❖The Transverse Myelitis Association❖

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From the Editor
Sandy Siegel

My column in this issue is about sex. If a frank discussion about sex is going to offend you, please skip to Deanne's column. I do not want to offend anyone, and Deanne is way too smart to write a potentially offensive column. Also, if you do not want your children to read this, please hide it away with your National Geographics and American Urology Journals.

I am writing this column about sex because it has become very apparent to me that this is a critical issue for so many adults who have TM. And for many adults with TM, it is not being dealt with reasonably, rationally or effectively.

First, I am not an expert. I am a cultural anthropologist, which pretty much makes me an expert of nothing. I am a forty-eight year old man who has a permanent relationship with a wonderful and beautiful woman who has TM. It is from my personal experiences and from the experiences I have shared over the past five years with other members of the TMA that I have developed my perspective. I have received many requests for information and have also had numerous discussions with people about these issues. This past month, I received an anonymous letter from a person asking for information; another cry for help. People are searching for answers in this important area of their lives.

Pauline's and my sexual relationship has changed since she contracted TM. Since her developing TM, we have read about dysfunctional sexual issues and the physiological causes both for men and for women.

Dysfunctional sex? Functional sex?

Trying to describe functional sex in American culture is probably a lot like describing the American family structure; exactly what version are we talking about? Sex is among the most complicated aspects of our behavior. It is most certainly a physical behavior, but it is also a social behavior, and a psychological behavior and a spiritual behavior. And for most people, the distinctions are not at all clearly drawn. What's my point? Well, my point is that there are lots of people in America and lots of couples in America who are fully functioning in the physical realm who do not have functional sex by someone's definition. It is not functional because they do not love their partner or they do not love themselves. It is not functional because they are not honest with their partner or they are not monogamous. It is not functional because it is not physically satisfying. It is not functional because the relationship is not emotionally satisfying. We are all going to define functional sex differently. And the definition is going to change with different partners and with the same partner at different times in our lives. We change a lot during our lives and our attitudes about sex change, our expectations about sex change, and our definitions of satisfying sex change. So, here is the first challenge; how do you isolate the effects of TM as a cause of sexuality problems?

You may have an easy answer to that question. And you may not.

And I certainly do not mean to imply in any way that the physical problems associated with sexual dysfunction are not significant. If I had TM, the first thing I would say to my neurologist upon diagnosis is that I need to be able to play golf, and I would like to be able to have an erection – and not at the same time. I am merely suggesting that the physical issues are only among some of the issues to consider, because the act of making love with your partner is much more than the physical act of sex.

It is critically important to talk to your neurologist and/or other doctors about your sexuality issues. It is important to understand the physiological issues; what is possible and what is not possible from a physiological perspective. A neurologist may suggest different strategies with you and your partner. They can also discuss your medications with you and can identify which ones might interfere with your sex drive or your sexual functioning. They might also suggest medications that would help in your sexual functioning.

My experience has been that these discussions do not occur as a matter of course. When you go to your neurologist or other doctors, they may go through a list of questions with you while they are performing an examination. Have you been asked about your sexual relationship with your spouse or partner? In all of the appointments I attended with Pauline

within the first two or three years of her onset, the issue of our sexual relationship was never initiated by any of the doctors who cared for her. And we have seen some very wonderful, caring, competent and skilled doctors. This may be due, in part, to the primary concern that both you and your doctor have for treating some of the serious symptoms you have with TM, such as pain, spasticity, or bowel and bladder functioning. There may be mobility problems, which become overwhelming and leave little time or energy for other issues to be discussed. Sexuality may just not make it to the top of the list of issues in comparison to some of the more severe symptoms you are experiencing. But from what I hear and read from our members, sexuality issues are not insignificant.

If you are going to begin to deal with these issues for yourself, for your partner and for your relationship, you are going to have to raise these issues with your doctor. They have information that can help you. But you are going to have to make yourself responsible for raising the issue. A good approach to take when visiting your doctor is to have all of your questions and concerns written out. It will keep you organized in your thoughts and will help you from forgetting your questions. Be sure your sexuality questions are on your list for your next appointment. And be sure that you receive information that you understand.

I learned an important lesson in my relationship with Pauline very early in her bout with TM. Pauline was totally paralyzed from the waist down at the onset of TM. She lost bowel and bladder function and she had lost a great deal of sensation below her waist. After two weeks of hospitalization, the doctors told me that I could bring her home for a weekend. Well, we packed up a bunch of loaner adaptive equipment on a Friday afternoon and I brought Pauline home. That night, between my shleping her on and off of the portable potty chair, we made love.

Here is what I was communicating to Pauline: *I love you. I find you not one iota less attractive or appealing or sensuous than you were two weeks ago. We are going to have a life together no matter what; please don't worry about anything. I am here for you.*

Here is how Pauline interpreted my message: *Wow, men are just totally amazing.*

I didn't know this until sometime much later when Pauline and I had a conversation about her first night home from the hospital. Pauline sometimes has a conception of men that is likely shared by many women in our society: men are capable of having a satisfying sexual relationship with an inanimate object, if the mood is right. I'm not going to tell you that I think sex is the same for a man and a woman; I don't think it can be. But I do think that men have evolved a little bit in the last 40,000 years. Hey, we have feelings, too!

So, again, what's my point? Well, Pauline needed to hear my communication more clearly than was possible from the approach I took in sending it. I needed to use my words. Then she would have had a chance to understand me.

When my boys went off to college, I offered them some advice about school and a variety of other subjects, among them being their relationships with women. Here are two pieces of advice that I provided them:

Knowing where the uterus and fallopian tubes are located isn't going to make you a good lover. Knowledge of anatomy doesn't translate into sensitivity, tenderness and care. Pay close attention to the effect you have on your partner. If you care enough how she feels and what she enjoys, you'll get it figured out. If you are in this entirely for yourself, there are less complicated and more efficient ways to achieve the same result.

Find a way to talk about sex. Most people have a difficult time communicating about the kind of breakfast cereal they like; don't think you are going to get what you like about sex communicated non-verbally. You'll be too old to try half of what you want to do by the time you get all of the grunts and groans of positive reinforcement figured out. If you are not uncomfortable to talk about it, you're made in the shade.

I also told them to study a lot every day, to never cut a class, even when they were sick, and to kiss their teachers' butts with great fervor and frequency.

So, this is the most important thing I have to say: please talk to each other, and talk to each other candidly and honestly. Sexual issues are complicated issues when all of the parts are in working order. When they are not, it is only much more complicated. And, of course, it is not just the parts involved in the complications. There are self-concept issues involved and there are relationship issues involved. You shouldn't assume anything about what your partner is thinking and feeling. I also told my boys that the only way they would ever know their partner in her totality would be if they were able to share every conceivable experience with her. Obviously, no one does. So, we do not

know everything about our partners. If you have never been through a serious illness with your partner, or if you have never been through a period of sexual dysfunction, you are likely going to find out a lot about yourself through this experience and you are going to find out a lot about your partner. You are also going to learn something about your relationship. How you learn it and what you do with what you learn is going to be very much dependent upon how much you talk about it with each other and how you talk about it.

