, as a teenager with TM with a teenage brother who has had to adjust, it was great to hear stories from siblings. Their words changed the way I felt. I had no idea how much of an impact TM could have on a brother's or sister's life. Looking back on my own experience, I can see how much time and attention was devoted to me, especially during my initial hospital stay. I can only imagine what my brother was going through. He must have felt so lost amongst the confusion.

I hope that I will have a chance to see the people who changed my life at the next Transverse Myelitis Association's Children's and Family Workshop.

Adam was hit by TM on June 15th 2001 when he was 13 months old. He was paralysed from the neck down, but has made a lot of progress and is now able to walk with a walker. He's still quite spastic, and has some bladder problems. His arms and hands are fine.

When we first heard about the Children's and Family Workshop in Columbus, Ohio last winter, we were sure that we would never afford to go there, but were looking forward to seeing the follow-ups on the internet. Fortunately, Adam's aunt encouraged us to try and do some fundraising and to find out how much it would actually cost us. And so we did. Some really nice people helped us find the money for the flight and the stay at the hotel, and the air line company also let us have a discount because of Adam's story. And so we were able to go!

It was to be a great weekend for all three of us. Like many other parents (and kids) we had the experience that for the first time, people didn't look confused when hearing the word of Transverse Myelitis, and for the first time, we saw other kids and adults living with the same problems as us. A lot of feelings went through us these days, both of joy seeing all these cool kids coping so well with their disabilities, of sadness realizing that our son is a child with 'special needs' and probably will continue to be, of anger thinking about how unfair this disease is, of relief acknowledging that Adam is very lucky compared to what he could have been, etc, etc.

The whole workshop was packed with information, and we had some new points of view that we have brought home to discuss with our neurologist and our PT. Fortunately, we were also confirmed that we have received a very good treatment and rehabilitation in Denmark. We were very happy that the participating specialists stayed at the hotel all weekend, so that everybody had a chance to discuss their special needs with whomever they wanted to. A special thank you to Doctor Kerr who took the time to evaluate Adam's MRIs with us and actually found a minor inflammation at the C-level that we hadn't heard of before (Adam's diagnosis was just at T6 and below), and which explained a few things to us. And, of course, we were happy that he told us that Adam should have quite a good prognosis!

Adam spent the days at COSI and at the ZOO, and he quickly fell in love with his special person, Hanni, who did a great job taking care of him. Thank you, Hanni! He also enjoyed the swimming pool, and kept asking for it for several days when we had returned back home. And he loved Maureen's songs. We hope we'll be able to go back some other time and meet up with all his and our new friends.

Finally, we would like to thank Sandy for being such a great, loving person, and for doing such a great job with this workshop! (and the food was great too!)

Greeting to all the families that we met in Ohio.

We are interested in being in touch with TMA members in Scandinavia. Please feel free to reach us. We would be pleased to share information and support.

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The Workshop: A Visit from Denmark

Mette and Thomas Nybo

The presentations at the Children's and Family Workshop were excellent. Parents were provided with critically important information on a wide range of subjects from research on TM to symptom treatment to family issues. We have prepared a ten-video set of

the complete workshop presentations for anyone who would like to order the tapes. If you would like to review the program and the contents of the tape sets, please refer to the program agenda on the Children's and Family Workshop page on our web site. The video sets follow the presentation schedule on the program agenda. The tapes cover the entire program, from Thursday evening until Sunday afternoon; more than twenty hours of information. The tapes are worth it just to see Pauline perform the thirty-two step tai chi sword form.

The tapes have been priced to recover the costs of copying the tapes, the packing materials and shipping. The differential price represents the shipping rates to various countries around the world from Seattle. The price identified includes your total cost, including the tapes, packing materials and shipping. There is no handling fee; Paula said that even if she holds a box of tapes all day, she will hold them for free.

If you live in the United States, the price of the tape set is: $75.
If you live in Canada, the price is: $90.
If you live anywhere in the European Union, the price is: $100.
If you live anywhere else in the world, the price is $110.

All of the tapes are in VHS format. If you live in a country that uses PAL format for video tapes, you are going to need to have the tapes converted after you receive them. We priced a converted PAL set and the lowest cost we were able to find was $250. We thought the price for you would be prohibitive, and are counting on your being able to convert them such that the total cost is still under $250. We are sorry for the inconvenience.

You may order the sets from Paula Lazzeri. Please write your check for the proper amount and please write the check for the amount in US dollars. You are going to need to determine the conversion rate to figure the correct amount. Please make your check payable to **The Transverse Myelitis Association**, and please write **Children's Workshop Tapes** on the check. You must include the address where you want the tapes shipped and it is imperative that you include complete address information and please write legibly. If you have an email address, please include it with your information in the event Paula needs to reach you. If you live in the US, please also include your telephone number. Mail your order and check to:

Paula Lazzeri
10105 167th Place NE
Redmond, WA 98052
USA

You will be able to view the workshop presentations on the TMA web site. Jim is in the process of preparing the tapes for streaming video. You can view the taped presentations by navigating to the program agenda on the Children's and Family Workshop page. To view a presentation, click on the identified link and the video will auto-load into RealPlayer. If you do not have RealPlayer loaded on your computer, Jim has provided you a link to download a free version of the program.

There are two discussion sessions from the workshop that will not appear as streaming video on the web page. These were very informative question and answer sessions that included personal information. We have included these sessions on the tape sets because we all agreed, including the parents who participated, that this was important information to share with other families who have a child with TM. It would not, however, be appropriate to include this information on our web site.

If you have any questions about the tape orders, you can reach Paula by email or phone at: plazzeri@aol.com or (425)883-7914.

We would like to thank Geoffrey Cutler and Matthew Ball of Family Treasures for taping the TMA Children's and Family Workshop presentations. The donation of their time and expertise is greatly appreciated. I would also like to extend our appreciation to Chris and Michelle Powell of Tullyvision for taking on the job of editing and reproducing the tape sets. They took on the job on very short notice and they have made a very generous donation to the TMA to help cover the cost of some of their valuable work.

The Children's and Family Workshop that was held in Columbus this past July only reinforced for me the importance of providing parents of children with TM the opportunity for networking. Parents and the children need the opportunity to share information and to provide each other with support. For the past few years, I have been attempting to organize and publish a TMA Children's and Family Network Directory to make this networking possible. In spite of my best efforts, I have not been able to find the time to make it happen.

Well, I am so pleased to announce that it is finally going to happen. Mary Troup has volunteered to organize the Children's and Family Network Directory. The TMA will publish and mail the directory as soon

TMA Children's and Family Workshop: Video Orders and Streaming Video on the Web

as Mary completes her work. In order to protect the children in the TM community, we will not mail a directory to anyone who does not have their own child listed in the directory. Your child should be eighteen years old or younger to be included in the directory.

In order to have your child and your family listed in the directory, please send your information to Mary Troup either by email or through the postal service:

Mary Troup
1734 McAdams
Memphis, TN 38108
work7days@aol.com

Please send the following information to Mary for inclusion in the directory:

Parent's Names
Street Address
City, State/Province
Country, Zip or Postal Code
Home and Work Phone and Fax
Parent's Email Address
Child's Name
Child's Email Address
Child's Date of Birth
Child's Age at Onset of TM
Year of Onset of TM
Spinal Cord Level of Effect
Please also remember to send any changes in your information to Mary Troup as we will try to update the directory annually as we do with the general TMA Directory.

TMA Children's and Family Network Directory

We are very appreciative for Mary's willingness to take on this important project. Please send her this information as quickly as possible so that we can finally have the directory published and mailed to the families in our TM community.

We were in need of purchasing a van lift and we needed help. We were referred to Variety – The Children's Charity, by one of Maria's therapists. We received great help from this organization. The people were very friendly. Before being referred to Variety, we had never heard of this organization. We believe that other families with children with TM might be helped by Variety. They are located across the United States and in countries around the world.

Variety — The Children's Charity is an international organization that has been helping children since the 1920s. Variety's mission is to provide life-saving and life-enriching assistance to children challenged by physical and mental disabilities, poverty, abuse, and neglect.

Variety — The Children's Charity assists at-risk children by providing medical treatment, artificial limbs and special equipment for afflicted children to help them become more mobile. They support local hospital and major university research and they fund crisis centers, hotlines, and therapy. Funds are allocated to various children's agencies and camps to aid disabled, disadvantaged, abused and/or neglected kids, as well as to children who need medical services or equipment such as wheelchairs, leg braces, augmentative speech equipment, hearing aids and all types of prostheses. Working with the Ford Motor Company, Variety provides passenger vans, known as Sunshine Coaches, to agencies and individuals to transport children throughout their communities.

Variety has an international program called Variety Children's Lifeline that is designed to assist children with medical problems in developing areas where resources might not be available. Variety Children's Lifeline has been working since 1982 to provide medical assistance to children throughout the world. The primary focus is open-heart surgery; however, no diagnosis is ignored if the need is great and the resources to help are available. Variety Children's Lifeline has two methods for serving children who need help. The Lifeline program sponsors teams of medical personnel throughout each year to go to

Help for Children in the United States and Around the World: www.usvariety.org

Morgan and Pam Hoge

developing countries where the medical community is ill equipped to handle very sick children. The program also sponsors children from developing countries to come to the United States for more extensive, complex surgical procedures. Each year, over 550 children undergo life-saving operations sponsored by Variety Children's Lifeline.

Variety has 51 chapters in 13 countries focusing on providing assistance for the treatment and care of disabled and disadvantaged children. All of the Variety chapters can be found on their web site. If you are in need of assistance, please contact the chapter that is located closest to your community. We hope that you find this information helpful.

Variety — The Children's Charity
8455 Beverly Boulevard Suite 501
Los Angeles, CA 90048
Tel: (323) 852-1300
Toll Free: (888) 852-1300
Fax: (323) 852-9677
E-mail: info@usvariety.org
STARBRIGHT World™ is a private online computer network designed for

seriously and chronically ill children and teens which is available in almost 100 children's hospitals across North America. Children are able to make valuable connections with peers who are also experiencing the challenges of a serious illness. The challenges for these children do not stop when they leave the hospital; they are often unable to attend school and are in and out of the hospital for outpatient care, missing out on the day-to-day friendships at school.

With the help of America Online ® STARBRIGHT has expanded access to STARBRIGHT World into a child's home for FREE. The program is still private and secure and solely used by seriously and chronically ill children who've been approved to access the system. STARBRIGHT World is available to children living in the United States and between the ages of 7 and 18.

The child will be able to exchange email and instant messages with other STARBRIGHT World users who are at home or in a hospital, and can join STARBRIGHT World chats. In addition, the child will have access to the games and Web sites that have been selected by STARBRIGHT.

STARBRIGHT is aware that not all children have access to a computer at home so, we have teamed up with the people of Dell Computers to support those families without a computer by offering a computer scholarship opportunity.

We have set up a link to STARBRIGHT World from the main page of our web site. This will take you to the STARBRIGHT homepage where you can take a virtual tour of STARBRIGHT World and learn more about the program. All of the information you will need to apply to become a member, as well as the necessary forms, are available from this site. For more information on this program please contact STARBRIGHT at:

800-315-2580
SBWhome@starbright.org
http://www.starbright.org

STARBRIGHT World™ Kids Connecting to Kids: Now available for children in the United States who have Transverse Myelitis

Our family of four [Jim, Arlene, Scott (16 years) and Dana (TM at 10 years T_{10} level; now 11 years)] took a family vacation to Colorado after attending the TMA Children's and Family Workshop in Columbus in July, 2002. We love the outdoors, and this was our first big family outdoor trip since Dana became ill. I wanted the entire family to participate in as many outdoor adventures as possible *together* while giving Scott something exciting and enjoyable to do. We also wanted Dana to build up self-confidence while enjoying outside activities, and empower her by teaching her new activities and skills. Dana has regained some use of her legs and can walk short distances with a cane, but for longer distances she requires a wheelchair.

I stumbled across the Adaptive Sports Center at Crested Butte (ASC) while reading a magazine. Crested Butte is a small town located in western Colorado in the Rockies, literally just South over the mountains from Aspen; but the road connecting the towns is winding, unpaved, and impassible during winter. Most people get there coming from the South via Gunnison on Highway 50, a distance of 30 miles. This program has been in place for 14 years, and there is a winter and summer program. The ASC touts family and group vacations as their specialty. The website is extensive, and the summer program offers overnight camping trips, handcycling, four-wheeled downhill mountain bikes, whitewater rafting and canoeing for persons with upper body or lower body limitations. We were attracted to the location and its emphasis on family participation.

We flew United Airlines from San Diego to Denver, then transferred to a United Express to Gunnison and rented a car. Like most ski towns, there is a free shuttle year-round that operates from the ASC and ski area to Crested Butte. The ASC charged $75 for each half-day Dana participated, which included at least one instructor from the ASC and all equipment. The total cost to our family for 3 half-days of mountain biking, rafting, and rock-climbing was $450. This included transportation to the activity sites by van, and we were picked up at our door each morning.

A Great Family Vacation at the Adaptive Sports Center at Crested Butte, Colorado
Dana, Scott, Arlene and Jim Mathewson

Words cannot describe how wonderful it felt to be outdoors and to see the joy on my family's faces as we played in Crested Butte with the help of the ASC. Dana and Scott both wrote down their impressions of those three days, and I think their excitement and happiness shines through their words.

DANA: The most fun days were when I spent them at the Crested Butte Adaptive Sports Center. My instructor's names were Hans Christiansen and Chris Read. The first day I did mountain biking on a

four-wheel bike. It had shocks in the front almost like a car. The bike was pulled by gravity so there was no pedaling needed by hand or foot. We biked down a mountain called Snodgrass. Very funny name, don't you think? It was awesome! I biked down that hill so fast that sometimes I could smell burning rubber from my tires. We did the run two times. We decided to bike back all the way to the Adaptive Sports Center on the road. That was fun too! When we got back, Hans and Chris brought out a tandem bike for me to try. The back pedal is independent from the front, so one person can stop pedaling and the other could power the whole bike. Chris rode with me, and I did well on this. It felt great to be able to ride a regular bike again. It really can make a difference in someone's life to feel confident that they can do something just like any other walking person.

SCOTT: Crested Butte is located in a glacial valley. Large mountains loom on the outsides of the valley, and you feel in a secluded place, away from all the hustle and bustle of the town. Our family engaged in activities with the ASC during the morning hours so that it was nice and cool and afternoon showers would not rain on us. Dana was outfitted with a full-suspension mountain bike that had four wheels. It was like a miniature car without the engine. The rest of the family was fitted with Kona dual suspension bikes. After Dana was able to get the hang of steering her bike, we packed all of the bikes into the van and went to the top. Since I've mountain biked before, I stayed behind a few minutes so that I could get a large stretch before heading down the trail. It was great fun. I was able to do bunny hops and do tail slides down the mountain. Little ramps were in place along the trail so I was able to get major air off of them. After going up twice, we decided to ride back to the Adaptive Sports Center Office along the road. Back at the office, Dana tried out a special tandem bike that allowed her to stop pedaling if she got tired. While she tried that out, I was able to fiddle around with my own bike. I was going down stairs, jumping up curbs, and bunny hopping in the air. This day was the best mountain bike experience with my family yet!

DANA: Day two was Rock Climbing. Hans came, but Chris didn't. The rock climbing instructor's name was Casey. We drove to a real rock cliff by the river, about two stories high. First, we had to be fitted into shoes that were almost two sizes smaller than our regular sizes. This was to enable more ability for everyone to climb. If the shoe is bigger than your foot like regular shoes, it might not be able to grip onto the tiny footholds. The soles of the shoes were completely flat, but the bottom gripped to everything! It was even hard to walk over the little rocks to get to the wall! There were several trails to get up. I tried the first one, which was obviously the easiest. You had to climb in a crevice, and it was hard. But very fun! Once you were at the top, you got to either ring a cow-bell, or a horn!

SCOTT: The people there had helmets, shoes, and harnesses in order to protect us when we climbed. The shoes they gave us were specially designed for rock climbing. The soles were made of sticky rubber in order to stick onto a small foothold when needed. Dana was assisted up the face by a pulley system rigged together by the people at the Adaptive Sports Center. The face had many climbing routes for all types of climbers. I went up different ways, and I was able to do the second hardest face before I got tired. Today was the most fun day for me because I was able to go at my own pace. I wasn't held down by the abilities of my sister. This is a great activity for all members of the family.

DANA: Day three was the most fun for me. We did whitewater rafting on the Taylor River in the morning. Hans came with us again along with a volunteer named Brendan. He was very nice. First, we went to the rafting store to get some spray slickers. Once we were suited up, we got in a bus with a different company than the ASC. It was called the Three Rivers Rafting Company. When we got there, one of the instructors gave a safety speech so we knew what to do if something happened. Then we got into the raft. Our instructor's name was Dave. First he taught us how to use the paddles. Then, we were off! We went into rapids so big that Dave and Hans had to hold on to me for fear that I might fall out. Was it fun or what? I say a big YES!!!!!! After the rafting trip we went to horseback riding! YAY!!! I love horses. We went up Snodgrass again, but it was on a different side. I thought it was much prettier. My horse's name was Taylor. The leader of our group told me that he doesn't go fast unless you kick him. She said that he knows how to, but also knows how to get away with it. He really responded to me though. I got him to trot and keep up with the others. The leader said I was a natural! The trip lasted an hour and a half. It started to rain just when we started to come back. We got drenched. Good thing I was wearing a hooded jacket and pants!