Anthropologically, I am fascinated by a society that produces individuals who are total strangers to me and send me email inviting me into some type of pictorial sexual excursion. The same society produces individuals who are uncomfortable talking about sex with the person they have the most intimate relationship with in their lives and with whom they have sex. Definitely, very fascinating natives!

I have entered about 470 respondent surveys to the TMA questionnaire. There are an amazingly small number of people who identify sexual problems among their past or current symptoms of TM. What does this absence of response communicate about where people are with this issue? From my observations of American culture, I would guess that it does not emanate from any lack of significance we place on sex in our society. Nor does it reflect any insignificance we place on sex as individuals.

If you are comfortable to talk, it would help to talk about it. And talking in details is a good idea. What feels good emotionally? How can I be more romantic? What feels good physically? What doesn't feel good? Where does it feel good? Where is it irritating? Where does it hurt? Would it help if I took out the garbage, did a couple of loads of laundry, and cleaned the bathroom?

Talking may not cure anything, but it is not going to hurt anything. Life has changed with TM. Whether you have TM or your partner has TM, your lives have changed and your relationship has changed. It takes a lot of time, energy and care to understand and deal with all of these changes. And it takes a lot of talking. If the talking is difficult for you, and it is for many, please be honest about it, and seek help. There are counselors who do this for a living and they can facilitate this discussion with you. And they can help you uncover some of the thoughts and feelings that you might be having a difficult time understanding on your own. Ask your doctors for suggestions about where you can find this help.

I am very grateful to Dr. Lynn and Leslie Moore for writing the wonderful article in this newsletter on the issues of sexuality surrounding TM. They offer some very important information and some interesting strategies. I know that many of you will find this information useful. I wish you all the best in this really remarkable journey we are on. Be kind to yourselves and to each other; and find a way to talk about these issues.

Take good care of yourselves and each other.

Our family recently recognized the 10th year since our daughter's transverse myelitis (TM) diagnosis. What a road it has been! While we have experienced losses, so have we gained something. The TMA has

From the President
Deanne Gilmur

provided so many memorable people who have inspired and enriched our lives with their personal stories of strength, bravery, and generosity in the face of this challenging condition. Week after week, I am contacted by many who are trying to come to grips with their TM diagnosis and manage the various symptoms associated with TM. Each person's struggle drives home the importance of the information provided by TMA and the mutual support offered by TMA members to each other. Thank you to the many who have given generously of their time and efforts to others and the TMA at large in spite of the additional hardships that either their TM symptoms or caring for a family member with TM has thrust upon them.

Congratulations to Cathy Dorocak for beginning the important fundraising program "Reading for Rachel" in honor of her young daughter who was diagnosed with TM at age 6 1/2 months. Congratulations to Cody Unser for developing the "First Step Foundation" to promote treatment and TM research (www.codysfirststep.org). Kudos to Pamela Schechter for organizing a meeting held May 27th in celebration of the first anniversary of the New York State "Transverse Myelitis Awareness Day." Bravo to Richard Boyle (Gunny) for getting the General Assembly of the State of Ohio to pass a Resolution setting June 6, 2000 as Transverse Myelitis Day, and for his soon to be published book that describes his experiences with TM. Good work Board member, Debbie Capen, who traveled across the country to attend and support the awareness event in New York. Thank you to Medical Advisory Board member Dr. Kerr for

speaking at the New York support group and, as is so characteristic, for giving so much professionally and personally to the TMA and to TM treatment and research. Thank you to Ann Moran from Ireland who took it upon herself to increase TM awareness during a meeting held by the National Broadcasting Service in her hometown which led to her appearance on the radio during which she talked about her experience with TM. Thank you to Errol White of the Transverse Myelitis Support Group in Australia who helped reduce TMA publishing and mailing costs by printing and mailing the last newsletter and this newsletter to our members in Australia and New Zealand. They also held their second TM Awareness Day on May 17th. I also want to thank the members of the Medical Advisory Board for their ongoing involvement and help in the Association. Thank you to Perry Peltier and Board member, Paula Lazzeri, for producing and distributing the TMA Symposium videotapes. And of course, I must say a special thank you to Sandy Siegel and his undaunted devotion to the TMA newsletter. I know that I have neglected to acknowledge so many others who have made generous and noteworthy contributions of their time and efforts to support the TMA. These extraordinary people of the TMA membership are making a difference in this Association's efforts to increase awareness of TM and TMA, to offer support where and when it is needed, and to encourage in every practical way possible research that will eventually have a positive impact on those diagnosed with TM. We are all more hopeful because of everyone's work.

During the past 6 months, TMA has made positive strides towards its goals for 2000 (see January 2000 newsletter). Video tapes of TMA's First International Symposium have been completed and made available for purchase (see January 2000 newsletter or website). Our talented website director, Jim Lubin, continues to add vital information to the TMA website (www.myelitis.org). The effect that this site has had in allowing quick access to pertinent information is immeasurable. Those who are recently diagnosed, often mention the quality and helpfulness of our site! Jim consistently enhances and updates the website so if you haven't visited it lately, please take another look at what a wonderful resource it is. Additionally, we have had a continuation of generosity by TMA members new and old who have donated funds that continue to support the Association's good work. Small and large donations are what makes it possible to meet so many of TMA's functions, such as this newsletter! The future of TMA depends on membership support of the Association's general operational activities and services. Please consider giving to TMA so we can continue to grow and develop, and meet the needs of our membership.

In the last newsletter the Board of Directors also announced the creation of the TM Endowment Fund. The purpose of this fund is to generate a lasting source of funds that can contribute to ongoing and future TM cure research efforts. The Board put forth a "challenge goal" to our membership to help build the Endowment Fund to $100,000 during the year 2000. We have received limited response to this challenge so far, but we are happy to say that the funds generated by the "Reading for Rachael" program have been designated for the fund. This brings the amount in the fund as of June to $6,550. TMA is hopeful that the "challenge goal" will be met by the end of the year. Every one of us wants to see medical research occur which will result in quicker diagnosis and initial treatment, improved and more successful treatments, and innovative and effective therapies that improves life for all those with TM. This takes a strong commitment by our TMA community to fund this kind of research. We are lucky that in recent months, perhaps for the first time ever, there has been an increase in public awareness and education on TM. While this increase in awareness may ultimately assist us in these efforts, we still need to strengthen our organizational advocacy and support for cure research. The Endowment Fund is a very specific and direct way to take this lead. As the Endowment Fund does not support TMA's operational activities and services, please consider an additional contribution as part of meeting the "challenge," or consider developing a local fundraising event/program that will benefit the Endowment Fund.

And lastly, our 2000 goal of having TMA members initiate awareness activities in at least six states and four countries is well underway with positive actions/events having occurred in New York, New Mexico, Ohio, Ireland and Australia. In previous newsletters I have discussed what I called "State and National Volunteer Representatives activities" and many individuals have contacted me and expressed interest in being involved in such roles. Following much consideration, it now seems best for TMA and our members to not formalize such roles for specific individuals, but to continue to support **all persons** with an interest in developing or participating in such activities to work together to develop these supports and working groups.

After a working support group gets started, the group can identify a specific representative or representatives for more formal coordination purposes. This should be a more effective and inclusive way to jump start local support activities. We hope those that have been interested in such activities or roles will now move forward and develop contacts with other TMA members to build connections, offer mutual support to existing members and those newly diagnosed, and to undertake TM awareness activities.

Responsibilities and Duties, and Guidelines for persons interested in developing local groups and serving as State and National Volunteer Representatives have been completed and will be included on our website. This information along with other information available from the TMA website may be accessed and replicated for these purposes. We also encourage you to be in contact with Pamela Schechter who has been developing a support group in New York. We have asked Pamela to chair this effort for TMA by being available to share the process that she undertook in her home state. This will hopefully be a resource to people who may be attempting similar processes.

The Board continues to work with the Johns Hopkins Transverse Myelopathy Center on the development of the Second International Symposium on Transverse Myelitis that is planned to be held July 12 - 15, 2001 in Baltimore, Maryland. Thank you to everyone who filled out the Patient and Family Needs Survey from the January 2000 newsletter. Your input will assist greatly in ensuring that the Symposium program addresses the needs of TMA members. TMA members will receive registration notices/packets by the end of the year. This will be an incredible opportunity to forge new relationships and to continue the Association's momentum that was started with the last Symposium. My best to all.

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

The History of TM: The Origins of the Name and the Identification of the Disease
Douglas Kerr, MD, PhD

How long has TM been around? Reports in the medical literature of "acute myelitis" date back to 1882 and are credited to Dr. H.C. Bastain, an English neurologist (Bastain, Quain's Dictionary of Medicine, 1st Edition, 1882). He described several cases of acute myelitis resulting in "softening of the spinal cord." He presented the pathologic findings of several autopsies from patients who died of the myelitis and divided the cases into those that he thought were due to "thrombotic events to blood vessels supplying the spinal cord" and those that were due to acute inflammation. A thrombotic event means a "stroke" of the spinal cord in which a clot forms in one of the spinal arteries, thus depriving the spinal cord of oxygen and causing death of nerve cells in that area. Most of these cases were due to syphilis (syphilitic endarteritis - meaning that the syphilis causes an inflammation of small arteries as they enter the spinal cord). The 'inflammatory' cases were postulated to be due to an infectious or an allergic mechanism. (Unfortunately, 118 years later we don't have a markedly improved concept of inflammatory transverse myelitis).

Dr. William Spiller at the University of Pennsylvania published a report in 1909 detailing thrombosis of the cervical anterior spinal artery and proposed strongly that virtually all cases of acute myelitis are due to blood clots, not inflammation (we now know that either blood clots or inflammation may cause TM). His patient in that report (named John W.) was an employee of the Philadelphia General Hospital who was required one morning to lift 100-pound blocks of ice with assistance of another man. (These blocks were then transported to each patient's room as "air conditioning" and to provide cool washcloths). Shortly after lifting the fourth ice block, John W. "began to have a sensation of coldness and pain between the shoulders." He then noted "stiffness, then lower limb numbness and weakness." He became paralyzed by the next day, and despite utilization of an iron lung ventilator, John W. died shortly thereafter. Autopsy of his spinal cord showed a blood clot in the cervical anterior spinal artery, and it was proposed that the lifting had caused the clot to form.

In 1922 and 1923, physicians in England and Holland became aware of a rare complication of smallpox vaccination: inflammation of the spinal cord and brain (reviewed by Dr. T. M. Rivers, JAMA, 1929). Given the term post-vaccinal encephalomyelitis, over 200 cases were reported in those two years alone. Pathologic analyses of fatal cases revealed inflammatory cells and demyelinization rather than the vascular pathology noted above. It was interesting to note that the ratio of

cases to vaccination was 1:50,000 in England and 1:5,000 in Holland. England carried out all its smallpox inoculations in children less than one year of age, giving rise to the notion that "infants are relatively insusceptible to post-vaccinal encephalomyelitis." What was perplexing then (and continues to be perplexing today) is that family members got the identical vaccine (or in many cases today got the same "cold"), but only one member of the family developed acute myelitis.

Dr. Frank Ford reported in 1928 (Ford, F.R.: Bulletin of Johns Hopkins Hospital, 1928) his hypothesis that many cases of acute myelitis are post-infectious rather than infectious in cause. His reasoning was that in many cases of acute myelitis associated with mumps, the patients' "fever had fallen and the rash had begun to fade" when the myelitis symptoms began. He proposed the idea, therefore, that it was an "allergic" response to the virus rather than the virus itself that caused the spinal cord damage. Dr. Ford also noted that "neuroparalytic" accidents had been noted even dating back to 1887. Specifically, many patients had become paralyzed following rabies virus vaccination. The paralysis was not found to be due to the rabies virus itself, but rather to the repeated inoculation of patients with brain tissue carrying the virus. Dr. Ford was not aware of the functions of the immune system, but we would conclude today that the immune response generated against the brain tissue then attacked the spinal cord and caused the paralysis.

Several cases were then reported over the next two decades showing that though Dr. Ford may be right in some instances, several infectious agents can directly cause acute myelitis, notably measles and rubella viruses (Morris and Robbins, Journal of Pediatrics, 1943; Senseman, Archives of Neurology and Psychiatry, 1945). It was in 1948 that Dr. Suchett-Kaye, an English neurologist at St. Charles Hospital in London, utilized the term "acute transverse myelitis" (Suchett-Kaye, The Lancet, 1948) in reporting a case of acute TM complicating pneumonia. Though not indicated in the initial report, the addition of 'transverse' reflected the common clinical finding that patients reported a 'band like' horizontal area of altered sensation on the neck or torso. Below this area, sensation was absent or at least altered and was associated with bowel and bladder dysfunction and weakness. Above this area, patients were normal. We now know by looking at MRIs of the spinal cord that this reflects inflammation or injury in a particular area of the spinal cord, with uninjured nerve cells above this area.

Since that time, the syndrome of progressive paralysis due to spinal cord inflammation has been known as transverse myelopathy or transverse myelitis. What is the difference between 'myelopathy' and 'myelitis?' Technically, any '…itis' means 'inflammation': 'Arthritis' means inflammation of the arthus (joint); 'sinusitis' means inflammation of the sinuses, for example. Inflammation means that the immune system is activated and recruited to the area, potentially causing damage. But several of the cases we see today may be due to vascular events like thrombosis, hemorrhage or dural AV fistulas (abnormal collection of blood vessels on the surface of the spinal cord). These are not truly inflammatory conditions since the clinical events are due to blockage of blood flow. Therefore, we utilize the term first introduced by Paine and Byers (American Journal of Diseases in Children, 1953) of 'transverse myelopathy.' This is an all inclusive term which indicates any focal injury to the spinal cord, whether it be infectious, post-infectious, vascular, traumatic or the dreaded idiopathic (which is a fancy term to mean that we do not know what caused the myelopathy).