SCOTT: Our guide happened to be a retired Navy Seal named Dave. Dana had no problems with falling out, as you can imagine. I sat in the front. He would tell us "Forward 2!!!" or "Left Side forward 3, Right Side back 3!" as we maneuvered our boat down the river. It was very exciting to listen to our guide and pay attention to what

was waiting for us downstream. Dana lost her paddle once and we had to go retrieve it for her. We took a break halfway down the river to give a few people breathers. By the time we had finished and gotten back into the truck, all of us were very tired. This was a great way for our family to work together to achieve something fun and exciting.

I would truly recommend the Adaptive Sports Center at Crested Butte, CO. It provides families with opportunities to have fun together and do things together that normally would seem out of the question. Not only was the equipment state of the art, but the kindness and hospitality that they showed was unbelievable. Our family is looking forward to going back to Crested Butte during the winter season to take advantage of the ASC's winter sports program. I would rate this a 10 out of 10 because all members of the family were able to do things together as a family at a pace that was comfortable for each person.

The ASC offers financial assistance through a scholarship program. We stayed at the Sheraton for $99/night as the ASC suggested, because it is approximately a block away. There are condo's available for a bit more per night. My only regret was not having time for fishing, because the fly fishing there is great. As Scott said, we had a wonderful time, and we plan to go back during winter. Check the place out! Their website address is www.adaptivesports.org; Program Office phone is 970-349-2296. Address: P.O. Box 1639, Crested Butte, CO 81224.

The Transverse Myelitis Association is a proud member of the National Family Caregivers Association (NFCA). We have established a link to the NFCA from the bottom of the main page of our web site. We support NFCA's effort to "Share the Caring" and acknowledge National Family Caregivers Month as an opportunity to provide community-based activities in support of family caregivers. NFC Month is designed to raise awareness that will help people recognize and appreciate the caregivers' vital role. The goal is to build caregiver self-esteem, expand caregiver self-awareness and teach caregivers to become their own advocates.

Please join us in celebrating National Family Caregivers Month. Please contact the NFCA for information regarding caregiver issues, including effective ways for communicating with your physicians.

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

Adam was a very healthy boy during his first year. He started walking when he was 11 months old and was very strong in all ways.

On June 14th 2001, Adam fell in his pram while he was sleeping. He fell on his back, just where the inflammation was later discovered. At first, he was screaming, but he was easy to calm down, and walked about a little before going back to sleep. For the rest of the day, nothing happened. He was happy and played around. In the evening, he went to a picnic with his father where he ate a lot of fruit. When they came home, he climbed the stairs three floors.

At midnight, 15 hours after his fall, he started crying. We couldn't comfort him. He kept on crying, even while sleeping, for five hours. In the morning, we called a doctor. I thought his stomach ached because of the fruit, but he acted very differently than ever before and was very dull. The doctor said that his belly was hard, and that he would probably have diarrhea later on. He never did. Instead, he was very sleepy. During the day, he had a fever. Then the paralysis started and without us realizing it. We just thought that he was like that when ill, because he had never had a

fever before! He was very tired but happy enough. He had no loss of appetite, but was so weak that we had to feed him and even hold his head. His hands and feet were swollen and hot, but still, as we had never had a sick child before, we thought it to be normal with a fever. We tried to call a doctor, but everyone was occupied, and it didn't really seem to us to be very urgent.

During the following night, Adam's temperature rose and we called a doctor. He sent us to the hospital as he didn't understand his weakness and couldn't find any reason. Then everything went fast. He was checked for meningitis because his neck was stiff. In the morning, a doctor thought of Guillain Barré syndrome. We went into Intensive Care, because Adam started having difficulties breathing. Fortunately, he didn't have to be put on a respirator. He just managed to breathe, had a little bit of oxygen to help him, but couldn't cough or sneeze properly. The following three

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.*

Adam Onset 13 Months
Copenhagen, Denmark

days, he had immunoglobulin IV (other people's antibodies) which apparently helped very much. He soon regained some feeling in his arms. His hands were very sore and still swollen, but within a week, he was able to pick up raisins and drink by himself. His eyelids were affected as well and stayed half-closed for about one month.

When we told the doctors about the fall, Adam had a MRI which showed white illuminations around T6. The doctors didn't believe that his fall had anything to do with him being paralysed. They kept the diagnosis this far, but apparently a neurophysiological test made them change it to TM. We don't really know why, because we went home, and the doctors forgot to tell us about this new diagnosis. We started physical therapy right away and are still seeing a therapist once a week.

Due to the summer holidays, we didn't see a neurologist until almost two months later. We finally insisted on seeing a neurologist because Adam developed a bad urinary tract infection. Nobody had told us to watch out for infections. As he's paralysed, he hasn't felt any pain, so we only found out because we went to a homoeopath. He had an antibiotic treatment for five days which cleared it out, and so far his urine is all right. We give him a homoeopathic diureticum and cranberry juice.

Well, back with the neurologist, he explained to us a little about TM. We were shocked to hear that the outcome was much worse than first reckoned with GBS, and felt very angry and disappointed with the hospitals. Suddenly, we had to cope with the idea of maybe having a disabled child. What is good is that it only changed things in our heads. When looking at Adam, we're always happy and optimistic because he is doing so well.

In August, Adam started going to a kindergarten with normal kids, and he loves it! He was able to drag himself around, and so they accepted to have him there without any extra help. In January, we could see though that he needed some help to do things like other children, and he now has an extra pedagogue every morning taking care of his special needs. She's great!

His legs are still weak and spastic, but it's getting better all the time. He crawls without difficulty, is able to stand and has even started walking a little with a "gator." His balance is getting better, as well. On April 1st, our neurologist was very optimistic, and assured us that Adam will be able to walk and maybe even to run! What a great relief! Adam is a real fighter and always very happy.

We're looking forward to coming to the TMA Children's and Family's workshop in Columbus this summer. It'll be our first time in the United States, and it'll be a great experience in every way. We are wondering how Adam will respond to English since he doesn't understand a single word.

Mette and Thomas Nybo
Copenhagen, Denmark

Cole was just like any other six-month-old boy, just learning to roll over, move around and beginning to sit up on his own. That all changed on Thursday, March 15th 2001. Cole was sitting on the floor playing when his back seemed to give out and he collapsed. When my wife, Wendy, picked him up, he began to scream in agony and became very weak and limp. We took him to the nearest clinic where the doctor barely looked at him and told us he was fine and to take him home.

Cole became even weaker over the next few hours and my wife took him to the Royal Victoria Hospital in Barrie, Ontario, while I stayed home with our other two children, Brian (10) and Bailey (3).

At the hospital, Cole could barely move and his breathing was very laboured. His legs began to turn red and purple (modeled) and swollen. Wendy noticed that his bladder was enlarged and very hard. He was retaining urine and had to be catheterized.

I joined my wife and Cole the next morning and found it hard to get anyone to listen to what had happened. They made us feel guilty, like we had done something to him. The more we insisted they concentrate on checking out his back, the more suspicious they became.

Finally, after a shift change, a new nurse and doctor listened to our story and began some action. Cole had a cat scan, ultra sound and a spinal tap. It was Saturday morning by the time any results came back and by then Cole was in very bad shape. The first diagnosis was Spinal Meningitis and he was immediately air lifted to Toronto's Hospital For Sick Children.

By the time we drove to Toronto, Cole was totally non -responsive and in critical care. This is where he remained for two weeks. An MRI was ordered. Cole's breathing was so poor that he was intubated and put on a respirator.

Finally, on Sunday, Cole was diagnosed with Acute Transverse Myelitis. Cole's spine was inflamed from C2 down. It is not known what caused the inflammation. It may have been a virus, an auto immune attack, or even a reaction to vaccines. He had been having on-going respiratory infections since his four month vaccine.

Cole: TM Onset 6 months old Barrie Ontario Canada

Cole was given massive doses of steroids and immunoglobulines. Some of his functions started to return in a couple of days. By Tuesday, he seemed to finally recognize us and started to move his arms slightly. The next day his hearing returned and he had a little more movement in his arms, but his breathing was still very poor and he remained on oxygen. He also remained paralyzed from the chest down.

We had never heard of Transverse Myelitis and could not understand why this syndrome had struck our son. I guess that's something that we will never know.

My wife and I joined the Transverse Myelitis Association. We discovered many things about TM. We talked with other parents of children with TM and people of all ages from all over the world. We are so lucky to have other people to turn to for their help and support.

It has been nine months now since TM hit Cole. He is still paralyzed and shows little improvement in his trunk and legs. He cannot walk, stand, or even crawl. He has, however, learned to sit up by pulling on his pant legs, and pulls himself around the house with his arms. We have not given up hope, but with each month it seems less likely that Cole will ever recover.

Cole has therapy four times a week, two physio and two occupational. He makes many trips to Sick Kids Hospital in Toronto and to Bloorview Macmillan Center. He sees neurologists, urologists, pediatricians, nurses and therapists there. At home, Cole has occupational and physio therapy and we are working with his physiotherapist doing neuromuscular electrical stimulation. She will also be helping us when we start water therapy in the new year.

Cole needs a lot of special equipment. He has a stroller called a kid cart that has several straps that hold him in. He has a prone stander that he is strapped into to help strengthen his legs, therapy balls, a specially made table, and a neuromuscular machine. We also have other things on loan, such as a caster cart, a para-podium brace he can stand in, and a suction machine for when Cole is sick and he cannot cough properly to clear his airway. These things can be borrowed for a short time, but eventually they will have to be purchased. We are also looking into different types of wheelchairs. We are waiting to try the “Rabbit.” It is like a stander with wheelechair wheels so he can get around the house. Cole wants to be mobile.

Cole was catheterized twice a day for a while. We no longer have to do that, but he is on a special diet and on suppositories every second day for bowel movements.

We are planning to attend a TMA Children’s and Family Workshop in Columbus, Ohio in July 2002. We hope to gain some knowledge there, and to meet other parents who have already gone through what we are going through.

All in all, it has been quite an emotional and financial drain on our family. We have a long road ahead of us, but we will try to overcome any problems that may lie ahead. Cole is a very smart and happy little boy, and we are lucky to have him in our lives. We thank G-d he has come this far.

My name is Michael Hartman and I am a T3 para. I contracted TM in the summer of 1999 and have been in a wheelchair ever since. I am 24 years old. I spent a year of my life in the hospital and rehab. I started in the summer of 1999 and was in ICU for three months where I was in a coma. When I woke up, I was a T3 para, but that was the least of my problems. During my hospital stay, I developed three pancreatic sudo cysts which have a 50% mortality rate. Along with that, I also had three severe skin issues on my calves and behind, which required plastic surgery. I had to spend two months in a sand bed. You cannot sit up until the surgery heals.

After the skin surgery, I underwent surgery to remove the sudo cyst. That was successful and the skin surgery was a success, as well. When the surgeries were completed, I went to rehab to learn how to live with my disability. That took about five months, because I was in such bad shape. When I went to rehab, there was little I could do until I regained my strength.

When I regained my strength, I was able to get moving and came home in June of 2000. I am still a T3 para. I am wheelchair bound, but I am getting around much better. If anyone is interested in talking to me, please feel free to contact me at my email or phone.

Michael F. Hartman
597 Old Clairton Road
Pittsburgh PA 15236
(412)653-3231
mcholhrtmn@aol.com

Michael F. Hartman
Pittsburgh PA

I want to share with you what happened to me and how I am doing now. First of all, I caught TM in 1999. Within the two and half years of contracting TM, I lost my youngest daughter, grandmother, my oldest brother, my middle brother, my father and my mother. Last June 24th my youngest brother died. Yes, I have really been through it. Dealing with my losses and prison and TM has just about taken its toll on me.

I don't know how I got TM, but maybe from having an infection in my body somewhere. I just don't know. I woke up on November 9, 1999 with chest pains. I thought I was having a heart attack. I laid back down and fell back to sleep. I then got back up and went to go to the bathroom and couldn't go. My legs felt wobbly and I could barely walk. It took maybe an hour and my body went numb up to my chest. My left leg went out from underneath me and my right leg was real weak.

I finally got to the hospital and was catheterized. I had a lot of doctors examining me, but they didn't know what was wrong. First they thought it was MS, but then they ruled it out. When they took an MRI, they still couldn't find anything. Finally, the second MRI showed some inflammation on my spine. I was then put on steroids intravenously. At that time they told me I had TM.

After being in the hospital for about a month, they weren't sure whether I would ever walk again. I wasn't going to the bathroom on my own and I couldn't control my bowels. I was a real mess. I didn't want to live that way. It has taken me a long time to get to where I am today. I started out in a wheelchair, then to a walker, then walking on my own.

I didn't have any pain for about six months and then I had so much pain that I nearly lost my mind. I couldn't even stand without having pain. Well, I then had to go back on my walker and start all over. I had nothing for pain, so I still walked and just dealt with it. I then got better, but I started having real bad burning sensations and muscle spasms. I was given viox, baclofen and two other muscle relaxers, but nothing helped.

I was self-catheterizing and just hoped that I didn't have a bowel movement when I was out. Well, next came spasticity and I still had the burning. I've tried everything for this spasticity and stiffness; nothing has worked. I got on pamelor for the burning and I'm doing really well with that. I do have some burning here and there,

Mary Alica Reynolds
Dwight IL

but not much. I still have the spasticity. When my leg wants to draw up, when I've been sitting for a while and have this tightening sensation, I've learned just to tell my mind to relax that muscle. It takes a few seconds, but it is working.

I've been told to exercise my leg, but I wasn't seeing any change in my leg. I just about decided to give up. I was getting tired of having to lay around all the time, because my legs hurt and I have a bad knee now from walking straight-legged. I got up and started walking as much as I could; pain and all. At first I thought, I can't deal with this pain. But the more I pushed myself, the stronger my leg is getting and I don't think about all that pain anymore. No, this pain isn't in my head. I really was hurting, but I just used mind over matter.

The better you start walking, the more determined you will get and the less pain you'll think about. I am walking very well now with my brace at a pretty fast pace. I can't believe how well I'm doing. I almost walk like I used to. I don't even use a cane. Getting your balance and watching your feet, how you step, then it is smooth sailing. I barely have a limp.

I quit catheterizing myself and started urinating all the time, only a little at a time. I was always on the toilet, but now I'm using my bladder on my own and I can even hold my bladder and not go on myself. I do wear panty liners for just in case. I can't believe that I'm doing so well and my attitude has changed so much.

I still have the bowel problem, and I do stress over that, but I use suppositories and make myself go even when I don't need to. This

avoids accidents. I do have them every so often.

It's been two years and I'm still getting return in my leg. I'm starting to practice going up stairs without holding on. My determination is what has gotten me doing so well. Don't give up. And if your doctor tells you that if you don't get return in three to six months then you won't, well, it is not always true. I am the proof of that.

I'm really doing well and I've had to pull myself through it with only myself and the help of G-d and reading Sandy's letters and the newsletters. Well, that's the story. I hope I've encouraged you to keep walking, to keep your mind strong, and to trust in G-d. It works!

Denice Stohr
Livermore CA

I was diagnosed with TM in January 2001. I was up on Mount Hamilton, playing in the snow with my grandchildren. We were having a wonderful family outing. Very seldom do I have the opportunity to see all of our grandchildren at once and we took advantage of our day together. I have gotten herpes cold sores since I was a child and didn't think much of getting an outbreak. I took my meds, as usual, and went on with the day. This time it was different. After the initial breakout was over, I got a new, more sever out brake the next day. This had never happened before in 38 years.

The next day when I woke up I could not move. I thought it was due to the fact that I am not usually in the snow and since I have scoliosis, my back was just giving me fits. It continued through the day and I became concerned. I went to the emergency room and they had no idea what the problem was. I had no reflexes in my arms, legs or feet. I had no pulse in my wrists or feet. They did an MRI and spinal tap. Their conclusion was that they had no idea and I should see my primary care physician the next day. I was worried about leaving the hospital since I still could not move.

I went to see Margaret, my nurse practitioner. She told me that I had an appointment with a neurologist later that day. Since I had not made the appointment and she had not made the appointment, we were both at a loss as to who did. I started to become really worried about what was happening. My dad took me to my appointment later that day. I met the neurologist. He told me that I would have to stay in the hospital so they could do a few tests on me. I will tell you at this time that I HATE hospitals. In the hospital I was poked, shocked, stuck, x-rayed, and prodded. I felt like a human pin cushion! I was released from the hospital after four days. Before leaving I was told that I had some strange thing called Transverse Myelitis. They had no idea how I got it, how long it would last or what it was. I was instructed to return to the neurologist in two weeks.