David Irani, MD is an Assistant Professor of the Department of Neurology, Johns Hopkins Hospital. He is also the Co-director of the Johns Hopkins Transverse Myelopathy Center. Dr. Irani obtained his MD degree from University of Michigan (Ann Arbor) in 1987 and completed his internship at St. Joseph Mercy Hospital at Ann Arbor. He then came to Johns Hopkins Department of Neurology as a fellow in Neurovirology (1988-1990) and completed his residency training in Neurology. In 1993, Dr. Irani joined the faculty of the Department of Neurology at Johns Hopkins Hospital and has focused his research activities in neuroimmunology and neurovirology. He has been actively involved in studies of viral infections of the CNS and leukocyte trafficking.

Transverse Myelitis-Related Research at The Johns Hopkins University School of Medicine: Current Status and Future Directions

Transverse myelitis (TM) remains a difficult problem from a variety of standpoints. Since it occurs relatively infrequently, even subspecialist neurologists may have little practical experience with the disorder. Since it may have many underlying causes (only some of which are uncovered at the time of the acute illness),

predicting the long-term clinical outcome for an individual patient can be difficult. And since we are still quite limited in our capacity to promote meaningful neurologic recovery once the inciting event has subsided, physicians may have few treatments to offer their patients during later stages of disease. In the face of such obstacles, one might be tempted to conclude that conducting research on TM is an impossible task. Indeed, the disorder has been relatively neglected by the biomedical research community, perhaps for some of the very reasons described above. Nevertheless, my colleagues at Hopkins and I have initiated a comprehensive research effort to study TM in both the clinic and the laboratory. Our goal is to take advantage of new scientific developments in the fields of neuroscience, virology, and immunology to better understand TM. We hope to make advances that will translate into new diagnostic and treatment applications which can be used in the hospital and the clinic in the near future.

One approach we have taken in our research is to directly study TM as it occurs in humans. There are several important issues we are trying to tackle: enhancing our understanding of the underlying causes of TM, improving our ability to predict a patient's eventual clinical outcome in the earliest stages of his or her disease, and testing whether there might be ways to improve neurologic function well after the acute illness has occurred. One hypothesis we are examining is that many cases of TM are caused by viral infections that develop in the spinal cord; viruses that go undetected because the diagnostic tests needed to identify them are not available. As a result, we are looking for novel viruses in the cerebrospinal fluid (CSF) of patients with acute TM using new laboratory techniques. We have already found that certain proteins which normally reside within nerve cells of the spinal cord are released into the CSF of some patients with acute TM. Detecting these proteins are clues to us that the underlying cause of TM in those cases is quite severe (the nerve cells are actually being damaged and are releasing these proteins). As a result, this assay may serve to help us predict how much function a given patient will eventually recover during the earliest stages of TM. We also plan to look for alterations in the immune systems of affected patients that may have made some of them susceptible to TM. We suspect that part of the susceptibility of certain patients to TM resides in the unique way that their immune systems respond to certain infections. To try and promote delayed recovery in patients well after their acute TM, we plan to test the effectiveness of drugs that increase the transmission of electrical signals in the remaining intact spinal cord nerve cells. On the horizon may be the potential to grow nerve cells or precursors that turn into nerve cells (called stem cells) in culture dishes for implantation into the spinal cords of patients who have had TM. In this setting, it is hoped that the implanted cells can re-establish some of the connections that were damaged during the acute phase of the illness and promote some degree of clinical recovery. The groundwork experiments for such an approach are underway in experimental animals (see below).

Successful disease-related biomedical research is often best accomplished through the direct study of affected tissue. However, since performing spinal cord biopsies on patients with acute TM is both impractical and potentially dangerous, we do not have access to such samples. To circumvent this limitation, we have developed a model of TM in experimental animals caused by direct viral infection of the spinal cord. This has allowed us to study how and why nerve cells degenerate in this situation, and because affected animals become paralyzed to varying degrees, it has provided an excellent model system to test the effects of new therapies that might eventually show promise in humans. Thus, we are now trying to establish the experimental conditions under which stem cells can be implanted into the spinal cords of paralyzed mice and be coaxed into resprouting new nerve connections. We have also begun to figure out how to interrupt some of the signals that the virus uses to trigger the death of infected nerve cells in the spinal cord. We hope this may lead to the development of novel drugs that could exert the same effect in humans. While we realize that the use of laboratory animals in biomedical research is highly controversial, there simply is no other way to answer the kinds of questions we are asking. Overall, while research progress is slow, we feel that we have already made some important observations and have plans to expand these efforts as future research support becomes available.

Despite some early optimism, it is fair to say that TM-related biomedical research is still in its infancy. Nevertheless, I believe that our laboratory efforts, in particular, will bear fruit in the foreseeable future. As clinicians in this field, it is the explicit goal of my colleagues and I to translate our laboratory progress rapidly, but safely, to therapeutic trials in human patients. We are actively working to increase

awareness and support of our research efforts.

Joanne Lynn, MD is an Assistant Professor of Neurology at The Ohio State University. She is on the staff of The Ohio State University Multiple Sclerosis Center and has special interests in clinical research on the treatment of MS. Dr. Lynn serves on the Medical Advisory Board of The Transverse Myelitis Association. If you have questions for Dr. Lynn regarding the Transverse Myelitis condition, please send those to Sandy Siegel; we will attempt to have your questions addressed in a future newsletter.

Member Questions and Answers from Joanne Lynn, MD: Issues of Sexuality Surrounding TM
Joanne Lynn, MD and Leslie Moore, RN

Leslie Moore, RN graduated from The Ohio State University in 1986. She worked in Neuro Intensive Care for seven years and through her work with spinal cord injured patients, the interest in bowel, bladder and sexuality issues began. She then worked in the Interventional Radiology Department for two years. To expand her role with education of patients, she took a position at the MS Center at Ohio State and as a faculty member of the Peer Support Program sponsored by Berlex. Leslie has moved to Wisconsin where she has continued as a faculty member with the Peer Support Program and works in the local ICU.

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

Q. If a person has bladder and bowel function return, is this any sign that sexual functioning could also return? What causes sexual dysfunction from spinal injury? Is sexual function an area of treatment that should be discussed with a patient's neurologist?

This question brings up the bigger topic of sexuality in TM. Sexual function with or without spinal cord injury is a very complicated issue and an important facet of life for both men and women. Much of what is included in this article comes from writings and studies of people with sexual dysfunction due to multiple sclerosis (MS). There is a significant body of literature regarding the mechanics and psychological ramifications of sexual dysfunction in MS, which also affects the spinal cord. People with TM should refer to some of the MS references listed at the end for more detailed and helpful information.
Erection may occur due to psychogenic stimuli (such as visual stimuli or fantasy). In this situation, nervous impulses travel in the autonomic nervous system down from the brain, through the spinal cord to the lower thoracic and upper lumbar levels. Fibers then leave the spinal cord and travel to blood vessels in the penis directing vascular engorgement in men and vaginal/clitoral engorgement and lubrication in women. This is part of the excitement phase. There is also a reflex component to erection which does not require input from the brain. Local stimulation to genitalia or even a stimulus such as a full bladder can lead to activation of a reflex arc involving the lower part of the spinal cord (sacral part) resulting in erection. Obviously, complete transection of the spinal cord will prevent autonomic impulses from coming from the brain to the lower cord. Injury to the spinal cord in inflammatory diseases such as TM or MS are often partial and may interfere with these descending pathways or ascending nerves bringing sensory information from the genital areas to varying degrees. Bowel and bladder function is also mediated by transmission of information through the spinal cord and improvement in this function may or may not be associated with improvement in sexual function; but it is a hopeful sign.

Specialists interested in sexual dysfunction break it down into several categories: primary, secondary and tertiary sexual dysfunction. Primary sexual dysfunction is the alteration in sexual feelings and response that is directly related to the neurologic spinal cord injury. This may include decreased libido, reduced or unfamiliar or unpleasant genital sensations, decreased vaginal lubrication, problems in achieving or maintaining an erection, and reduced ejaculatory force or ability to ejaculate, and decreased orgasmic response. Secondary sexual dysfunction results from the various symptoms that may be caused by TM, including fatigue, spasticity (increased muscle tone), bladder and bowel problems, and pain. Tertiary sexual dysfunction is used to describe effects caused by psychologic responses to the effects of TM.

Primary sexual dysfunction

Decreased libido is a difficult problem which can be stressful to both the person with TM and his/her partner. Often changes in libido may be due to changes in emotional state caused by the response to illness and perhaps decreased independence if neurologic impairment is severe. Individual and couples counseling is often helpful to explore feelings and improve communication. Efforts should be made to determine if there is a component of underlying depression and this should be addressed.

Evaluation of male sexual dysfunction

The initial step in the evaluation of male sexual dysfunction involves significant sexual counseling. Testing to determine if erectile function is intact may be useful. Urologists may use Doppler Studies to assess blood flow in the penis and monitor for nocturnal penile tumescence. There are several therapies available to assist or augment penile erection. The newest is oral sildenafil (Viagra). Studies in the traumatic spinal cord injury population have shown that a majority of patients have success when sildenafil is used in combination with vibratory stimulation. Sildafenil 50 to 100 mg is taken one hour before sexual intercourse and results in improved erectile function when combined with psychologic and/or tactile stimulation. This drug dose has some known side effects which include nasal congestion, headache, flushing, and heartburn in approximately 6 to 18% of patients. In addition, this drug must never be taken in combination with nitrates which are drugs that are used to dilate the blood vessels of the heart and there is significant danger of heart attack or other cardiac problems including death in patients with heart disease. Vibratory stimulation may be used to enhance erections and to assist in stimulation towards orgasm.

Vacuum erection devices have been used successfully in spinal cord injury and in patients with multiple sclerosis. These consist of a plastic tube that is placed over the penis. A pump is used to pump air out of the tube, creating a vacuum that draws blood into the penis (didn't someone say nature abhors a vacuum?). A constricting ring is then slipped over the base of the penis to prevent blood from returning to the heart, thereby helping in maintenance of the erection. Some men find this approach uncomfortable or painful, or report that their penis is cold. Some feel that this approach seems less natural. This approach also requires a significant amount of manual dexterity. However, others use this relatively inexpensive approach with good success.

Another approach towards improvement of erectile function is that of introduction of vasoactive medications into the penis. *Vasoactive* means a medication that has effects on the blood vessels. One such medication, prostaglandin E1, may be introduced as a suppository into the penile opening of the urethra. Other medications, such as another form of prostaglandin E1 or papavarine may be injected right into the shaft of the penis. Obviously, one must overcome the natural fear of such an objection but many men and/or their sexual partners do master this technique. There is a high rate of success for this type of treatment. Complications include priapism which is a painful prolonged erection with risk of damage to the penis itself. This occurs approximately 0.8 to 1.5 % of the time and requires urgent treatment by a urologist. Repeated use can cause fibrosis or scarring within the penis tissue itself in a small number of men (0.5%).

Another option for treatment of neurogenic erectile dysfunction due to TM is the use of penile prosthesis or implants. There are several types of prostheses including inflatable and semirigid. One problem with these implants is that they may become infected as may any foreign implant such as an artificial joint (estimated rate 1.2 to 1.8%). At least one study has shown that men that choose this option have sex more frequently and with higher personal and partner satisfaction than men on injection therapy.

Evaluation of female sexual dysfunction

Decreased genital sensation is a major problem that contributes to sexual dysfunction in TM. This is often the cause of sexual dysfunction for women and there are fewer fancy gadgets or treatments than are available for male sexual dysfunction. Treatment of decreased genital sensation often requires exploration with different and more intense stimulation both in the genital area and exercises to allow a person to learn a wider range of sexual pleasuring outside of the genital area. Increased use of oral stimulation of the clitoris may be useful. Use of a vibrator, which can be purchased at a medical supply store, may also enhance genital sensation and increase ability to have an orgasm. There are many different types of

vibrators and some strap-on to deliver stimulation to the clitoris directly without interfering with intercourse. Stimulation to other erogenous zones such as breasts, lips, neck, ears may be useful to heighten excitement and pleasure and to enhance the likelihood of orgasm. Increasing the amount of nipple stimulation may increase vaginal lubrication and uterine contractions which could increase ability to reach orgasm. One tool used in sexual counseling is to request that the couple work on making a map of personal erogenous zones outside of the genital area. This requires that the couple talk about this and work together, devoting time to finding new ways to pleasure each other. There is often benefit to increasing non-erotic stimulation such as handholding, backrubs, etc. Reviving romantic gestures such as gifts of flowers, hugs, etc. may also help to stimulate libido.

Decreased vaginal lubrication despite sexual stimulation can be caused by spinal cord injury and can contribute to pain during sexual intercourse. Water-soluble lubricants such as Replens are available to deal with decreased vaginal lubrication. K-Y jelly may also be used. Vaseline should not be used because it is not water-soluble and may cause urinary tract infections. Women should also be aware that vaginal lubrication may decrease as a normal response to decreased estrogen levels during menopause and vaginal tissues may thin. Hormone replacement therapy may be beneficial for sexual function for women at this stage of life as it may reverse some of these age-related changes.

Some sexual therapists recommend Kegel exercises to strengthen and increase responsiveness of the pubococcygeus muscle in the pelvic floor. Contractions of this muscle occur during female orgasm. The Kegel exercise is performed by alternatively tightening and relaxing this muscle (which may be identified as the muscle which stops and starts urine flow midstream).

Secondary sexual dysfunction

Many people with TM find their sex lives hampered by other symptoms related to the spinal cord injury. One example might be that a woman or man would find it difficult to relax if he/she was always worrying about whether urinary/fecal incontinence would occur and how his/her partner would react to this. There are things that can be done to establish a good bowel regimen to make this less likely. A bowel program can be established by choosing a specific time each day to have a bowel movement, usually after a meal. Increase fiber to increase softness of stool. For more persistent bowel problems a program including a suppository each day may be needed. Simply remembering to void the bladder before sexual activity is sufficient to prevent accidents for some; urinary self-catheterization can help others to ensure that the bladder is empty.