When I got home, my husband and son brought the extra twin bed downstairs and I tried to get around as best I could. If it were not for my friends and family, I don't think I would be here. Those were the longest two weeks of my life! I went to see the neurologist and was told that my condition was permanent. I could not believe the words that were coming out of his mouth. In fact, he had to repeat them three times! My mind was reeling! I would never walk again? I would never be able to be a clown again (that was my profession)? I would never be able to drive? All this was happening too fast! I could not fathom that my life had changed so much so fast! I was wheeled out into the waiting room where I saw my dad. He casually asked how it went and I lost it! I was inconsolable! In the days and months since then I have endured 12 spinal taps in one day, that didn't close and I had to receive 'blood patches,' 23 MRI's, 16 CAT scans and various other attacks on my body.

I am now able to walk with braces and a walker. Due to the meds I take, I have very little memory. I have broken just about every dish in the house, because my brain will forget to tell my hand that I am holding something. I have incontinence trouble, and am in constant pain. I can not feel my feet or most of my hands. I was given anti-depressant drugs for the pain, which do nothing to stop it. I am taking 3600 mg. of a drug called Neurontin. I wish I knew how to get the doctors to listen to me! If they can grow an ear on the back of a mouse, I can't understand why they can't come up with some way to stop the pain!
I have been very touched by the other letters I have read in the newsletter. You all have made this unwanted journey a little less frightening by sharing your stories and I want you to know I appreciate your words. My heart goes out to those of you who have not, as of yet, made the progress you have desired. Keep trying! Don't give up! I am pulling for you! You are always in my thoughts and prayers!

Your friend!
Denice Stohr
nieceepoo@earthlink.net

Hi, my name is Ruthie and I live in

Atlanta, Ga. I am 51 years old and I was diagnosed with TM back in 1999. First, I would like to thank Sandy Siegel, for his work for the Association. This is the only way that I was able to get all my information about TM. Sandy thank you, thank you, thank you.

I worked for the Atlanta Public Schools as a computer lab manager. On March 4,1999 I went to work. My day started out a normal work day. We were having a program around 9:00 that morning. After the program I had my lunch around 11:00. About 1:00 my principal asked if I wanted a piece of her fish; I said only a small piece, because I had already eaten. About 2 minutes after I had eaten the fish, I had a bad case of indigestion. I drank a Coca Cola and ate mustard afterwards, but nothing released the pain. School ended for the students at 2:30 and 3:00 for the staff. Around 1:45 I asked if I could leave; I left around 2:30 still in pain. I didn't know if it was indigestion or gas. On my way home, I stopped by the drug store to pick up something to take. I then went home, took the medicine and laid down.

Around 4:00 my son came into my bedroom and woke me up. He said, "Dr. Leslie called to see how are you doing, because you left work a little early due to your not feeling well." I said, "yes I did; I don't know if I have gas or indigestion." I had taken something, but the pain was still in my chest. My son said, "why don't you get up and walk around." I said, "I have been walking all day and that didn't help; but I will get up within an hour." I laid there for one hour. When I got ready to get up and go to the restroom, my right leg started tingling and burning. Then it went numb from the knee down. I picked up the phone and called my sister. I asked her, "how do you feel when you are having a stroke?" She said, "girl, I don't know, I never had a stroke. You need to hang up and call your doctor." I hung the phone up and called the health desk. I explained to them what was going on. She asked me if anyone was at home with me and I said, "No." She told me to hang up the phone and call 911. I hung up the phone and called my sister back, and asked her if she would come and take me to the doctor. She said, "I'm on my way."

The tingling and burning started in my left leg. Some of the feeling in my right leg had come back. I went to get out of bed again and had a hard time getting to the restroom. I finally made it. I made it to the family room. I sat by the door so that when my sister arrived, I could get up and open the door for her. When my sister arrived, I tried to get up

Ruthie Landers
Atlanta GA

and open the door. I couldn't move my legs. I fell on the floor. From my waist down I was paralyzed. I then had to drag myself to the door. We went to the hospital around 7:00 p.m.

The doctor ran all kinds of tests. They found everything normal. The doctor told me they couldn't find anything wrong, but that they were going to admit me in the hospital. The doctor told me that he would do a MRI the next morning. I asked the neurologist what was TM because I had never heard of it. He said *Transverse Myelits*. I then asked, how do you get it. He said you could get it from having a real bad cold or if you had the flu, it set up an infection in your spinal cord.

I was in the hospital for eight days. The doctor came in and told me that I would be transferred to a rehab center for three to four weeks. I went to rehab and went to therapy three times a day. I was doing so well that I asked if I could go home early. I was told on my twelfth day that I could go home early. I said, thank you G-d. I had to go to physical therapy twice a week for three months.

I went back to work in May. I couldn't do it; my legs were too weak. I had the burning. I couldn't control my bladder and bowel; that was bad. I ended up going on disability. As of today, I'm having problems with the burning in my legs 24 hours a day and the numbness. Last week I had something happen to me which I had not experienced in two years. I was sitting in my family room. When I tried to get up, my legs went out. I have not had this problem since my first encounter. I am asking that if anyone has found a medication that has helped them with the burning, to please let me know. These are the medicines that I have taken since I had TM:
Neurontin - 300MG
Methocarbamo - 75MG
Cyclobenzaprine - 10MG
Gabitril - 2MG
Topamax - 25MG
Naprxen - 500MG
Celebrex and amitriptyline.

A big thanks goes to my friend, Mrs. Charlie K. Hardnett, for going on the internet and finding The Transverse Myelitis Association. Thank you, Sandy Siegel, for all of your work for this Association. I will keep every one of you in my prayers.

Ruthie Landers
4071 Ester Drive SW
Atlanta GA 30331

Hello, my name is Violet. On April 28th 2002, I complained to my

husband that I had a pain in my side. The pain extended across my lower chest. Because of the time of day, he decided to take me to the ER. After testing, I was diagnosed with Iron Deficiency Anemia. I was admitted to the Hospital. The next day I was treated with antibiotics, iron supplements and blood transfusions. I was discharged and went home on April 30, 2002.

The very next day 01 May 2002, I started to stump my left foot as I would walk. My husband thought it could just be a reaction from being discharged from the hospital. I had a follow-up appointment scheduled for the 7th of May. My husband called the doctor's office two times to report the problems. When he called the second time, he told them that I was now not able to even walk. I was told only to keep the appointment for the 7th of May.

The appointment date finally arrived. By this time my husband had to take me to the doctor's office in a wheel chair. The doctor examined me and said he could not diagnose the problem. I am a post stroke patient so he made an appointment for me to see my neurologist. My husband talked to the neurologist who stated that my illness had nothing to do with my previous stroke three years prior. My husband took me to the ER again on the afternoon of the 7th of May.

Tests were run again and I was admitted back to the hospital. This time I was diagnosed with TM. I was treated with different drugs after MRIs, x-rays and other treatments. After being hospitalized for seven days, I was transferred to a rehabilitation center where I spent another seven days. I came home on the 21st of May 2002.

I am trying to recoup the best I can with the help of God, doctors and my husband, who is very understanding. I can now walk with the assistance of a walker and sometimes a cane. I discovered TMA on the internet. I have read all of the amazing stories and was very moved. I have learned a lot about
Transverse Myelitis that I never would have dreamed without TMA.

Pleased to meet you and may God Bless you all.

Violet

Hello, my name is Theresa Dempsey and I am 31 years old. I live in Horsham, West Sussex, England. I suddenly became ill on the 27th March 1999 when I woke up with a stiff neck. I thought that I must have slept in an awkward position and it got a bit better during the day. That night I went to bed and I woke up in the early hours of the next morning feeling very strange and my chest felt very tight and it was difficult to breathe. I managed to get to my hallway to try and get help (as I was living on my own at the time), but I started getting tingling in my fingers and I could not dial the numbers on the telephone. I then started to get tingling throughout the rest of my body and could not stand and eventually collapsed and I remember thinking this is it; I am going to die.

Violet B. Laws
Winchester Virginia
jenny@visuallink.com

The next thing I remember is waking up in ITU at Crawley Hospital wondering where I was. I was later told that I was found early on Monday morning by two of my work colleagues, as they were concerned when I had not arrived at the office. When I was discovered, I was very hypothermic, as I had lain on the floor for over a day. It was 'touch and go' in the ambulance and at A & E.

I was assessed by loads of doctors who undertook various tests including a MRI scan. I was told that I had a slight swelling on my neck and after a small operation I would be okay. I was transferred to the local Neurological Centre for this. When I got there I was told that they thought I had Guillain Barre Syndrome (GBS), but the doctors wanted to do more tests. I was asked loads of questions. I remember being told that I might need to be ventilated, as my breathing was getting harder. I then woke up a few days later having missed Easter on a ventilator, very disorientated, and not knowing what was true and what was not. I have very vivid memories of going to Manchester and Scotland for tests which I know I did not and other very strange hallucinations which I now know to be quite common with GBS. I know I was treated with Steroids and Immuglobin, but I do not know how quickly I received this as my symptoms kept changing; as one day I would have an knee/ankle reflex and the next day I did not.

After a lot more tests comprising several MRI scans, Nerve Conduction Tests, Nerve and Muscle Biopsy, three Lumbar Punctures my diagnosis was finally decided as Guillain Barre Syndrome and Transverse Myelitis after a complication with the Mumps Virus. The doctors kept asking me if I had had mumps, but as far as I am aware, I didn't. I was weaned off the ventilator very slowly and finally came off it in June 1999.

Unfortunately, I developed a severe pressure sore so I was confined to bed-rest and was not able to undertake my rehabilitation until February 2001.

Theresa Dempsey
Horsham West Sussex England
tsdempsey@hotmail.com
20th November 2001

By this time I was in the Spinal Unit at Stoke Mandeville Hospital. I had gained movement in my left arm only, but no real finger movement; only a flicker in the second and third fingers of my left hand.

I am now confined to an electric wheelchair and have a 24-hour carer and live in an adapted two-bedroom bungalow. I manage to eat with a feeding strap, use a computer with a typing splint and write with a writing splint and do other daily tasks with splints. I have also been left with several other problems, including severe pain in my right shoulder (I have had an operation on this as it was dislocated whilst I was on bed rest). I also have patchy sensation in both of my legs and a tingling feeling all of the time and a feeling that my legs are being "strangled." I still only have movement in my left arm and head and neck.

The reason for me writing is that I have been told by my Neurologist that I am unique as he has researched my case with other Neurologists and also on the internet and has been unable to find any record of other combined cases. I have also read articles both in the GBS magazine and website and also the Transverse Myelitis Support Group magazine and website and have not come across any similar case to me. I would be very interested to hear from anyone with similar experience to me and has been diagnosed with both Guillain Barre Syndrome and Transverse Myelitis and would be grateful if you could contact me either by e.mail tsdempsey@hotmail.com or by post to 30 Park Terrace East Horsham West Sussex RH13 5DN.

Correction

In the last newsletter Conrad Brown wrote an article about the TENS unit and how he has used it to help control painful spasms. He listed contact information in the event that anyone wanted to reach him to discuss the use of a TENS unit. An incorrect phone number was identified. The correct contact information for Conrad is as follows:

Conrad Brown
518-392-6101
fax 392-0149
VZConrad@earthlink.net

Functioning as a group requires cooperation and shared responsibility by group members and a willingness to participate in the pre-planning and preparatory work at all levels. This increases the chances of success of the support group by increasing the participation of as many people as possible. It provides everyone with a sense that they share in the ownership and have control over the direction of the group. And it increases the possibility that the group will not end from a lack of interest.

Members of groups in which attendance is sporadic and irregular should be encouraged by the leader to formulate an appropriate plan of action. Some of the issues that could be considered when evaluating participation are the meeting times and dates, the location of the meetings and the content of the meetings. People have busy and complicated lives; support group meetings need to be convenient for people to attend. Another consideration is whether there is a cost associated with the meetings. If a lunch or dinner meal is served that some members might not be able to afford, the group might consider holding some of the meetings in places where a meal does not need to be purchased, or members should be made to feel comfortable attending the meetings and not buying the meal. Finding appropriate solutions to some of these issues will ensure a core group of members regularly attend the meetings and will enhance the group's effectiveness and staying power. To that extent, the leader should not be reluctant to delegate responsive action to secure this core group. Involving the whole group in finding the solutions ensures that the group will find the solutions that work.

Members who wish to get involved and to share the work load should have the opportunity to do so. This employment of group members provides the leader with additional resources that can be used to bolster attendance and to ensure the continuity of the group. Some of the activities that can be delegated and shared by group members include, writing the meeting notice that is posted on The Transverse Myelitis Association website; finding and arranging the meeting place; if meals are to be served, selecting the meal items and making the arrangements for member payments; preparing and printing and mailing invitations and notices for meetings which include the time, date and directions; helping to prepare a schedule of future meeting dates; volunteering to make copies of literature and materials that will be distributed to members at the meeting; and volunteering to make phone calls to members to remind people of the meetings.

Shared responsibility in planning often results in increased clarity of purpose. Such clarity increases the member's ability to make an informed decision about whether he or she wants to participate in the group. Thus shared planning can result in

TM Support Groups

Functioning as a Group: Shared Responsibility
Pam Schechter

minimizing domination by the leader and maximizing individualism and self-determination. Shared responsibilities and pre-planning can help to set the group's priorities and assures that the group's needs are meaningful and helpful, that they will make a real difference.

Another way to share responsibility in the group is to share the responsibility of leading the meetings. The group can rotate this activity between members who are interested in taking on this role. The person leading the meetings can take on the activities of making sure that new members are introduced to the group and asked to share their background, history and reasons for joining the group; by allotting time to each group member to update recent experiences regarding his or her attempts at recovery and other happenings since the last meeting; by introducing topic discussions and the agenda; and by leading general discussions on questions and concerns posed by the members.

As group survival tactics, shared responsibility and shared pre-planning are key elements for the perpetuity of the group. The use of these elements reinforces the dynamics of the group, because everyone has a stake in the group's success and continuity.

Good luck to those of you who wish to start a regional support group. I hope my suggestions help to improve your chances of success and that responsibility for the group is a "shared" effort by all of your members. If you wish further advice or suggestions or wish to exchange your own suggestions and helpful ideas about support groups, please e-mail me at:

Littleprincess900@hotmail.com
Regards to all,
Pam Schechter

Luke contracted TM in April 2000 at the age of five and half months. Luke is now two years old. He is a quadriplegic and has limited movement of his arms and hands. He has some sensation in his lower limbs. He breaths abdominally. There is some small independent and conscious movement in his legs. *(Luke's story appeared in Volume 4 Issue 2 of the TMA Newsletter).*

In April of this year, Luke was in the hospital with a cold. As fate would have it, the Premier of New South Wales, Mr. Bob Carr, was also at the hospital opening a new wing. Ali saw all of the press outside and that is how we had discovered that the Premier was at the hospital. I told Ali that he was very strong on his support for embryonic stem cell research. Ali jumped to her feet and went down to see him. She thanked him for his support on stem cell research and asked if he would like to come up to see Luke; a boy who would likely gain so much if the research was approved. The Premier changed his schedule and came straight up - with about 15 others. He was truly inspired by Luke's plight and spent nearly an hour talking to us. Since then, we have kept in fairly close contact as we both try to encourage legislation to be passed through the Australian government to have unrestricted research into embryonic stem cells. We certainly appreciate the sanctity of life, but we also see the enormous benefits to society from such research.

A few weeks ago the Premier requested another visit to see Luke, this time at our home. We, obviously, said yes. Anything we can do to encourage exposure to Transverse Myelitis and Stem Cell research will help Luke, and we have a strong sense of responsibility to do that.

The Premier arrived with 30-40 media people and swamped our house -- in a semi-controlled fashion. Luke was a little over-awed, but then settled down to his charming self. He completely stole the show. We told the Premier about Dr. Kerr's research with stem cells and we showed him Dr. Kerr's video of the partially-recovered rat following the stem cell injection. We talked to the Premier in front of the media about Luke and TM and stem cell research. We then had a press conference outside where more issues were discussed. The coverage of Luke has been on the four Statewide news stations, national radio several times, and the two local news channels. The story appeared in all of the state newspapers, including front page coverage. Luke's story also was covered in two local newspapers. In addition to this, both Ali and I were on talk back sessions on radio to push the case.

Ali told the media that our main aim was not to get Luke walking again. She said that the main problem was Luke's chest, which had limited function forcing Luke to breathe with his abdomen and leaving him susceptible to illness and infection. For every single respiratory illness he

Making a Difference in Australia
Steve Alderton
alderton@shoal.net.au

has he is hospitalized and requires ventilation. If we could have Luke with a better chest and improved hand function then that would be great; and it would be exceptional to have Luke having mobility of his legs.