Fatigue is a problem for many; planning the time of sexual activity for periods of the day when energy is highest can be helpful. Obviously, painful leg spasms will detract from sexual activity and can often be reduced by proper medications (taken two hours prior to intercourse) or by working gentle stretching into the foreplay period to reduce spasticity. Some people with TM develop painful sensations (such as tingling, burning, stabbing, tightness) in the legs or genital areas that interfere with sexual function. Sometimes just being rubbed or stroked by one's lover might evoke pain rather than pleasure. Various medications may be tried to decrease these painful sensations called dysesthesias, including Amitriptyline (Elavil), Gabapentin (Neurontin), and Carbamazepine (Tegretol). This is another situation in which couples will benefit from working together to map out body areas in which stimulation causes pain or pleasure. Experimentation with different positions for sexual intercourse may also minimize problems associated with fatigue, spasticity or painful dysesthesias.

Tertiary sexual dysfunction

Tertiary sexual dysfunction is a complicated area in which psychological responses to TM may impair sexual functioning. Weakness or other dysfunction may lead to changes in self-esteem and self-image that affect sexual performance. Both an individual with neurologic dysfunction and/or the partner may perceive that disability makes the person with TM less attractive or less masculine or feminine. Some partners who give significant care in the form of dressing, transferring, bathing, urinary catheterization, etc. may have difficulty switching gears from the role of caregiver to that of lover. Frustration, resentment, and fears of abandonment may be unspoken emotions that hinder the expression of love and sexuality. Open communication between partners and psychotherapy are the best approaches to deal with these problems.

Perhaps the most important thing is that a couple approach sexuality with an open mind and a willingness to try new things. Some people with spinal cord injury think along the lines of

"If I can't have sex the way I used to, forget it!" Sexual therapists remind us that our society tends to view sex as a goal-oriented activity directed towards achievement of orgasm. While this is, of course, a worthwhile goal, it may be helpful to refocus on a broader range of sexual activities that bring physical and psychological pleasure and wellbeing. A willingness to try new approaches to romance and sexual stimulation will open new doors to positive expression of affection and sexuality and this will have benefits for the relationship beyond the bedroom.

It is absolutely appropriate to discuss sexual function after spinal cord injury with your neurologist. However, in truth, very few neurologists have any sort of formal training during their residencies in sexual function or spinal cord injury. Therefore, forgive your neurologist if he or she is inexperienced and unable to tell you much and try to work with him/her to address these various issues. You may also find assistance from seeking out neurologists, nurses, urologists, sex therapists or physiatrists who care for patients who have experienced spinal cord trauma or multiple sclerosis, especially at a large hospital, rehabilitation center or university center. The National Multiple Sclerosis Society (1-800-FIGHT MS) also has some literature on sexual dysfunction and MS which is applicable to TM.

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Foley FW and Werner MA. Sexuality in Kalb RC. Multiple Sclerosis - The Questions You Have, The Answers You Need. Demos Vermande, New York, 1996: pp. 223-247. (This is an excellent chapter on sexuality in MS. It is set up as common questions followed by detailed answers. **Highly recommended**).

Geiger RC. Neurophysiology of Sexual Response in Spinal Cord Injury. Sexuality and Disability. Vol 2 (4). Winter 1979.

Kalb RC and LaRocca NG. Sexuality and Family Planning in Halper J, Holland N. Comprehensive Nursing Care in Multiple Sclerosis. Demos Vermande. New York, 1997: pp. 109-125.

Kaplan HS. The Illustrated Manual of Sex Therapy (2nd edition). New York: Brunner Mazel Publishers, 1987.

Neistadt ME, Freda M. Choices: A Guide to Sex Counseling with Physically Disabled Adults. Malabar, FL: Robert E. Krieger Publishing, 1987.

The Foley and Werner chapter in the Kalb book also lists several catalogue sources for sexually oriented materials not specifically targeted towards people with TM, but potentially helpful:

Eve's Garden International, Ltd. 1-800-848-3837.

Good Vibrations, Inc. 1-800-289-8423.

Lawrence Research 1-800-242-2823.

Thinking About Return to Work after Severe Injury and Illness

Denise Rabold, Ph.D. and James A. Arnett, Ph.D.

Drs. Rabold and Arnett have been writing a series of articles for the TMA Newsletter on the process of adaptation to the effects of severe injury and illness. Dr. Arnett is a faculty member in the Division of Rehabilitation Psychology, Department of Physical Medicine and Rehabilitation at The Ohio State University. Dr. Rabold has a private practice. Rehabilitation Psychology is a specialty of psychology that serves individuals with disabilities as they adjust, adapt, and progress toward healthy and satisfying lifestyles. Psychologists working in rehabilitation use education, remediation, counseling, and advocacy to minimize effects of impairments due to disabling medical conditions and promote wellness through optimal psychological and social functioning. Dr. Arnett has a broad base of experience with a range of disabling conditions, and specializes in evaluation of mental performance and adjustment issues associated with impaired brain function. Dr. Rabold is licensed as both a psychologist and speech-language pathologist. She specializes in counseling and cognitive remediation for work, school, and community re-entry after acquired brain injury.

As noted in our second article about adjustment and adaptation following severe disabling injury and illness

(Dealing With Change. TMA Newsletter, Volume 2, Issue 2), the adaptation process involves moving beyond a focus on losses. This is a difficult process, and unique to the individual. It is often very difficult to move the focus of attention to the future when so much appears to have been taken away. Adapting to crisis involves restoring emotional balance, dealing with effects of illness, establishing and maintaining relationships, and planning for the future. Restoring and maintaining emotional health must involve dealing with these adaptive tasks. Moving forward toward a more functional, independent, and productive lifestyle means moving away from the illness and its effects. Time is an important healing agent; although the time required to effectively manage these adaptive tasks varies greatly among individuals.

Work, whether for pay or not, is a major part of life. Regular involvement in some productive activity brings structure and meaning to life, along with a feeling of control. To work means to be on a schedule, which in turn leads to planning ahead for activities outside of work. Work also brings human interaction, which is stimulating and essential to basic human needs. For those persons who were employed before illness onset, the return to work helps greatly to restore a sense of normalcy, competence, and self-worth.

The effects of illness vary greatly. Consideration of the return to work process must allow for great variations in severity of physical impairment, and the physical demands of certain jobs. We will attempt to address two rehabilitation processes: First, return to the same job held before the disabling illness; and second, considerations of work when it appears return to the old job will not be possible because of the effects of illness. We must also make the assumption that the effects of the illness are stabilized and relatively permanent.

Returning to the Old Job

In many cases, a person with new physical impairments can return to a formerly held job, with reasonable accommodations. Work involving primary activities of thinking, reasoning, problem solving, and communicating fall into this category. The first step in the return-to-work process is to determine whether or not it is possible to perform the former job with present functional status.

Returning to a former job and work environment can be frightening and possibly overwhelming. The process can be simplified by mobilizing a support system to assist with education, problem solving, advocacy, and implementation of needed accommodations.

A first step in the return-to-work process may be a referral to the Bureau of Vocational Rehabilitation (BVR). BVR is a government-funded agency whose goal is to assist individuals with disabilities in returning to gainful employment. Services provided include evaluation, training, work adjustment, and identification of modifications and accommodations that may be needed to facilitate the individual's success.