It is so important that research into embryonic stem cells be advanced. There is incredible potential in both Adult and Embryonic Stem Cells. Both areas of research must be pursued. This will be the way medicine goes in the future. Ali and I are interested in helping our son, Luke, and everybody else ***now***. We do not want to wait five years. There is too much suffering now. It would be morally wrong for us not to fight strongly for this to happen. It is our responsibility.

Since the media exposure, we have had endless calls from people supporting us, some who have had TM. When the general public sees someone like Luke, it is hard not to be moved, not to be inspired. What is right and wrong becomes immediately obvious; all the other arguments fade away.

The Premier continues to call to check on Luke's progress and has a picture of Luke on his desk.
The bill went to Parliament in late August. Alison and I went to Parliament on Monday, August 19 with the Premier of New South Wales to give a presentation in support of ESC research legislation. The bill on the use of Embryonic Stem Cells has made it through the House of Representatives with a 75/25 split. This is good news. It is now under a month research review by the senate. It should go through there with a reduced majority, and then it will be law; hopefully, by the end of the year.

We will continue to fight. We realize that if Australia and other countries, like Britain, pass this legislation, then the tide will begin to turn on this issue, and everybody, including our son, will win.

My name is Ursula Mauro. I contracted TM in June 2001 and I'm in the process to start a German TM support group. After I introduced myself in the last newsletter and via email to the German membership, I wrote an email to the German TMA members and asked about people who want to get active. A few answered and slowly we started to get in regular contact with each other. Once in a while I sent new little letters out there, also to the new addresses of German members. Sandy transfers to me all new members from Germany, I make contact with them and some more people reacted. (Thanks, Sandy for all your support)!

In January I announced the first (informal) TM support group meeting and asked who would be interested. The months between the announcement and the meeting were pretty exciting for me, also because it was so unsure about how many people would attend. Some couldn't come because of understandable reasons as relapse, vacation, hospital stay, a long distance; some didn't know until the last second. Unfortunately, also my neurologe couldn't come because his wife had a baby a few weeks before.

A few days before the meeting I had 6 obliging announcements.

Then the 20th of April 2002, the day of the event.
I had ordered a quiet table for dinner at 5.30 pm in a middle-class Hotel/ Restaurant in Kehl and at 6 pm we were eight people from all over Germany, five with TM and three companions. We all saw each other for the first time, so I was excited and curious how it would work out with us. We really did have a good evening, the meal was fine, the conversation also. We used the benefits of a little group, spoke a lot about our experiences with TM, treatments, difficulties, about some ideas, for example, to create a German page on the TMA Home Page and stayed together until about 11.30 pm. We all want too stay in contact and a German network develops. I'm real happy about it and see the meeting as a success.

And I'll try to organize the next support group meeting in November 2002 and hope that many people will attend. I also search for people who would get busy with raising funds for the TMA in Germany. I think that's a very important job; we need money urgently, because the TMA has no membership fees and also much money is needed for the research.

So whoever is interested, please get in contact with me.
Ursula Mauro
umauro@t-online.de
Tel.: 07807-3154

And finally, I want to thank all the German TMA members who were willing to get involved and to start with me a German support group!

You all take good care about yourselves,
Ursula
Hello TMA, Ireland here!

I am so delighted to report what a

TM Support Group in Germany
Ursula Mauro

wonderful mini-symposium we had here in Ireland, July 5th 2002.

What was only a wish in 2000 turned into an excellent day for all of the people in Ireland and the UK with TM. I had been contacted by several people here with TM after doing a radio interview on a national radio program.

I had been trying to get funding from different sources for a TM meeting, but to no avail. Then I was at a Christmas dinner for the regional (West of Ireland) MS Society last December and spoke with the regional manager about whether we could organize some kind of information day for TM through the MS Society. Thankfully, he was very interested. This is how a Neurological Information/Awareness Day in Galway came about. There was a speech about motor neurons given by a neurologist from Dublin, as well as a speech about MS by a neurologist from Co. Cork. Dr. Kerr from the Johns Hopkins Transverse Myelitis Center came all the way from Baltimore and spoke about TM. Dr. Kerr spoke in terms, which were about the patient, making very complicated subjects easy to understand.

I was delighted with the turn out of TM clients who traveled from near and far corners of Ireland and England. There were also medical professionals, occupational and physio therapists who attended from several places in Ireland. There were some alternative therapists who expressed great satisfaction with Dr. Kerr's speech. They indicated that he was a neurologist and scientist who understood the benefits of therapy, diet, and exercise.

Our meeting brought back memories of the First International Symposium, which I attended in Seattle. It was a very emotional experience. There were many people with TM meeting other TM'ers for the first time. It was just great watching them all. After the meeting was over, many people stayed to talk to each other and many were comparing their experiences. It is a great benefit just to be able to talk to someone else who knows exactly what you are going through. In the association, we all know about that. It's so good to share knowledge and ideas.

There was a mother and her baby who came from England specifically to see Dr. Kerr. She was delighted to have him on our side of the world. She had traveled to see him at Johns Hopkins earlier in the year. They had a very good discussion about progress since their visit to Baltimore.

There were also other clients from England who attended. Geoff Treglown, the support group leader from England, also came to the meeting. Geoff prints and mails all of the TMA newsletters and directories to our members from all over Europe. He expressed an interest in having Dr. Kerr to visit England for a support group meeting. So, we will be working on that idea with Dr. Kerr!

Ireland TM Support Group
Ann Moran

Dr. Kerr was his usual wonderful self. He is so easy to listen to, and makes everything interesting. The TM clients were thrilled with him. He is such a great person. The TMA is very lucky to have him. He is very dedicated to our cause. He stayed about two hours after the meeting and met people individually, sharing his knowledge.

We also enjoyed having Chitra attend the meeting. She is Dr. Kerr's assistant, and is also very knowledgeable about TM. She spoke with the TM clients also.

It was also so nice to meet Dr. Kerr's wife, Kathleen, and little Caroline, who is the apple of daddy's eye. He even ended his notes on screen with Caroline's picture! A lovely personal touch. All of our guests enjoyed a short break in my hometown, Westport, before returning to Baltimore.

One of the very positive results of the meeting was a decision to form a membership address list of people with TM in Ireland. This will make it easier for us to keep in touch with each other. I have contacted the National Rehabilitation Centre asking them to be sure and inform newly diagnosed patients of our Ireland TM Support Group.

I really am so delighted that I was able to organise the day. As I said to Sandy the day following our meeting, "I was like a dog with two tails." I was so happy with the way everything turned out. Photos of the Ireland meeting are posted in the web version of the newsletter.

Take Care All.
Love to everybody in the TMA.

Ann in Ireland - still cold and very little sunshine this year!

First Meeting to Be Held

Plans are underway for the first meeting/social get-together for people with TM in South Africa; it will be held during the first week of

November in Johannesburg. One of our members, Paul Swart, has kindly offered us the use of a house overlooking the tranquil Vaal River. The aim of our meeting is firstly to get to know each other, to share our TM experiences and to look at ways in which the SA TMA can become more proactive in creating awareness regarding TM.

Creating Awareness: Workshop on Accessibility

TMA member, Tanishka du Plessis's employer – the Provincial Legislature – held a workshop on accessibility at the Legislature on the 24th of July, as to educate those in government circles about the needs of the disabled regarding accessibility of government institutions. This workshop follows a petition submitted by Tanishka to the Legislature in 2000 citing that the inaccessibility of the Legislature building was discriminating to the disabled community and hampered their participation in legislative proceedings. Tanishka was given the opportunity to address the Members of the Provincial Legislature and Government Department representatives on the importance of their role in ensuring that the voice and concerns of the disabled community is heard and seen to. She also shared her TM experience and the aims of the TMA. The feedback was incredible. The provincial chairperson of Disabled People of South Africa, who was a participant at the workshop, expressed a keenness to learn more about TMA and to look at the possibility of including SA TMA in its activities.

Rehab Meeting

Tanishka was invited by the Provincial Rehabilitation for People with Physical Disabilities to share her TM experience at a monthly Forum for People with Disabilities meeting on 15 August 2002. She encouraged people to become actively involved in disability issues as this would help to guide society in understanding the special needs of those who are disabled.

News from the South Africa TM Support Group

Tanishka du Plessis

My name is Ulrika Pettersson, I am 23 years old and I live in Uppsala, Sweden. I have been a member of the TMA since 1999. A few weeks ago Sandy asked me if I wanted to start a local TM support group in Sweden. I said yes. So, I thought this might be a good time for me to introduce myself to my fellow TM'ers and share with you all my story.

The onset of TM

It all started on October 23rd 1991, when I was 12 years old. I had had a cold for about a week and I had a terrible cough. During my lunch break I was playing in the schoolyard and as I bent down to pick up a ball I felt a sudden, sharp pain in my back. It hurt really badly, but I figured it was all the coughing that had caused the pain and so I didn't think too much about it. Later that evening, I was lying on my bed when I suddenly got a tingling feeling around my knee. It soon spread to the rest of the leg. I thought it was very unpleasant so I got up from my bed and went down to the kitchen. A little while later I started to loose the ability to control the movement of my legs. As I tried to take a step forward, my leg crossed the other so that I walked into things. My sister, who has always liked to tease me, asked me what I had been drinking. I, however, did not find her joke very amusing. My mother thought that I had just overstrained myself and so she sent me straight to bed. By then both my legs hurt really badly. It was very similar to having bad growing pains. My mother rubbed my feet for a while and that made it a bit better.

I finally fell asleep. But about one o'clock in the morning I woke up and now the pain in my legs was horribly bad. I sat up, put my feet down on the floor and tried to get up, but I couldn't. My legs were too weak. I had to find another way to get downstairs to my parents' bedroom. For some strange reason I didn't want to wake my sister up so I slowly and quietly sat down and started to shuffle along the floor, using my hands. Somehow I managed to get down the stairs without getting hurt. When I got down to the hall outside my parents' bedroom, I gently called my mother. She woke up, came out to me and asked me what was wrong. I told her that my legs were so weak that I couldn't walk. She and my father then immediately called the local hospital. We were told that we should go straight to the hospital so that I could be thoroughly examined. So my mother helped me to put some clothes on and then my father carried me out to the car and we went to the hospital. There, a doctor examined me and quickly decided to send me to the nearest university hospital for further examination.

Waiting for the diagnosis

I arrived at the university hospital in Uppsala at about half past three in the morning. A doctor examined me and checked my reflexes. In the right leg I had a negative patella reflex, whereas my Achilles reflex was intensified. I didn't have any Babinski reflex. For my left leg the situation was the same apart from the fact that the patella reflex was highly intensified. The sensation was normal in the right foot and calf, but I had no sensation above the knee. A few blood samples were

Hi everybody!
TM Support Group in Sweden
Ulrika Pettersson
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taken and then I was sent to have a lung x-ray.

The following day the patella and Achilles reflexes in the right leg were gone, whereas the reflexes in the left leg were back to normal. I couldn't move the right leg at all, but I could lift the left leg a little bit from the bed. However, I couldn't hold it up for very long. On this day the doctors performed a lumbar puncture. That was awful for me. First of all I had to lie on my side and that was very difficult for me because it hurt, and then the doctor had to stick me a few times before he hit the right spot. I didn't cry but when it was over my face was all wet with sweat. This was also the day when the physiotherapy started, but I wasn't really in the mood for it. I was very introvert. I think I was in a state of shock. I was really very calm; almost apathetic.

The next day I was moved from the emergency ward to a regular ward. I didn't like this. I had started to get to know the nurses and doctors on the emergency ward, but now I had to get to know a whole bunch of new people. The tiny sense of security that I had built up was shattered.

The fifth day at the hospital I was examined on the new ward. First the reflexes, coordination and strength of my arms were checked and everything was found to be normal. My left leg had lost the Achilles reflex and I couldn't lift it up from the bed anymore. In the right leg the patella reflex was back, but it was still only a very weak reflex. The sensation was strongly impaired in both legs, but more so in the right leg than in the left. The boundary of the sensation impairment was found to be at the level of the twelfth thoracic vertebra. What bothered me the most at this point was that the muscles of my bladder had been affected by the illness. I couldn't empty my bladder. I didn't want a catheter, so I didn't want to drink anything. But after a while I just couldn't take it anymore. My bladder was so full that I thought it would explode. So I got a catheter. I found that very unpleasant, because it hurt and also because my sensation was impaired so it felt really weird. Plus I was very shy. I felt sort of insulted but once I had the catheter I was still relieved, because I could finally allow myself to quench my thirst. On this day I was also sent to have a MRI. It may sound strange but I actually liked that. It gave me a chance to be alone with my thoughts. The MRI didn't show anything pathological.

On the sixth day an EMG and a neurography were done and on the seventh day I underwent an ECG and an EEG. I was also sent to have a myelography. That examination was done with anesthesia. I really appreciated that. First, I was given a local anesthetic in my right leg to keep it from hurting too much when I was moved between beds and then I got a couple of tiny pink pills to calm me down a bit. I smiled and thought to myself that those ridiculous pills couldn't possibly have any effect whatsoever. But, of course, they worked. I soon started to feel really relaxed and a little while after that I was having a very difficult time trying to count the people around me. I got my anesthetics and fell asleep. I think I slept for about an hour, but when I woke up I felt like I had slept an entire night. It might have been that the artificial sleep wasn't disturbed by dreams or worries. I don't know. Anyway, the myelography was normal.

Now that a week had passed and all sorts of tests had been done the doctors were certain that what I had was TM. I was given steroids for eleven days; first intravenously and then in the shape of pills. The dose was reduced gradually. I also underwent an SEP.

Rehabilitating and making progress

As soon as the diagnosis was made, the physiotherapy began in earnest. I got a physiotherapist who was really good. I felt like she really cared about me. Not just my condition, but me. That made a huge difference. She took the time to talk to me and get to know me before we started the therapy. She made me want to fight and prove that I could do things. In the beginning of rehabilitation we mostly worked on stimulating the muscles. I would try to move my feet, toes or legs and at the same time try to focus on what it used to feel like when I could move them. It was difficult and sometimes I lost my patience, but after a while I started to make progress. I started to be able to move my left foot and toes and there was a slight activity also in the right foot. My sensation got better too and the boundary of sensation impairment was now at the level of the first lumbar vertebra.

At this time I was allowed to get up in a wheelchair for the first time. This was almost two weeks after the onset of TM and I bet you can all guess that I was now fed up with just lying in the bed all day. The chance to get some change of scenery that the wheelchair offered was really what I needed and it made me feel a lot better. I have to say though that getting up in the wheelchair for the first time was more complicated than I could ever have imagined. My muscles had got so weak from me just lying in bed for so long that I actually had problems holding my head up the first day.

As soon as my legs were strong enough, I was put on a special kind of bunk that could be tipped up so that I got to put some load on my legs. I also did a lot of arm training with dumbbells. Gradually, the training got tougher. I had to practice getting myself out of and back into the wheelchair. I practiced falling out of the chair and getting back in it. That was really hard and scary. Sometimes the training was so hard and it all felt so hopeless and difficult that I just sat on the floor crying. It was all so unfair and I just wanted to give up. At those times my physiotherapist meant everything to me. She never really lost her patience with me. Instead, she sat down next to me, hugged me and tried her best to make me feel better and want to fight again.

On November 17th I could, for the first time in more than three weeks, lift my left leg an inch or so from the bed while lying on my back. I cannot even begin to describe how wonderful that felt. A few days later I could lift my left leg up to about 60 degrees. The Achilles reflex was back in the left leg and I had also started to regain the strength in my left foot. I could also move my right foot a little bit. I couldn't lift my right leg yet, but there was some activity in the thigh muscle.

In mid-November the catheter was taken out, but I still couldn't empty my bladder so the catheter had to be put back in the same day. The physiotherapy got even tougher and I started to train in the hospital pool. It was scary, but at the same time nice. I also started to practice with a walker. But I didn't really walk. It was more like shuffling along using my left leg and putting almost all my body weight on the walker. Around this time I was also allowed to go outside for the first time. That was great. My physiotherapist took me downtown and we went to a hamburger restaurant. That was very nice as I was starting to get tired of the hospital food.

For each day that went by I got stronger and I soon started to use walking trestles. Sometimes I secretly tried to use crutches in my room, but that was still too difficult. At one time I nearly fell and after that I didn't dare to go on. But I really longed to be able to take care of and do things for myself so I just felt that I had to go on trying new things. But I did it all on my own when no one was watching me. I wanted to prove that I could do it without help. It paid off. At the end of November I managed to get myself from my wheelchair to my bed and back again without anyone helping me. And I noticed that I could lie on my side again. I had always slept on my side before I got TM. I hated sleeping on my back, but when I first got ill I had no other choice. But now I felt so free. I think that one has to experience it to fully understand how such a small thing could mean so much. I immediately showed the nurses my new skills and they, of course, reported to the doctors. The catheter was removed for the second time and now I could actually empty my bladder, but not very well.

According to the medical experts I was now too well to stay at the hospital, but not well enough to go home. I needed intense physiotherapy and I needed to learn to take care of myself and the daily chores. Therefore, I was to be sent to a rehabilitation home. I protested, of course, but no one paid any attention to that. Once again, I felt like my world, my sense of security and my faith in the doctors had been shattered.

On December 2nd I was discharged from the hospital. I was allowed to go home for the weekend, but after that I was to stay at the rehabilitation home for two weeks. Being home again was really great. I was so happy. I felt like my home town somehow had become so much more beautiful. And it was great to be back in our house, eating mom's homemade food and sleeping in my own bed. Coming home was one of the happiest moments of my life.

The rehabilitation home

But the weekend passed and it was soon time to go to the rehabilitation home. That was the most horrible place I have ever been to. I didn't want to be left there and I cried. But my mother and father were told that it would be better once I got settled in. But things didn't get better. If anything, they got worse. I was so alone the first evening there. No one had the time to talk to me or pay any attention whatsoever to me so I just rolled into my room and felt completely abandoned. I don't remember if I cried, but I think it's quite possible that I did.

The second day somebody came to wake me up. I was really sad and didn't want to get up. A little while later the person came back and told me I had to get up, take a shower and get dressed so that I could eat some breakfast before I had my first physiotherapy session. I think it was now about 7.30 and I was told that the physiotherapy was to begin at 8.00. I tried my best to hurry up. I rolled into the bathroom and took a shower and then got dressed, but it took me a while. I then rushed out to get some breakfast. A girl who worked at the rehabilitation home helped me to get something in my stomach, but while I was eating my new physiotherapist came into the room yelling at me for being late. I got very sad and upset, but felt ashamed that I hadn't got up

on time. I had trouble holding the tears back as I went with her to get my first training session at the rehabilitation home. This physiotherapist was not very good. Yes, she teased me and tried to make me laugh, but sometimes it actually felt like she meant what she said when she called me different bad things.

When it was time for lunch I asked the people in charge of the food if I could have something else than orange juice or milk to drink, because the doctors had told me that I shouldn't drink orange juice or milk. They then answered that any other beverage they had must only be used at coffee time and that I could drink water. I was very surprised and a bit upset. At home we always had some sort of table beverage, apart from milk.

Some time in the afternoon, a person came and asked me what I was doing just sitting around in the hall. I was supposed to be at school. But no one had told me anything about that. Anyway, I went with her to school. That turned out to be the only place where I felt reasonably comfortable. The teachers there chose to encourage me rather than yelling at me and they made me feel normal.

I was also supposed to take music therapy. It was held by a middle-aged man. He told me to beat a few different rhythms on a drum. A couple of years earlier I had, however, had a music teacher who thought it was really important to know at least five basic drum comps so I found the music therapist's exercises a bit simple. I told him that I could play five comps and showed him. Then he looked a bit offended and said that I obviously didn't need any music therapy. The man just didn't seem to understand that something I liked to do could be useful, if for no other reason than that I liked it.

By the forth day I had become really fed up with it all. I called my old physiotherapist and told her how awful it all was and I cried. Then I called my mother and said that I just couldn't stay there anymore. She came over and talked to the staff and they convinced me to stay one more day. I was told that I wouldn't have to spend the evening alone. Mom went home and I started waiting for someone to spend time with me. But of course, something came up and I had to spend the evening alone anyway.

The next day I had made up my mind. There was no chance that I would spend another week at that awful place. When my physiotherapist found out that I was going home she got angry and told me that if I didn't work hard with the physiotherapy now I would never get any better. I felt guilty and got a bit scared, but still I was convinced that I wouldn't get better physically as long I was miserable. So I went home that day and never returned to the rehabilitation home. Mom called the hospital and told them that I hadn't exactly got on well at the rehabilitation home. It was then decided that I should come back to my old physiotherapist and have two sessions a day with her five days a week. That was truly a load off my mind.

The way back

At the hospital they seemed a bit disappointed with me for not staying at the rehabilitation home, but I don't think they understood what it was like for me. I soon started to feel a lot better both on the inside and on the outside. After a few days with my old physiotherapist, I could extend my right leg against resistance and I could also start to walk with crutches. On Christmas Eve I managed to walk up the stairs in my home for the first time without using the crutches. I managed without them when I was inside the house, but I still used them when I was outside. I didn't drop them completely until after a couple of months. After the Christmas break, I started to have physiotherapy in my home town.

My biggest problem now was the bladder. I had urinary tract infections more or less all the time from the removal of the catheter until the end of February when I was put on Furandantin (a urinary tract antiseptic medicine). That put an end to the infections. My kidneys and bladder were examined, as well as my ability to empty the bladder and it turned out that I had a certain type of bladder dysfunction, where the urinary sphincter doesn't cooperate the way it should with the muscles that contract to empty the bladder. This caused retention and was the reason why I had had so many infections. About six months later, my bladder was examined again and by then the bladder function was better. This meant that I could stop taking the Furadantin.

The last real motorial improvement occurred some time during the spring 1993 when I started to be able to move the toes on the right foot a bit.

Child or grown up?

I think one of the reasons why I've coped so well with going through the experiences with TM is that I'm very stubborn. When I want something, I get it. But it wasn't always easy. There were a lot of things that the medical people could have done better. I was often sad or angry when I was at the hospital. To me that seems normal. I mean, who wouldn't be upset in that situation? Apart from having to deal with the pain and the

other physical issues I also had to deal with being away from home for a long time. I had never been away from home before, apart from the times I had stayed over at a friend's house for a night. My parents couldn't be at the hospital all the time so I was left alone a lot. And most of the time, when my parents weren't there, no one really had the time to talk to me or spend time with me. I felt like everybody at the hospital (apart from my physiotherapist) just tried to make me suppress my feelings. What they should have done, I think, was to try and find out why I felt the way I did. Also, when the diagnosis and treatment were discussed I was treated like a child. If anyone even talked to me, instead of just talking to my parents, that person would explain things to me as if I were a baby and didn't understand anything. But when I was angry or upset or sad I wasn't allowed to be a child. Instead, I should suddenly be all grown up. Once when I was angry and impatient a nurse actually yelled at me that I should "pull myself together." I have often wondered how that nurse would have reacted if she had been in my shoes.

My medical history after TM

After TM I had no real problems with my health until 1996 when I got a urinary tract infection again. The problems continued and I also got blood in the urine; so much in fact that the urine was all red. In the autumn of 1997 I got another urinary tract infection and started to get blood in the urine pretty often. I went back and forth to the local hospital, but didn't get any help until after a few months. By then I was really scared that there might be something seriously wrong with me. In the beginning of 1998 I underwent a cystoscopy and the doctors found a bladder stone that was a couple of centimeters in diameter. A couple of days later they removed the stone and since then I've had no more infections. But as if I wasn't tired enough of hospitals after that, I got an ovarian cyst at the end of 1998, and it was removed with laparascopic surgery in the autumn of 1999. But my problems didn't stop there. In the summer of 1999 I started getting problems with pain. My doctor thinks it's nerve pain, but she isn't sure and nobody seems to know if it is connected to TM or not. This kind of burning pain is rather common after TM but my pain problems didn't start until seven and a half years after the onset of TM, so… Anyway, if I say that I think I've seen enough of hospitals and had enough of physical problems, I don't think you would be too surprised.

My life today

I didn't recover completely from the illness. I don't have any nerve contact with the calf muscle and the muscle on the back of the thigh of my right leg. Those muscles are atrophic. Because of this I limp a bit when I walk and I can't run. I still have problems with bladder retention and I have developed my own technique to empty the bladder as thoroughly as I can. The bladder problems are the worst of my physical problems. I get jealous sometimes of people who can just go into the bathroom to empty the bladder and then be back out again within a couple of minutes. When it comes to the pain problems, I am still fighting to get help. I have had to fight before to get help from the medical people. I don't know why some of them have such a hard time understanding the needs of their patients. Sometimes it is tempting to give up. I admit that. But if I don't fight for my needs, then who will? I am an expert on my body and my problems and I have the right to demand help when I need it.

When my problems make me feel down, I turn to a very special friend of mine. He has also had TM and I got to know him through the TMA. It really helps to talk to someone who has gone through the same things that I've gone through. I know that he doesn't just say that he understands; he actually does understand. He has helped me a lot the last couple of years and I know that I have helped him a lot too. He will always have a very special place in my heart.

Although my TM problems do take up quite a bit of my time, I will never let them take over my life. I have far too many other things to think of to ever be tempted to do that. I do get tired of the problems sometimes and I want them to just go away, but still I love my life and I love being alive. I have my family, my friends, a very sweet boyfriend and the cutest dog and cat. And I am only a few months away from getting my master's of science degree in engineering physics. My dream is to then go on to get a PhD in either medical engineering or scientific computing and to some day in the (far) future get married and hopefully start a family.

By sharing my story with you, I hope that I can help someone just as I have been helped by reading the stories that some of you out there have shared with me and all other TMA members in previous newsletters. I hope that you are all as well as can be expected and, of course, I hope that, with the help of science, there will one day be a cure for all of our problems. It may happen, it may not. I don't know. The important thing is that we mustn't stop hoping, but also that we mustn't forget to make the most of our lives while waiting for a possible cure. We may have our problems, but life still has a lot of great things to offer. So, come on and let's make the most of it!!!

Since the last newsletter I have moved house. My new address and phone number are at the end of this article. My apologies if this has made it difficult for you to contact me. My e-mail address has not changed.

I am aware that some of you have experienced problems using a credit card to make donations to the TMA. Helping.org has for a couple of months been accepting USA addresses only. You can now make credit card donations from the UK using CharityWave.org. There is an article about CharityWave and online donations in this newsletter. Please try it out!

I am often asked by TMA members from the UK about the availability of "alternative treatments." With any condition which claims to have no cure, a search for alternatives is always attractive. Two therapies which can assist mobility can be found in the Yellow Pages. Horse riding for the disabled (look up *Riding Schools*) will be suitable for many, even those in a wheelchair. It can be very helpful with balance problems and if properly organised it can provide an enjoyable social outing. The use of hydrotherapy pools can also provide a social outing as well as good mobility therapy. Pools are advertised in the Yellow Pages under *Swimming Pools* and under *Health Clubs*. You need one that has a physiotherapist in attendance rather than the type with a beautician!

I have been experimenting by attending a Chinese Health Doctor but sadly after eight weeks and a total of five different concoctions, we agreed that he was not able to do anything for me. Meanwhile another TMA member (from the Northampton Group) has also been experimenting with Chinese medicine but he tells me, "After much testing and alternate medicines, I'm sad to say there was no change." However, he reports that, "I have been having Reflexology treatment for the past few months and my walking ability improved about the time I started it." I have heard other positive comments about reflexology from the Telford Group.

One of their members has also heard of a recipe for arthritic relief. The logic of the recipe comes from Biblical times when juniper berries were thought to have healing properties. The recipe requires large golden (light) California raisins to be soaked in gin (cheapest) in a shallow dish until the gin has evaporated. Gin is made from juniper berries and natural grains. The process takes about a week after which you are supposed to eat the raisins at the rate of nine a day. Improvements are apparently noticeable in about a month. (NB alcohol may not be appropriate in combination with other medicines).

I have also come across A Good Health Guide: *Stopping Restless Leg Syndrome*. RLS is similar to the twitching limbs that many TM sufferers experience. The condition is also known by Ekbom's Syndrome and PLMS (periodic limb movement during sleep). Anyone suffering from these conditions might find the 90 page simple booklet helpful. It can be obtained from The Bristol Group, 36 Stephenson Road, Totton, Southampton SO40 3YD; price £11.90 including p&p, payable to Bristol Health.

Have you tried any alternative treatments? Has anyone had any experience of acupuncture? Please let me know so I can report in the next Newsletter.
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California TM Support Group
Cindy McLeroy

Hi, everyone. My name is Cindy McLeroy. I have undertaken the role as co-coordinator for establishing TM support groups in California. The other co-coordinator is Debbie Capen. Most of you probably know Debbie. Debbie serves on the TMA board as Secretary. She has been such a support in all the symposiums the TMA has sponsored. Most recently she worked hard on the Children's Workshop in Columbus, OH. Actually, with Debbie we get a 2fer. Her husband, Michael, is right there to support our group. I am hoping to have the first meeting in September.

Even though I have been a member of the TMA since its inception, I have never shared my story. Perhaps before I write about our hopes for California support groups, I'll tell you how I got started on the Transverse Myelitis path.

In October of 1992 I was scheduled to go to New Orleans on a business trip. The Thursday before I had a deep root canal done and the specialist advised me that after dental work this extensive I could experience "something" in other parts of my body that appeared unrelated to the root canal. He gave me a prescription for antibiotics just in case. That weekend, I went to breakfast with my parents but had no appetite and just felt like a real slug. We then went to check out the local garage sales. I picked up a heavy crock and as I stood up, it felt like some one punched me in the back hard enough to knock the wind out of me. At that point I went home and

laid down. The next day, Sunday, I went to a concert in the park. Normally, after the concert, my friend and I would walk around the lake four or five times. My back hurt so badly, I couldn't make it once around.

Monday I hopped a plane to New Orleans. This trip I was staying in the French Quarter at a beautiful hotel on Bourbon Street. I made the meetings on Monday afternoon, all day Tuesday and Wednesday. I had worked with the other folks in the meetings for many years. We worked for the same company and over the years had become good friends. We would work hard all day and then spend the evenings together. Wednesday night I had dinner out at Lake Pontchartrain where I enjoyed fried calamari (some blamed this for causing TM). Sometime, not long after midnight, I woke up and felt nauseated. I got up, threw up and went back to bed.

Thursday morning I was up early. About 6:30AM I jumped into the shower. While shampooing my hair, my legs started feeling weak and "squashy." They felt like they would not be able to hold me up much longer. I quickly rinsed the shampoo out of my hair and sat on the edge of the tub. I never did step out of that tub. Those moments in the shower were the last ones I stood on my own power. I managed to get on the bathroom floor. Luckily, there was a wall phone in the bathroom and I was able to knock it off the receiver and ask for help. I was also lucky that I was able to reach my nightgown and get it on before hotel security arrived to break the locks on the entry door to my room. I was on the floor, with no movement or feeling in either leg, so I was unable to open the door for help as the latches were up high. Strangely, I was not scared. At that time I was not in pain. I managed to get in touch with one of the ladies attending the meetings and she came to my room as I was being put on a stretcher. I thought I would be taken to the hospital, given some magic injection, feel great, slip into my levis and head back to my meetings. Not to be.

I was taken to Tulane University Hospital, an excellent teaching hospital. There I suffered through the numerous tests most of us have experienced. I remember having four MRI's, two spinal taps, all the tests for MS, etc. After eight days I was told I had Transverse Myelitis. I have reviewed my medical records from Tulane and they suspected TM from the time I entered the emergency room, where, by the way, I spent 12 hours. I received very little information on TM and most of my questions were unanswered.

After 11 days at Tulane, I was transferred to St. Jude's Hospital in Fullerton, California. I arrived by way of a medical air flight. It was supposed to be on a Lear jet; instead it was a prop job. Try that for nine hours lying down with nowhere to move or unable to turn over. Not fun. I was at St. Jude's for six weeks for physical, occupational and recreational therapy. I also had the tests repeated that had been done at Tulane. After leaving St. Jude's, I did about three months of outpatient therapy.

I returned to work seven months later. My company had made some modifications for me, mostly parking and entrance to the building, plus, of course, the bathrooms. Luckily my office was big enough for me to maneuver around in easily in my wheelchair. I went back almost immediately to 10-12 hour days. They were pretty draining, but I had found that distraction was better than any of the pain meds I had tried. I worked for seven years and finally, due to changes where I worked and also the fact that I was just so fatigued, I left the company where I had worked for 32 years.

Whoa, that was a long way to get to SUPPORT GROUPS IN CALIFORNIA.

Since I stopped working at a paying job, I have become involved in many volunteer jobs. I am on the board of two nonprofits and have several really fun projects I work on each year. One of the boards I serve on is for a nonprofit agency. It is the largest independent living center in California. While it is a wonderful ILC, it serves all disabilities. I have decided that I really want to direct my energy, such as it is, to The Transverse Myelitis Association. I can do this by working with Debbie Capen to start support groups in California.

Debbie and I have become great friends and we have agreed to work together to start support groups in California. We both live in Southern California about 80 miles apart. Initially, our focus will probably be just the Southern California area. California is so large that any one wanting to help, please let us know. We had some spirited discussions of what folks were looking for in a support group at the TM California Conference in June. We will try to incorporate as many ideas as we can. Saturday seemed to be the best day for most people so we are trying to find a place that is easy to get to and that will provide a room on a Saturday at no charge. Originally, I mentioned

that we could probably have something ready by August, but it will have to be moved to September.

If you are interested, please let one of us know. I can be reached at (714) 638-5493 or email at cindymcleroy@sbcglobal.net. Debbie can be reached at (909)658-2689 or dcapen@myelitis.org. I will also put out a notice on the TMIC list. Debbie and I hope to get to know all of you in California.