As a second step, the assistance of a Rehabilitation Psychologist should be considered. This professional is trained to provide needed education, remediation, adjustment counseling, and advocacy to assist the individual in realizing their potential. It is often important to work with a professional who can view the case holistically, giving consideration to impairments, potential, work demands, and employer demands. The Rehabilitation Psychologist will consider individual perceptions of job demands and concerns from the perspectives of both the employee and the employer. Contact with the employer is often made to obtain a job description, and possibly to visit and evaluate conditions at the job site.

Changes in job duties are increasingly a factor in return to work. In our experience, a person who is off work for three months or more is very likely to find significant changes have been made to the job they left. Change compounds the difficulty of returning to work. The individual not only must manage some level of disability, but must also deal with a job that has changed to some degree.

Following a severe and protracted illness, a gradual return to work is always recommended. Returning to the old job after an extended absence can be an emotional and physical "shock." In spite of efforts at physical conditioning, most individuals returning to work after a long absence find the effort very exhausting, both physically and mentally. Useful guidelines involve a return-to-work schedule, which includes part-time employment for a period of two or more weeks. Plans vary greatly; and as an example, the initial workweek may involve two to four hours per day, or four hours every other day. Of equal importance to hours per day, is the definition and assignment of responsibilities. Most jobs, no matter how well they are described on paper, involve many, often small,

undefined or poorly defined duties. These "as needed" duties can be time consuming and can easily interfere with early return success. A clear description of work assignments is helpful during the return-to-work phase. Our practice is to always attempt to place the returning individual in a situation where they can experience success and a feeling of control from the very start of the return process. It is not productive and often harmful to have the returning individual experience a failure in trying to meet work demands in a job they once did well. A feeling of success and a feeling of "I can do more" is always preferred to the experience of anxiety about failure and questions of performance.

Considering New and Different Work

In many cases the effects of illness make it impossible to return to the formerly held job. Often jobs involving a high demand for physical labor will no longer be possible. The individual must now consider other options including exploration of opportunities and investigation of their interests and abilities. The individual with new physical limitations may need to think about new and different occupations, many of which were never considered before illness.

We have found that the career typology theory of John Holland is a useful way of describing and thinking about work and work interests (Osipow, 1983). Holland's theory has been widely researched and offers an excellent way of evaluating career interests. A career interest inventory, The Self-Directed Search, which is based on Holland's theory and used by Psychologists and Vocational Counselors, is a very commonly used device for helping explore work interests.

Briefly, Holland's theory divides all jobs into six types (Holland refers to Occupational Environments): Realistic, Investigative, Artistic, Social, Conventional, and Enterprising. As the theory goes, these six environment descriptors can be used to describe any job. Going a step further, by examining the interests an individual has in different jobs, it is possible to describe that individual's interests in terms of a "Holland Code" made of the three strongest Occupational Environments.

The Holland occupational environments offer a useful and interesting way of thinking about work and work interests. As job descriptors, the occupational environments work this way: Realistic jobs are characterized by active behavior, interest in activities requiring motor coordination, skill, and physical strength. Truck Driver is a good example of a "realistic" occupation. Investigative jobs are characterized by thinking, organizing and understanding. These jobs are well represented by chemists, biologists, and laboratory technicians. Artistic jobs involve self-expression and relating to others through artistic expression. Social jobs involve working with others in a teaching or helping way, as do Teachers, Social Workers, and Therapists. Enterprising jobs require verbal skills and influencing others, as with sales and politics. Conventional jobs involve following procedures, rules, and regulations. Bookkeeper and Bank Teller are examples of conventional job types.

As noted, the Holland theory is a useful way of describing jobs, and a useful way of exploring interests. Most people's interests are best described by three of the Holland work environments; although, there may be one type that is strongest. As an example, a person with a "Holland Code" of S-E-C (Social, Enterprising, Conventional) may find interests in a large number of jobs that are assigned to one or more of these three environments. Working with a Vocational Counselor or Rehabilitation Psychologist can be helpful in considering work interests and options. Again we encourage the use of agencies such as the Bureau of Vocational Rehabilitation.

We have found many inspirational comments in the "In Their Own Words" section of the TMA Newsletter. Two of these appear very relevant to this article: "[Adapting meant] Coming to terms with the fact that it is unlikely that I'm going to achieve the goals and aspirations that I had set for myself in the future, especially in terms of things like work." Success may involve setting new goals, and considering new opportunities. It is vital not to close doors. Develop a support team by getting connected with friends and others who can help. We must also recommend "supportive group" activities involving others with similar experiences. As another TMA member writes, "I cannot state strongly enough the need for a positive attitude."

Reference:

Osipow, S.H. Theories of Career Development. (3rd Ed.) (1983). P Englewood Cliffs, N.J: Prentice-Hall.

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Why a Person with TM Should Consider Physical Therapy
Robin Sopher

received her BS degree in Physical Therapy from The Ohio State University College of Allied Medicine. She has participated in prosthetic and orthotic clinics at both the Medical College of Ohio and The Ohio State University. She has special interests in orthopedic structural assessments and bracing/ orthotics. She works with clients diagnosed with either orthopedic and/ or neurological problems.

One may ask; what is a physical therapist and what could a physical therapist do for me? A physical therapist is a specialist trained to evaluate and treat neuromuscular and musculoskeletal disorders. Physical therapy means the evaluation and treatment of a person by physical measures and the use of therapeutic exercises and rehabilitative procedures for the purpose of preventing, correcting, or alleviating disability. As physical therapists, our goals are to strive to train and teach each client to be as independent as possible. We may use modalities (various machines) to relieve or minimize pain and to try to optimize strength gains. We make our patients work hard, not because we like to see people sweat, but rather the fact that we want the clients to maximize the quality of their lives. To become a physical therapist, one must complete two years of undergraduate work, apply to a physical therapy program and then undergo two to three years in a physical therapy program. This will give a therapist a BS or MS degree depending on the length of the program. Some therapists may go on to achieve one or more specialist degrees. We are then required to attend a specific number of continuing education courses every two years.

When a therapist initially sees a client, he/she performs an initial evaluation. This consists of a thorough exam of medical history, current medications, pain, client goals, muscle strength, range of motion of the joints, gait (walking), posture and structural assessment, balance, sensation, specialized tests, functional abilities and basic neurological testing. This tells us the client's baseline so that we can assess progress during the duration of treatment. We continue to re-evaluate the above information to advance the difficulty of their program.

Physical therapists work with clients that have been diagnosed with transverse myelitis (TM) in various settings. One may initially see a physical therapist (PT) in acute care (hospital), inpatient rehab (when the client is still staying in a rehab center), outpatient rehab (when the client has been discharged to home) or home health rehab (if the client is considered home bound).

When one reads about the rehabilitation for a client with TM, it may be compared to the rehabilitation of a client with a spinal cord injury. This is because the resulting physical effects are similar. A spinal cord injury (SCI) can be categorized into a complete or incomplete SCI. A complete means the patient does not have sensation or motor function including sacral segments of the spine. We may see this with severe cases of TM or in the beginning stage of TM. Usually within 1-3 months, you may begin to see these strength and sensation deficits change in an individual with TM, but this does not change in an individual with a complete SCI. However, an individual with an incomplete SCI may have similar changes. The difference between SCI and TM is the method of injury to the spinal cord. A SCI is usually the result of a traumatic incident like a car accident, fall, gunshot wound, etc. and TM is caused by inflammation of the spinal cord.