Since the publication of the last TMA Newsletter in October 2001, we have planned and organized the sixth and seventh New York State Support Group meetings which were held respectively on November 8th, 2001 and June 22nd, 2002. As with prior meetings, they were held at Ben's Delicatessen and Restaurant in the Bay Terrace Shopping Mall, Bayside Queens. The room we reserved at the restaurant provided us with the privacy and the time we needed (12noon to 4PM) to cover our general purpose and agenda.

Common to both meetings were the amount of attendees, which included members, families and friends, and totaled approximately twenty-two to twenty-four persons. They traveled from all parts of the metropolitan area including Long Island, Westchester County, New Jersey and New York City.

All areas were readily accessible to the restaurant. The sixth meeting on November 3rd, 2001, again was chaired by Ms. Hope Klopchin, our principle speaker and leader of group discussions. At the meeting, Ms. Klopchin was officially recognized as Dr. Hope Klopchin, having successfully completed her doctorate in counseling psychology at the State University, Buffalo, NY. This degree is a tribute to Dr. Hope Klopchin's tenacity and courage, because she was afflicted with Transverse Myelitis at the age of twelve, went through a long recovery period and still managed to obtain this high academic degree.

The discussion centered on several themes, the most prominent theme concerned the stigma of having a disability and what the members thought having a disability meant to them before and after they developed Transverse Myelitis. We compared and contrasted the pre-conceived notions about how we felt about people with disabilities versus our current thoughts about the reality of our own disabilities from TM. An interesting question posed by Dr. Klopchin concerned the perceptions and thoughts we had about, for example, persons in wheelchairs, prior to our illness, did we feel that they were lonely, depressed, lacked self-esteem, were poorly dressed, etc. A lively discussion ensued and most members ran the gamut from all of the above, adding more to the list, to a more optimistic approach to those in wheelchairs. We also discussed the possibility that these pre-conceived notions may reflect a societal or cultural bias attached to being disabled.

We discussed the Americans With Disabilities Act of 1990 and how frustrating it was being disabled in a non-disabled world. For example, some of the members had attended the July 2001 2nd International Transverse Myelitis Symposium, cosponsered by Johns Hopkins University Hospital and The Transverse Myelitis Association and held at the Holiday Inn Hotel in Baltimore, MD. The general opinion was that the hotel offered a number of amenities for the disabled, but fewer rooms that were handicapped-accessible were available to them. Other members who did not attend the symposium also related experiences of less than friendly accommodations for handicapped persons at restaurants and other public facilities.

We ended the meeting by distributing literature compiled by TM members Mrs. Vilma Mithchell and Ms. Susan Tilotta. Our special thanks to them for the wonderful job they did in collating the important information which was obtained from the Johns Hopkins website. Each attending member received a compilation of all the lectures and events that were presented at the symposium. We scheduled the next meeting for June, 2002.

At the seventh meeting, June 22nd, 2002, we were privileged to obtain as our principle speaker, Dr. Shariq Ali, Ph.D., Assistant Professor, Department of Pharmacology, Toxicology and Medicinal Chemistry, Long Island

New York State Support Group Meetings

Pamela Schechter

University, Brooklyn, NY. Dr. Ali's credentials are impressive. He obtained a B.S. degree from Long Island University and Doctor of Philosophy degree in pharmacology from New York Medical College in 1999. Dr. Ali has done biomedical research at Mount Sinai School of Medicine. During his research career, Dr. Ali has published extensively in leading peer reviewed scientific journals.

Dr. Ali's presentation was a basic and general overview of the common drugs that TM members use, the properties and possible interactions between the use of multiple drugs. He started the discussion by listing the possible causes of TM. They included viral infections, such as pneumonia, that may trigger an abnormal immune response leading to inflammation of the spinal cord. Other possible causes were vaccination as an example of a deficient immune response and an-

other cause might be a lack of blood supply to the affected area causing inflammation. He stated that the causes of Transverse Myelitis can be idiopathic (unknown), as well. Dr. Ali briefly outlined some of the symptoms of TM which included weakness, pain, sensory alteration or bladder or bowel dysfunction. He explained that the first time therapy for an acute attack of TM was intravenous steroids. He stated that the problem with using steroids is that they decrease the immune response. Therefore, you are more prone to develop a secondary infection. He also discussed the risks versus the benefits of using this drug. Another drug used in acute TM is Immunoglobulin therapy. This treatment is usually reserved for patients that are responding poorly to steroids or recurring attacks. Dr. Ali discussed the use of Plasmapheresis. This is a treatment in which blood is taken out of the system, purified and put back in the system. The premise of using this treatment is to remove substances that cause inflammation. Other drugs used to treat TM include Neurontin, a drug that suppresses pain and tingling sensations. It helps with symptoms of neuropathic pain. He explained that anti-depressants are also used to relieve the symptoms of pain. Anticonvulsants, for example, Tegretol, are used for neuropathic pain and sometimes for spasticity.

Dr. Ali mentioned that a common side effect of anti-depressants was dizziness. There are a number of anti-anxiety drugs, such as Clonazepam, that are used to treat neuropathic pain. A drug called Baclofen is used to treat spasticity, a symptom of Transverse Myelitis. Other drugs used include, Ditropan, commonly used to control bladder dysfunction and Clonidine, a drug used for neuropathic pain.

The final portion of Dr. Ali's discussion concerned new drugs being used for the treatment of TM. The most promising and prominent drug Dr. Ali mentioned was called Fampridine-Sr (4AP). He cautiously referred to the drug as a potential cure. According to Dr. Ali, the phase two clinical trials of Fampridine have been completed for chronic spinal injuries (which includes Transverse Myelitis and Multiple Sclerosis). Patients in these trials have shown marked improvements in a variety of functions, including decreased spasticity, improved sexual function and increased bladder and bowel control. Fampridine enhances conduction in damaged nerves and is the first compound that has shown to restore some neurological functions in patients with spinal cord injury. Dr. Ali described how it works. Fampridine predominantly blocks specialized potassium leaks from nerve axons. When the axon is demyelinated after injury, potassium channels are exposed and leak potassium resulting in short-circuitry of the axons. By blocking this leakage, Fampridine permits the axons to transmit nerve impulses again, even in the demyelinated state and restoring some neurological function. Dr. Ali's explanation of how this drug works and what it can mean was received with extreme interest and enthusiasm by the attendees, because it offered them hope.

The final segment of Dr. Ali's lecture was a cautionary warning about using Valium or Xanax, because these drugs can become habit-forming. However, Ambien, a drug which might be a good alternative to Valium or Xanax is not habit-forming.

After the meeting adjourned, Dr. Ali said that he would be pleased to serve in an advisory capacity for the New York State Transverse Myelitis Support Group and The Transverse Myelitis Association. His suggestion was welcomed by all. Both meetings were considered successful in providing important education and information and offering material for future discussions.

Ohio Support Group of The Transverse Myelitis Association

Stephen Miller

Inaugural Meeting

The inaugural meeting of the Ohio Support Group of The Transverse Myelitis Association was held Saturday May 4, 2002 at the Radisson Hotel in Worthington, Ohio. There were 14 people with the TM diagnosis present along with several of their family members and friends. Discussions were held regarding ways to organize the group, its meetings, goals, social events and networking amongst both current and new members to the TMA. The afternoon went by quickly and new friendships were formed during the time together. As a result of the first meeting, a committee was developed to welcome new members, develop an Ohio TM newsletter, an Ohio TM web site, and to organize and plan future meetings and events.

September 14th Meeting

The Fall Meeting gathered at the same location on Saturday, September 14 and there were over 40 in attendance, 16 who share the Transverse Myelitis diagnosis. Lunch was served, stories were swapped and old friendships were renewed and new ones developed as everyone enjoyed the time together.

After lunch, the first of two guest speakers was introduced and took the podium. Dr. Joanne Lynn of The Ohio State University and The Transverse Myelitis Association

Medical Advisory Board addressed the group about what Transverse Myelitis is, the common theories which the medical community believes could be it's cause and some of the therapies available for treatment of symptoms. Dr. Lynn also spoke in depth about the mechanics of the central and peripheral nervous system and explained the "why" behind many of the long-term symptoms TM is common for, such as spasticity, sudden involuntary motion of affected limbs and confusing sensations like a feeling of wet or burning skin. An in-depth oration regarding the relationships between TM and other neurological conditions was also given. The similarity between multiple sclerosis and TM was discussed and Dr. Lynn fielded numerous questions from those attending. It was a very beneficial time for all and we are very grateful for Dr. Lynn's time and efforts on the behalf of our group.

Next, Sandy Siegel, President of The Transverse Myelitis Association took the stage and spoke about the history of the organization, his efforts and successes in fundraising, the Children's & Family Workshop which took place in July, 2002, as well as some of the upcoming plans and events the Association is developing for the future.

Finally, the group discussed possible fundraising opportunities and various ways that Ohio can get involved to support the TMA at large with volunteer time, writing and editing for the bi-annual newsletter and aiding in logistical issues associated with mailings and information distribution. Additionally, the Ohio TMA group is in the early stages of planning social events in and around the state for members not able to travel or otherwise attend the meetings in Worthington. Please check in to the Ohio Support Group page on the TMA website for additional information regarding future events.

The meeting was scheduled from 11:00am to 3:30 pm; however the last of us didn't leave the hotel until nearly 5:30. It was a great day with great food and even greater company. Thank you to the Radisson Hotel for their professionalism and warm hospitality and to those who had a hand in organizing this event. Your efforts are certainly not without notice and we extend our deep gratitude.

Be sure to look at the Ohio Support Group web site by following the

"support groups" link from the TMA's main web site: www.myelitis.org.

The Ohio Support Group Committee is comprised of individuals diagnosed with Transverse Myelitis and living in the state of Ohio. If you have any questions, would like additional information about the Ohio TMA Support Group, or have an idea for a social event or fundraising opportunity, please contact one of the committee members.

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The Virginia TM Support Group started out with three "TMers" and their spouses meeting for lunch in Williamsburg, the colonial capitol of Virginia. Having corresponded only via email, my husband and I sat in the lobby of The Williamsburg Lodge, one of the restaurants in the restored area, looking around for others who looked like they might have TM. I admit this was a weird, unfair, perhaps irrational approach. I didn't look any different; why would they. Ron knew that I used a cane and I knew that he did. We both used walkers off and on. Jesse used a walker. We found each other.

After being seated for lunch, we talked about TM, our families, and general stuff. Our waitress was great. The food was good. The atmosphere was wonderful. So, the six of us sat there for four hours talking about when TM affected us and how, what we missed the most, and how it wasn't fair. The two of them didn't have the same "Why me? This really isn't fair" period which I was still going through after nearly five years! They appeared to me to have adjusted to their TM limitations more readily than I. Ron and Rachel made reference to the fact that I was their daughter's age and that I had missed out on so much in my life. So what if I had? I can't change it. We agreed to meet again after the holidays.

Our second meeting ended up being a lunch with Ron and Rachel, Bill and I. We learned that discussing bodily functions in public was not a good idea. Other than that, things were okay. The discussion at this meeting focused on the caregiver. It was good for Bill and Rachel to have time to

talk. I know that it is difficult to care for persons with a chronic illness. As a nurse, I used to see it when I worked. I could never see it from Bill's perspective anymore than he could see TM from mine. It was good for us to have the opportunity to talk with the two of them on a focused topic. It is really amazing how TM affects everyone within a family or within a group of friends. At times, it really feels like TM consumes everything around you even though you promise yourself that you are beyond that. The caregiver support is essential. The conversation of that day was extremely helpful not only to me but to Bill. I had to work at making him see that I would not want him to have TM as a way of making me better. No one should ever have this illness. This seemed to be a common theme at future meetings, as well as emails received after the meeting.

By March, we had a total of 20 at our meeting! This was pretty exciting for all of us. Email contact is nice for the day- to-day, I need a hug, are you there communications. This meeting allowed us to put faces to Cookielady11, jnsmith, rhutton6, MillerGH. The computer age is fascinating, if only to connect us to friends we haven't met. Our set topic on pain management was mentioned briefly at my end of the table and I believe I may have heard it at the other end, as well. I don't think pain was a problem for many of us on this day. We were just a group of friends with their spouses, having lunch and getting to know one another. I was in awe how the two words, "I'm new" in a subject line in an email could go so far. These are the words in the subject line of the messages sent to me by new members from the Virginia Support Group. We decided our next meeting would be in two months.

May in Charlottesville; how gorgeous. John volunteered to do the planning and organizing for the May meeting. We discussed ways to reach more people in Virginia since Virginia is such a large state. This is something that we are still working on. Support is important. People are important. Numbers are insignificant. Webster's defines a group as "two or more individuals assembled together or having some unifying relationship." This is US.

Please send me an Email or call, if you are interested in getting involved in our group. I know that some people prefer quiet, private ways of dealing with illness.

Virginia Support Group
Pamela New
wnew@erols.com

Planning for our July 27 meeting was a little more difficult for me than previous meetings. I wasn't sure what the difference was until my son asked me if TM was hereditary. I think that his fear in spite of his knowledge of TM really put things into a different perspective for me. This is a child who has had to grow up very fast over the past five years since my TM first appeared in May 1997. He just turned 12 in March 1997. He now knows enough about TM to manage fundraisers, to educate his teachers and bosses, RN's in emergency rooms, and emergency room doctors who know little about it. He and his brother and sister know how to care for mom, which side is numb, which car the walker should be in, when to help with cooking and when not to help. They know more about neurology than any kids should. This is where a support group comes in. This helps me help them. Webster's dictionary defines support several ways. These include, "to make more pleasant or bearable, to give assistance to, and to keep from losing courage." All of these meanings make the two words "I'm new" take on more significance each and every day in my life.

"Trapped in a sleeping body" was going to be the name for the memoirs I started writing ten years ago when I got TM. At that time, 1992, I had just turned twenty years old, was in my fourth year in college and had two part-time jobs. I had everything going for me.

One day I got the chicken pox, the kind you can hardly notice, because there were just a few marks, which, at first, I thought was acne. A few days later I had the strongest headache ever. I could barely open my eyes. Three days after dealing with the chicken pox symptoms, I stopped urinating and was walking really slowly and with back pain. That night, which marked the beginning of a whole new meaning of life for me, I had the worst pain ever in my lower back. My parents suggested to me that I sleep on the floor to ease the backache. The next morning I couldn't get up on my own. My legs were weak and I still couldn't urinate.

I was rushed to the hospital and in the emergency room I was diagnosed with Guillian-Barre. They then transferred me to another hospital where they said that they had the proper equipment for me. On our way to the hospital, the ambulance had mechanical problems and a second ambulance was called. The paramedic of the first ambulance quickly began to work on it, and by the time I was almost in the second ambulance, he had fixed it and insisted on taking me. He was so determined that he drove me to the hospital. Once we got there, I needed to be catheterized urgently, because my bladder was full. But he requested a time alone with me to pray. I am

Catholic, but it was the first time I had heard the phrase, "faith moves mountains." I have never seen the paramedic again, but his determination and words have been with me always.

After several examinations, the neurologist diagnosed TM while everyone else insisted that I had Guillian-Barre. Immediately, they administered intravenous high dosages of cortisone. By the way, dealing with that moon face was not easy. Shortly thereafter I began physical therapy. I remember the day I took my first steps. I was in the rehabilitation area and was the youngest one there. I was placed in between the bars. I moved my leg forward and took that step and did the same with the other leg. Everyone in the room applauded me. It was the greatest feeling.

I was doing pretty well with my legs, but two weeks after being hospitalized they lowered the cortisone dosage too much and I suffered a relapse. It was literally beginning from scratch, being bathed in the bed, unable to move my legs; it was devastating for me, as well as for my family.

That day after the relapse, when I got to PT, my legs wouldn't respond. Next to my mother, who was always with me, sat a lady that took a little plastic saint from her purse. After watching me struggle to get my legs moving with no results and my eyes full of tears, she told me that once she had been very sick and someone else, already cured, gave it to her with the condition that when she got well, she had to pass it on. So my crying mother came to me and handed me the little saint. I thought maybe it was worth trying, so I took it in my hands and started praying from the bottom of my heart. Immediately, my legs started moving and I was even able to take my usual steps standing in between the bars. Who would know; faith does move mountains.

After thirty-two days in the hospital, I finally went back home. I would wake up in the mornings and listen to a song by Michael Bolton, "When I'm back on my feet again." I would go for physical therapy three times a week and the other two days my brother and boyfriend (who is now my husband and has been an angel sent from G-d) would take me to the pool for more therapy. My legs started getting stronger, although my bladder and intestines were not functioning normally. I was able to finish school the next semester and got a bachelor's degree in journalism and went back to work.

My Story and Announcing a TM Support Group in Puerto Rico

Yvonne Lugo

In 1994 I was diagnosed with avascular necrosis in my left hip as a secondary effect of the high dosages of cortisone. It was very hard for my loved ones and for me to deal again with the struggles of walking, only this time with pain. A so-called doctor did a drainage in my hip and when I walked again after four weeks on crutches, the pain was still there. He told me to go to my neurologist, because he didn't know what was wrong. For two years I walked with a limp, because of the unbearable pain. I had several doctors tell me that I would never be pain free and that I had to learn to live with it. I used a cane for five months. I finally found a wonderful doctor that was concerned enough for my quality of life.

By this time, I was twenty-five and both hips were bridled, because of the condition. I ended up with two total hip replacements. I walk now pain free and even cross my legs better than before. By the way, the first surgery I had with the so-called doctor was unnecessary, because this procedure is obsolete for this condition.

A few months later I was diagnosed with epilepsy. I was on several medications for some time, but currently I am seizure and drug free for two years now.

For a long time I lived feeling like I was a victim and that people had to feel sorry for me. And since that was what I projected, that is how people treated me. Also, a big issue that I needed to deal with was the fact that the people that once were my friends never visited nor called when I was sick. Some even stopped talking to me. They made me feel as if I did something wrong. The only support I had was from my family and relatives. But deep inside I did not like feeling victimized. I was a fighter. So, I decided I needed to change. I started reading motivational books which helped me regain my self esteem and confidence. I began doing exercises and weights and I learned to extract from the not-so-good experiences the positive side of them. Someone once told me that all experiences are blessings. The not-so-good ones are part of our development and formation and the good ones are happy moments, but both are necessary for us to be who we are. Incredibly, my body as well as my mind responded. Since my muscles are much stronger, I can walk at a faster pace, my bladder has improved, and I feel more in control of myself and independent.

Today, I have a full and normal life. I work, travel and do things I once thought I would never do again. I still have my neurogenic bladder. I have rare involuntary movements and

sensorial patches in my legs and I have severe constipation due to spasticity in the puborectalis muscle. While I was searching for information on my symptoms, I came across the TMA. I was thrilled to read about it and to discover that there were others like me.

Today, I am very happy to announce that Puerto Rico will have a support group. I have started, with the guidance of Sandy, searching for TM patients and distributing informational brochures to medical offices, PT centers and everywhere I can imagine. My father has a printing shop and he was kind enough to let us print the TMA brochures in both English and Spanish free of charge. My brother did a great job making this happen. Jim has posted the TMA brochure we produced in Spanish on the website. I really hope that we can make a difference in the lives of those patients affected with TM. I encourage all those Puerto Ricans to reach out and contact me. We can all learn from each other.

God bless you all,
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Raising Funds and Awareness
Two Hop-a-thons and a Hoop-a-thon

An Opportunity to Win Ann's Beautiful Quilt
Debbie Capen

Many of you have had the privilege of meeting Ann Moran from Ireland. She has had transverse myelitis since 1990, being paralyzed from the waist down. Despite physical disadvantages, she takes on all challenges with a very contagious enthusiasm. Ann has traveled alone to the United States to attend both TM International symposiums, and another trip just for enjoyment. She has started a TM support group in Ireland, has been interviewed on the radio to promote awareness of TM, and this past summer Ann single-handedly organized an Information/Awareness day on July 5th with Dr. Douglas Kerr of the Johns Hopkins Transverse Myelopathy Center as a keynote speaker.

As many of you also know, Ann started a project that she hoped would ultimately promote awareness of TM, would be a valuable keepsake for somebody to hand down to loved ones for generations, as well as raise funds for operating costs of The Transverse Myelitis Association. Ann is a remarkably talented seamstress and loves to make quilts. She belongs to a quilting group in the town where she lives. Ann posted a message to the TMIC list of her intentions to start this project, and asked for people to help her by making quilt blocks and sending them to her. The outcome was that she received blocks from Australia, Canada, the United States and her own contributions. Once she received the blocks, Ann put them together to make a beautiful "TM Quilt."

Ann presented her finished quilt to the TMA at the Second International TM Symposium in Baltimore, MD in July 2001. We have discussed how we could best offer this quilt for sale to the maximum number of TMA members, and have decided that this would best be done by announcing it in this newsletter. We are going to offer this beautiful quilt by means of selling raffle tickets. This will be a worldwide sale, but the sales of the tickets must be presented in US dollars.

If you would like to see a picture of the quilt, you may visit the TMA website at www.myelitis.org/quilt. We will begin selling raffle tickets immediately. The purchase price of the tickets will be $2.00 for each ticket, and three tickets for $5.00. The proceeds from the sale of the tickets will be donated to the TMA for operating costs.

This would be a great opportunity for those of you in church groups or other clubs to sell tickets to members of your clubs and even members of your community. If you would like to receive quantities of tickets for selling, please contact me via email at dcapen@myelitis.org. I can also be reached by telephone at (909)658-2689. You may also mail me a request. My address is identified below. I will be happy to send you batches of tickets. Once you sell them, please have the person buying each ticket fill out the stub with their name and contact information and return the stub to you. Have the buyer keep the larger portion of the ticket. When you have completed the sale of all of your tickets, please send the stubs to me along with a check or checks made payable to The Transverse Myelitis Association. Please write 'Ann's Quilt' on the checks. My address is identified below.

In order to make this easier for you to obtain tickets to sell or purchase, we will also have a link set up at the TMA website. All that you will need to do is print the tickets from this link and do the same with these tickets as you would with the ones that I will be distributing. All tickets will be put into a container, and there will be a drawing for the quilt. This drawing will take place at a meeting of TMA members in Southern California on Saturday, May 31, 2003. To be included in the drawing, I must receive your stubs by Saturday, May 24th.

If you have any questions, please contact me either by email, letter or telephone. Please, if you have access to a computer, look at the picture of Ann's quilt. It truly is beautiful. We thank Ann for all of her hard work in putting this together and we thank all of the people that contributed their squares.

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Raising Money for the TMA with Friendship Bracelets
Kate Harris

Hello. My name is Kate Harris. I am ten years old and I live in England. My brother, William, got Transverse Myelitis when he was six years old; he is now 12. During the summer term I decided that I wanted to raise money for The Transverse Myelitis Association to help William and others like

him. I made 70 friendship bracelets and my friends also made some, so in total we had 120. We sold them one lunchtime at school together with candles that I made out of beeswax and 90 cakes. If you don't already know, friendship bracelets are made from different coloured threads woven/plaited together to make brightly coloured bracelets that you give to your friends. We made £150 altogether. We really enjoyed making all the things for the sale and organising it all ourselves.

Reading For Rachel: How You Can Help

Cathy Dorocak
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When Rachel first got sick on October 9, 1999, we were in such a state of shock and sadness for our baby girl. She was only 6 1/2 months old when TM struck, right when she was just beginning to become mobile. Life had been so good, and overnight all that changed. Three years ago, as a 1st birthday present for their sister, our sons, Matthew and Kevin (ages 6 and 4 at the time of Rachel's illness), thought of "Reading for Rachel", where all funds collected would go towards research to find a cure for TM. This continues to be our gift of hope to her since this has become our annual fund-raising event for The Transverse Myelitis Association.

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

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

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

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

In addition, we would like as many school systems to get involved in the Reading for Rachel Program. It is particularly effective if students can relate to this illness because TM affects a family in their school. For example, last year, Reading for Rachel was promoted at Worthington Estates Elementary School in Worthington, OH. Pauline Siegel (who has TM) teaches 2nd grade at this school. It was enormously successful because the children learned about the medical condition that affects one of their teachers at school and this was the connection to Rachel. All of the students watched the video of Rachel and Pauline was able to share her story as well. Because of the success of the program at Pauline's home school, it will be introduced to all of the elementary schools in the Worthington school district this year!! So please take the time to talk with teachers, school administrators and PTA's regarding this activity. Many school systems have "Right to Read" weeks and this is a good activity to tie into the events of that week.

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

- Monetary contributions (not tied directly to any reading activity) have been received from individuals and organizations, including PTA units.
- Contributions from pre-schools were made for every book that was read to students during a particular time period.
- Individuals have sponsored our own children's reading efforts from around the world. This year, we will read a total of 93 books - (one book for Matthew, Kevin and Rachel for each of the 31 days in March). If you would like to sponsor our children, please contact me at the e-mail address above.
- School Book Fairs - A percentage of the profits have been donated to "Reading for Rachel".
- Heart Grams - During Valentine's week for the past two years, children at one school purchased paper hearts for 25 cents each. They wrote messages on them and they were delivered to students/teachers throughout the school.
- Penny War - This was done during "Disabilities Awareness Week" and was a very fun activity. Each grade level had a container in the lunchroom. Students brought in as many pennies as they could and they put these into their own grade level's container. Students brought in silver coins and they put these into the other grade level's containers since the value of the silver coins was subtracted from the value of the pennies. They loved sabotaging each other and the grade with the highest net penny value won! They won a pizza party, but the actual value of all the silver coins, in addition to all the pennies, more than made up for that!
- Sales of anything!! - Last year, Rachel's Grandpa made birdhouses, sold them, and all of the contributions were sent to Reading for Rachel!
- Memorial Contributions - contributions to Reading for Rachel have even come from people in memory of someone who recently passed away.

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

In July 2002 Cathy Dorocak was selected as CIGNA's Volunteer of the Month and was awarded $500 to be donated to the charitable organization of her choice. Cathy has donated the $500 to the Reading for Rachel Fund for TM Research of The Transverse Myelitis Association.

Cathy Dorocak: CIGNA Volunteer of the Month

Cathy was honored during a Town Hall Meeting held in the CIGNA offices in Cleveland, *the best location in the nation*. Cathy is so deserving of this honor and award. Her family established the Reading for Rachel Program as a way to raise funds for TM research. She promotes the program throughout her community and in the TM community around the country and around the world. Through her tireless efforts, she and her family have raised thousands of dollars for TM research. Her dedication and her drive have helped to motivate others to get involved in awareness and fundraising activities.

We are so proud of Cathy's honor and her accomplishments. We are so grateful for her hard work on behalf of everyone in the TM community.

As a monthly award winner, Cathy is now in the running for Volunteer of the Year; the award for this honor would mean $2,500 for the Reading for Rachel Fund of the TMA.

You go, girl!

It is a tradition at St. Paul's Nursery School to have a hop-a-thon in April of each year to raise money for a charitable cause. The 3- to 5-year-olds who attend St. Paul's select the cause and raise money by getting pledges to sponsor each of them while they hop 100 times.

In 2001, St. Paul's Nursery School decided to hold its hop-a-thon for Caroline to raise money for The Transverse Myelitis Association. Our daughter contracted TM when she was six months old. She was paralyzed from the waist down. Caroline is five years old and has had a good recovery from TM; she works very hard.

Transverse Myelitis Hop-A-Thon
Steve and Colleen Blandford

The preschoolers at St. Paul's decided to hop for Caroline and The Transverse Myelitis Association again in 2002. We asked that the money that was raised be used for the TMA Children's and Family Workshop and also to fund TM research. In addition to the fundraiser at St. Paul's, Michael Flannery became involved in our efforts. Mr. Flannery is a reported for WCPO, an ABC affiliate in Cincinnati, and has a program called "9 On your kid's side." He did a program about Caroline and about the hop-a-thon. He also asked for pledges and participated in the fundraising.

Through Caroline's efforts and those

of her friends at St. Paul's, and through the generous support of Michael Flannery, the hop-a-thon was able to raise $10,170.40 for The Transverse Myelitis Association. Dana was a healthy, athletic ten year old girl until July 2001 when she contracted Transverse Myelitis (TM) and became paralyzed from the waist down. She came home after a month's stay at Children's Hospital San Diego, uncertain of what the future held for her. Thanks to caring family, friends, classmates, doctors and therapists, she is slowly regaining use of her legs.

Dana's Hopathon Fundraiser Raises $6100 for The Transverse Myelitis Association
http://spiff.ucsd.edu/Dana/

Dana and her family attended the first-ever Pediatric TM Workshop in Columbus, Ohio in July 2002. The Workshop was sponsored by The Transverse Myelitis Association (TMA) and moderated by Douglas Kerr, M.D., chairman of the Johns Hopkins Transverse Myelitis Center (JHTMC). The Center is the only one of its kind in the country dedicated to studying the epidemiology, potential causes and mechanisms of spinal cord injury in TM. The Workshop allowed Dana's family to meet 24 other families who had children with the illness, and learned that TM is a rare disease, striking 1 in a million people, and of these, approximately 10% are pediatric cases. The illness is often misdiagnosed or there is a delay in diagnosis – with dire consequences for the patient. Dana's parents are both pediatric physicians and were concerned that there were perhaps missed opportunities for better outcomes due to lack of awareness by treating medical personnel. They were also concerned that many families were not receiving well-coordinated rehabilitation services, and realized that education of the public as well as medical personnel about the TMA and the Johns Hopkins TM Center is vitally important work. Physicians who access the JHTMC website (http://www.hopkinsmedicine.org/jhtmc/) will find detailed information to assist them in the diagnosis and treatment of a patient who has non-traumatic spinal cord injury, and there is good general information for non-physicians as well.

There is virtually no research or support funding for rare diseases like TM from the federal or state governments, and the TMA receives support only through donations of its members (there is no membership fee). The physicians, counselors and every officer of the TMA are volunteering their time and services to help educate patients, caretakers and physicians. Although there is no staff salary overhead, the costs to maintain the TMA are significant – the costs of publishing a biennial newsletter containing current literature and articles written by the medical board, along with office supplies and mailings must come from donations.

Dana attends physical therapy twice weekly, and was learning how to hop and jump over a rope. This relatively recent development was the basis for a fund-raiser; the Mathewson family counted the number of consecutive hops Dana could make, once a day, for one month. Pledges per hop or fixed donations were collected, with all proceeds going to the TMA. The fundraiser was extremely successful, with Dana accomplishing 186 hops and raising more than $6,100. These funds were applied to the Association's general fund for the purpose of printing and mailing the TMA newsletters and other educational materials, plus maintaining the website.

Prior to this event, Arlene considered herself a very reluctant fundraiser, with asking anyone for money an onerous task. She was amazed at the generosity of family and friends. The fundraiser proved attractive to everyone because it was based on Dana's daily efforts, and her progress could be followed on the fundraiser website, adding excitement for all. The Mathewson Family hopes that other members entertain the possibility of a fundraiser of their own for the TMA and help raise awareness of the disease that affects all our families.

Our mom has Transverse Myelitis. She first got sick in 1997. She is a nurse and was the boss on an OB floor. When she got TM, she had some other problems that the doctors found at the same time. She had an AVM in her brain and had brain surgery in February 2000. She has an aneurysm and seizures, too. Right now the big problem is the TM. We wanted to help her get better.

Hoopathon for the TMA and TM Research
Adam New

There are three kids in the family. Laura is our sister. She is in college at Emory and Henry. She was home on break. I am Adam and I am 14. William is 16. The three of us tried to think of a way to raise money for research to find a cure for TM. We know about it because of our mom. Her side is numb. She uses a cane to walk. She cannot tell when things are hot or cold. Her feet feel like they are burning on fire. Her hands and fingers are like pins and needles and always hurt. She is upset a lot, too. We

decided that we needed to do something that we were good at so we would get a lot of money.

We talked about it and when Laura came home on break that's when we decided to shoot basketball free throws. We collected pledges and donations from our families, friends and neighbors. Most people gave 10 cents or 25 cents for each made free throw, but some people gave a donation. A reporter from the local newspaper came to do an interview about the fundraiser. We were happy because she mentioned TM, the symptoms, and that it needs to get research for a cure. Mom had to talk to Mr. Oliver, the principal at the high school. He let us use the gym. Laura set rules and she and mom made sure we didn't cheat.

My best friend, Ryan, wanted to help and so did my friend, Joseph. They both like my mom a lot. Laura and mom joked that we needed some estrogen to shoot basketball. My mom's friend, Lisa, let her daughter miss school to come shoot hoops with us. She said that this was an important life lesson that could not be learned at school. The day of the shootout, we practiced for awhile before the clock started. William and I are both good at basketball and we were ready for it. When we were shooting, a lady came into the gym. She had the newspaper article with her. She said that she was on her break and wanted to bring us a donation. It was cool. After four hours of shooting basketballs, our arms hurt badly. Amanda could only shoot for three hours. I made 237 shots, William made 348, Ryan made 167, Joseph made 234, and Amanda made 101. We made $1,682.92 for TM research and we had fun.

Adam New, age 14
William New, age 16
Laura New, age 20
Amanda Yuhase, age 13
Ryan Rodriquez, age 13
Joseph Moore, age 13
How many of you woke up this morning with the following goals:
I want to make a fashion statement;
I want to foster awareness of Transverse Myelitis and the TMA; and
I want to raise money for the TMA.

What a coincidence; we have the same goals. And, we have great news for you. We have established a web-based logo store through Cafepress.
http://www.myelitis.org/store.htm

The TMA Logo Store

Jim Lubin and Sandy Siegel

You can purchase numerous items with the TMA logo, as well as the beautiful Reading for Rachel and Children's Workshop logos designed by the brilliant and talented graphic artist, Nik Niland. We have purchased many t-shirts, coffee mugs, and sweat shirts, and the quality of the items is exceptional. There are new items offered all of the time, some of which are seasonal, so you need to check back at the store often. There are also occasional sales, sometimes including free shipping. The logo store items would make wonderful Christmas and Hanukah presents. No family member should be without an ample supply of TMA logo boxer shorts.

Some of the clothing items also come in children's sizes. During the Children's and Family Workshop in Columbus, many of the families had on their Children's Workshop t-shirts; it was very cool seeing all of the kids in their logo shirts! The Ohio TM Support Group has designed a logo for their group; there are Cafepress items being sold with this logo. If your state or country support group designs a logo, you can send it to us, and we will consider the sale of logo items from your page of the support group site as we have for the Ohio group. The TMA makes a small percentage on the sale of the logo store items.

Be the fashion plate you have always dreamed about. Help to foster TM and TMA awareness among your friends and neighbors. Help us fund the important work of The Transverse Myelitis Association.

Making Donations to the TMA On-Line: from the United States and Internationally

www.CharityWave.com
Making a Contribution On-line Internationally and from the US

CharityWave was created by Wave Systems Corporation. CharityWave is a free online contribution service. CharityWave absorbs the costs associated with processing charitable transactions, and guarantees that every dollar contributed goes directly to the TMA. They also pay all of the credit card processing fees for donations up to $500. There are no administrative or processing fees charged to you or the TMA. When you make a donation to the TMA using CharityWave, they will send you an electronic receipt. In the US, this receipt may be used for income tax purposes. Please check the tax laws in your country to determine the purpose of this receipt.

To make a contribution to The Transverse Myelitis Association using CharityWave, go to their web site using their address in your browser or by clicking on the link from the TMA web site. You may also go directly to the charity list by using the following address:
https://prodpub.wavesys.com/cw/

charitylist.asp.
You may scroll down to The Transverse Myelitis Association which appears in the list or type our name into the search tool. Once in the TMA area of their site, you can click on the amount you would like to donate, or fill in an amount in the space provided. You will be given the opportunity to make the contribution in honor of someone or in the memory of someone. You will also have the opportunity to specify as to whether you would like the person you are honoring or their family, to be notified of the donation via an email.

We are thrilled to have an easy, safe and private way for people from around the world to support your Association. As we do not charge membership fees, we are dependent on our members to offer their generous support of our activities. Please help us to provide you with the quality of service that you so much deserve!

NetworkForGood.org
Making a Contribution On-line within the US

Helping.org was developed by the AOL Time Warner Foundation to serve the nonprofit community by providing comprehensive online resources and tools to help nonprofits integrate the power of the Internet into their strategic planning and to organize, recruit, fundraise and publicize their mission and successes online. Helping.org was used as a foundation to build the Network for Good Web site. Helping.org has joined Network for Good (networkforgood.org), a coalition of leading Internet companies and nonprofit organizations that has developed extensive online resources and tools to make it even easier for individuals to donate, volunteer, speak out on issues and make more informed decisions about supporting the causes they care about.

If you live in the United States, you can make donations to The Transverse Myelitis Association by visiting NetworkForGood.org – Jim has also created links to this site from the TMA web site. The TMA will receive 100% of your donations. We pay no fees, charges or commissions on the contribution. Network for Good covers all of the transaction costs associated with collecting and distributing contributions, including the fees charged by the credit card companies. When you make a contribution using Network for Good, you may specify how you would like your donation to be used; Network for Good passes along your request with the donation. For instance, you can specify that you would like your donation to be used for the general operating costs of the TMA, such as for the printing and mailing of the newsletters; or you can request that your donation be used for TM research.

You can dedicate donations to someone or make donations on behalf of another person; Network for Good passes along the dedication request with the donation. Individuals are also given the option to send an e-card to the person for whom they made the donation.

Network for Good does not accept in-kind donations, such as clothes, cars or other items. You can use Network for Good, however, to locate charities in your area that may accept in-kind donations. In addition, MissionFish.com, an online auction site, enables users to donate in-kind items for auction with the proceeds benefiting charity. Other sites such as InKindex.com and GiftsInKind.org also offer information on making in-kind donations.

When you make a donation to the TMA using Network for Good, your credit card statement will show Network for Good's name instead of the TMA. Please be assured that 100% of your donation goes directly to the TMA; the transaction and credit card verification is processed by Network for Good and PipeVine. You will receive a record of your contributions for tax purposes.

Please keep us informed of any changes to your mailing address, your phone number and your email address. You can send changes to me via email at ssiegel@myelitis.org; you can send changes to me by mail, you can call me (614)766-1806; or you can fill out a change of information form on the web site: http://www.myelitis.org/memberform.htm – just click on the box indicating that you are changing existing information.

The Association does all of our mailings using the postal service bulk, not-for-profit rate within the United States and our territories and protectorates. We save a considerable amount of money by doing our mailings in this fashion. Unfortunately, when you move and don't provide us with the change, our mail will not be forwarded to you, after your grace period, and this class of mail is not returned to the sender. Thus, we have no idea as to whether you received the mailing or not, and we are not made aware of the change by the post office.

We Don't Want to Lose You And Finding You Has Become Very Expensive

As a result of this situation, I had to do a mailing this year that was devoted to checking the accuracy of the TMA membership database. The process involved a lot of work, a lot of money and about four months of time to complete. I had to make hundreds

of changes to our member's information and we lost about 200 people due to our inability to find them via the mail, email or phone. I have to say that it was very painful to lose that many people in such a short period of time. And the cost to the Association is substantial, because until we perform a mailing to correct the address information, the materials we are mailing to a bad address just ferment on some post office floor. These are wasted printing and postage costs.

Please keep your information current. Your diligence is greatly appreciated.

http://www.myelitis.org/newsletters

The web version of the TMA newsletter includes color graphics and photographs. When you submit an article, consider including photographs or color graphics You can send photos or graphics to me via an email attachment or you can send it through the postal service and I will scan it and return it to you. Please be sure to provide me with captions for the photographs.

$5-25

Action Concrete
Dana Alexander
Ralph and Joan Allen
Fred and Cleora Armbruster
Elizabeth Arroyo
Lara and James Bailey
Doris Ballou
Michael Ball
Jenny Bannist
Frederick and Joyce Beiner
Alice Birkenmeier
Sandra Blake
Marvin and Helene Blaustein
Richard and Bonnie Brickhouse
Donna and Richard Brown
Conrad and Margaret Brown
Martin and Bonnie Brozosky
T.J. Buccitelli
Dale and Mary Callaghan
Douglas and Judy Carlson
Barbara and Jude Carluccio
Gladys Coffey Memorial:
Thelma Rollins
Brian and M. Cissel Collins

The Transverse Myelitis Association 2001 Donors

We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through their generosity that we are able to offer the services to our membership; they also make possible the expansion of services to our existing and future members. The following persons and organizations made donations to The Transverse Myelitis Association in 2001. The donations made by members of the Board of Directors include non-reimbursed

Linda Combs
Alan and Kelly Conner
James and Sylvia Darby
Owen and Ann Davis
Robert and Myrna Dekoff
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$100-200

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Tuller Family Trust
Brenda Visser

$1,000-2,000

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$2,000-2,500

Dick and Deanne Gilmur

$3,000-4,500

Blandford Hopathon Fundraiser; Steve & Colleen Blandford
Kenneth and Julie Jones
Reading for Rachel Fundraiser

$5,000-$6,000

Claddagh Foundation, Inc.; Jack and Joanne Callahan

$7,000-7,500

Sandy and Pauline Siegel

$11,000-12,000

Children's Workshop Donations

$45,000-50,000

Kevin's Cause Fundraiser; Tom and Jeanne Hamilton

The Transverse Myelitis Association 2001 Statement of Financial Activities (in US Dollars)

Paula Lazzeri

The following tables present The Transverse Myelitis Association Annual Report for 2001. 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 2001. This column includes funds/activities reported in the TMA (General) Fund as well as non-reimbursed expenses paid by members of the Board of Directors. These non-reimbursed expenses also are shown as Donations made by Board of Directors under Revenues. The Donations made by Board of Directors line item presents the amount of funds spent by members of the Board of Directors that were not reimbursed by the TMA (General) Fund.

The Transverse Myelitis Association Treasurer's Annual Report 2001

	TMA Funds	Total Donations and Expenses to Benefit TMA
INCOME		
amazon.com Donations	109	109
Children's Workshop Donations	12,351	12,351
Endowment Donations	1,590	1,590
General Donations	35,498	35,498
iGive.com Donations	57	57
Research Donations	57,084	57,084
Endowment Interest	198	198
Interest Income	1,395	1,395
1st Symposium Video Sales	80	80
Donations made by Board of Directors		12,127
TOTAL INCOME	**108,362**	**120,488**
EXPENSES		
1st Symposium Video Production	125	125
2nd Symposium	576	576
Bank Fees (cashier checks, merchant svcs)	112	112
Board Meeting Expenses		4,306
Domain/Web-site	309	519
Internet Access		1,141
Johns Hopkins Research Fund	1,195	1,195
Membership Fees		60
Mileage and Parking		132
Office Equipment		1,194
Office Supplies		1,644
Postage	9,344	10,393
Printing	14,798	15,963
Secretary of State Fees	70	70
Telephone and Fax		1,226
TOTAL EXPENSES	**26,529**	**38,656**
Net Income	**81,833**	**81,833**

Transverse Myelitis Association 2001 Statement of TMA Account Balances

Operating Fund	**43,052.49**
Research Fund	**55,888.91**
Children's Workshop Fund	**12,351.00**
Endowment Fund	**9,491.57**
Endowment Interest	**281.00**

Finding Information About Transverse Myelitis

The TMA Newsletters

http://www.myelitis.org/newsletters

If you became a member of the TMA after 1997, you probably have not been mailed all of the TMA Newsletters. The first newsletter was published in January 1997. When a person becomes a member of the TMA, one of the items they receive from the Association is the most recently published newsletter. We do not mail out back issues of the newsletters primarily because it would entail an enormous expense to do so. Pauline has already observed that our home's décor already reflects late twentieth century warehouse.

If you are looking for information about TM, it is important that you read the earlier versions of the newsletter that were published before you became a member. Jim has posted all of the newsletters on our web site. He has them posted in a printable format which will save your color cartridge by not printing the color background. Also, beginning with Volume 4 Issue 2 of the newsletter, the web version includes color graphics and photographs. I would encourage you to print and read these newsletters, if you have not already done so.

If you do not have internet access, please find a friend or relative who will print the newsletters for you. Most public libraries around the country have access to the internet and will allow you to do this printing.

TMA Symposia and Children's Workshop

http://www.myelitis.org/events.htm

A tremendous amount of information on TM has been made available at the TMA Symposia and Children's Workshop. This information is available through the **events** link. Clicking on **highlights** will take you to the program agenda. The information is organized by presenter throughout each program agenda. You can review information in a number of formats. Handouts from the presentations are available in pdf format. Some of the PowerPoint presentations are available. Also, there is streaming video of the presentations from the Second International Symposium in Baltimore and from the Children's and Family Workshop in Columbus. Jim and I are currently reviewing video from the First International Symposium in Seattle. We will be posting some of the presentations from this symposium within the next year. There is an enormous amount of information about TM in these presentations. If you are searching for information about TM, I strongly urge you to watch these videos.

The TMIC Archives

http://www.myelitis.org/tmic

The Transverse Myelitis Internet Club Archives also represent an enormous amount of information about TM. Jim established the tmic in 1994. Since its inception, hundreds of people with TM and their caregivers have been participating in this community of information sharing and support. The site provides a valuable patient perspective on all of the physical, emotional, psychological and social issues which are experienced by children and adults who have TM. If it could happen to a person with TM, it has been talked about on the tmic.

Every message that has been posted to the tmic has been archived. Jim has a search engine set up so that you can do a concept search of the archives. This archive represents a tremendous resource to our community; one which, I believe is not used to its full potential. Allow me to provide an example of how I believe you might consider using the archive. Let's say your doctor has suggested a particular procedure for you, such as the use of a baclofen pump, and you decide that you would like to think about it before moving forward. You can enter *baclofen pump* into the tmic search engine and every message that contains the words *baclofen pump* will be retrieved from the archive. Not only can you read what the messages communicate about the pump and people's experiences with it, you can also identify their email addresses from the messages. You can then contact these people yourself and ask follow-up questions. You will get a wide range of opinions about every subject. Ultimately, you will be a much more informed patient when you discuss these issues with your physician.

The Johns Hopkins Transverse Myelopathy Center

http://www.myelitis.org/jhtmc

The Johns Hopkins Transverse Myelopathy Center web site provides a great deal of information about TM. Dr. Kerr has compiled information on the web site about Transverse Myelitis and about the Center. If you are seeking information about TM, it would be important to read all of the information on the JHTMC site.

NIH TM Fact Sheet

http://www.myelitis.org/nih

The National Institute of Neurological Disorders and Stroke, National Institutes of Health has prepared a fact sheet and brochure with good information about TM (July 2001). Jim has created a link for the TM Fact Sheet from our web site, as noted above. The brochure can be ordered on-line from this site; an electronic order form is provided. You can also call the NINDS Office to order the brochure (NIH Publication No. 01-4841) at (301)496-5751.

disABILITY Information and Resources

http://www.makoa.org

Jim's disABILITY Information and Resources site is the most comprehensive collection of information on disability issues that I have found on the internet. His site covers everything. If you have not reviewed this site, please do so. You will not find a more useful collection of information anywhere. If the subject relates in any way to the resources of interest to a person with TM, you will find it on this site.

http://www.myelitis.org

Jim has recently made modifications to the TMA web site. Our web site is a continual work in progress. Jim is constantly tinkering with it. The changes are directed at providing people with the most accurate, useful and up-to-date information possible. Jim is always looking for ways to make it easier to find information and to more easily navigate through our site. He works tirelessly at trying to automate as many processes as possible. He has made becoming a member of the TMA a very easy experience for people; even those who have little experience with computers and the internet. He is always looking for ways to create an electronic form for information we are trying to collect from our members. He is always on the hunt for newspaper articles or stories on the television about people with TM; he posts this information on the site regularly. He is on the constant lookout for internet relationships with various companies and organizations which create fundraising opportunities for the TMA. And he works at making the site look both very professional and really great. Jim has helped to make the TMA look like an organization with a staff of two hundred people located in a large office building. I once had a man admire our site and compliment our IT Staff, making it sound as though the site were created and maintained by a group of 20 people. I laughed and told him that our IT Staff was Jim Lubin. People find my phone number on the main page of the web site and call me. They are always surprised to hear that I am talking to them from my kitchen while I'm making dinner.

In the past month, I have received requests for help from people with TM from Panama, Jamaica, Pakistan, England, Denmark, Italy, Brazil, Australia, Germany and from all across the United States. And Jim has found ways to have sections of our site translated into eight different languages besides English. He is currently engaged in a project with Ursula Mauro, our Germany TM Support Group leader, to have the membership form available in German to assist our new German-speaking members. He is also working on a bulletin board system, in German, for our Germany TM Support Group.

Every time I receive one of these messages, I am reminded of Jim's hard work and dedication. No one works harder than Jim to provide information and support to the TM Community. Jim brings so many talents and gifts to our Association. We are all so fortunate to have him working for our cause. I am so truly blessed to have him for a friend. Thank you, Jim.

Membership Listing and Participation in Support Groups

If you signed up for membership to The Transverse Myelitis Association using the form on our web site, you were given the option as to whether you wanted to be listed in the membership directory. If you checked the box that you did not want to be listed, the TMA will not divulge your name or information to any other TMA member.

There are TM support groups operating all over the country and all over the world. New support groups continue to be initiated and existing support groups are growing. If you have indicated that you do not want to be listed in the membership directory, the TMA will not share your name and information with the support group leaders. The lists I send to the support group leaders are used primarily for invitations to support group meetings.

If you are currently not listed in the directory, and would like to become involved in a support group if one exists in your area or be notified of a new support group, should one be initiated in your area, please call, send me an email or a letter and let me know that you would like to change your listing status. Jim has established a support group page on our web site: http://www.myelitis.org/support.htm. You can learn of new support groups and keep track of upcoming events of existing support groups by regularly checking back on this site.

The listing will make it possible for you to participate in a TM support group when one is initiated in your area. Your listing will also make you available as a resource to someone in your area who may need your help. As TM is a rare condition, we need to be there for each other to share information and support. Please consider being listed in the TMA membership directory.

The Transverse Myelitis Association

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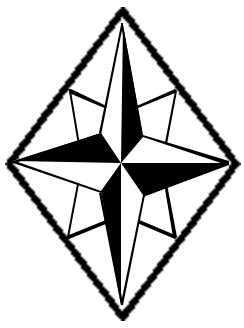

Gregory N. Barnes, Adam I. Kaplin, Leslie Morrison, Frank S. Pidcock join The Transverse Myelitis Association Medical Advisory Board