An individual with an incomplete SCI and an individual with TM present with similar abilities. Both of these diagnoses, however, have various types of clinical presentations. This means the return of strength and sensation in various combinations in the body. There are no two people that present with all the same symptoms. It depends on what areas and what levels of the spinal cord are injured. The physical therapist's general plan is the same for both of these clients, to continue to strengthen and maximize function of whatever the client has remaining. Individualized goals will be set from that initial evaluation. Some individuals will return to walking, some may not. Let's say a person gets strength back in most of the muscles on one side of the body, but the foot on that side is weak and limits their ability to pick up their foot without falling. We may choose to use a brace at that point to assist those muscles in which the strength does not return, which allows the person to still walk safely. Again, the goals of physical therapy are to make the client as independent as possible.

Because a physical therapist is highly trained in gait evaluation, he/she is able to determine if a type of bracing for the lower extremities would be appropriate. He/she can fabricate a temporary brace to help during gait training, but an orthotist fabricates a more permanent brace. All the decisions about bracing must be approved

by one's physician. A therapist usually tries to delay recommending a permanent brace for the feet or legs until the end of therapy. The reason this is done is because the client's strength may change. When selecting a brace, one must feel fairly confident that the current strength of the area being braced has reached a plateau or will not be making any immediate dramatic changes. For example, if a client started out with significant weakness upon the initial evaluation, one may recommend long leg braces (braces extending up to the thigh area) at that time. However, during therapy this client's strength may change to the point where at the end of therapy he may only need an AFO (a brace extending to just below the knee). Therefore, the effectiveness of the brace depends on an overall evaluation of the client's abilities and an observation of his/her progress over time.

The treatment plan is different for each client. The treatment plan refers to what the client will be doing each time he/she comes for a session and the overall strategy to reach the patient's individual goals. The plan is developed based on the initial evaluation of the client's abilities. Strength is a major factor in determining what types of treatments are appropriate. Strength is classified on a scale of 0-5. Zero meaning that there is no palpable or visual contraction of a muscle and five meaning that the therapist cannot break the client's contraction of the muscle. In between, one through four, are various intensities of muscle contractions. The treatments may initially start with teaching strategies for basic self-care and daily living needs. For example, learning to roll over in bed, sit up, transfer from the bed to a chair, sit to stand, transfer for bathing and toileting, etc. An initial exercise program should be initiated for whatever level of strength the individual has. Aquatic therapy is very beneficial in the beginning, because the buoyancy of the water can be used in ways to assist the client's movements. Buoyancy is a property of water that exerts an upward force. This will make the limb feel lighter. There will be exercises the client can do in the water that he/she cannot do on land. Walking can also be facilitated earlier in the water as opposed to land therapy. The physical therapist will ensure that there are components of both land and water therapy to ensure optimal carryover regarding function. One should be prepared for changing levels of assistance needed by others. In the beginning, a lot of assistance from your therapist may be needed to move and this should gradually decrease during your therapy, depending on your potential for recovery.

Land therapy or therapy in the gym/community will progress as one's strength progresses. Physical therapists are known to always make exercises harder when they become easy! This challenge to the muscles is necessary for strength gains. Some exercises may not seem like what one is used to, therefore the therapist will usually explain their rationale for his/her creative exercises. These creative exercises are not only to add some fun to therapy, but most importantly to add balance training, multiple simultaneous muscle function, coordination training, etc. The client may do work with swiss balls, balance machines, cones, therabands, traditional weights, parallel bars, rocker boards, etc. Electric stimulation machines may be used to help facilitate stronger muscle contractions during the exercises. During gait training, one may progress through the use of various assistive devices. They may start with a walker (one with wheels or no wheels) and progress to a quad cane (four-prong cane) or straight cane. Some clients may benefit more from loftstrand crutches (forearm crutches). The amount of bracing needed for the legs will also help to determine what type of assistive device will be achievable.

Part of inpatient and outpatient rehabilitation is to help orient the client back into the community with the new strategies they have learned. Tasks that were not given any consideration prior to the injury, at first, seem like overwhelming obstacles. Activities such as grocery shopping, going to a restaurant, or going to a mall may be community activities in rehab. This lets the physical therapist evaluate the client's ability to walk or propel their wheelchair community distances, cross the street in a safe amount of time, negotiate curbs/ sidewalks/ stairs/ inclines, open doors, negotiate shopping carts, public restroom accessibility, elevators, escalators and any other community obstacle available. This lets the client try these tasks with the safety of their therapist if they may need help or direction. The chance to do this is a large step toward gaining a sense of independence.

Another area in which a therapist can be of assistance is to decrease or alleviate pain. Pain may manifest itself in various forms in a client with TM. It could be joint or muscle pain in which stretching may help. It could be due to faulty posture in a wheelchair or while sleeping and the therapist can recommend changes. If it is due to nerve pain, a tens unit may help. Sometimes a previous problem can be exacerbated by the current muscle weakness and types of support may be recommended. Physical therapists also use machines to heat

tissues to facilitate stretching and help with inflammation and the pool can even be used to decrease pain secondary to the warmth of a therapeutic pool.

I, myself, have seen individuals with various severities of TM. I have seen clients that needed assistance for self and home tasks at the end of therapy. I have seen individuals that regained enough strength to function independently, but needed the use of bracing and/or a wheelchair. I have also seen individuals that were able to return to walking and independent living. Each stage is difficult for the client, because they are never sure exactly what they will get back and they are forced to find new ways to do previous tasks. If someone will need to use a wheelchair, even part of the time, a team of experts should recommend it. The posture one has in a wheelchair can influence their skin, breathing, eating, comfort, proper joint function, proper muscle function and level of community function.

What would happen to someone with TM if they did not receive physical therapy? They would not maximize their potential for recovery of function. It could be compared to an athlete without a coach. A therapist is trained to evaluate and recommend appropriate treatment during the entire duration of recovery. Something as minor as an ankle becoming tight while you are in a stage of relative inactivity can become major if it is allowed to stay tight for too long. It can significantly impact your ability to walk. Problems such as this are caught early by a physical therapist and actions are taken to avoid or correct them.

Theresa received a Bachelors degree in Early Childhood Education from The Ohio State University and went on to receive a Masters degree in Occupational Therapy from Medical College of Ohio in Toledo. Theresa has been employed at The Ohio State University Medical Center, Dodd Hall for seven years. She is currently the Spinal Cord Injury System of Care Team Leader. She facilitates programming for individuals with Spinal Cord Injuries across the continuum and ensures that their needs are met from a therapy perspective. Theresa also coordinates and runs a wheelchair seating and positioning clinic with Lisa Fugate, MD. Theresa is very active in community organizations and is a strong advocate for community reentry, as well as adapted sports.

Why a Person with TM Should Consider Occupational Therapy
Theresa Frasca Berner, MOT, OTR/L

Occupational therapy is a health and rehabilitation profession designed to help people regain and build skills that are important for health, well being, security, and happiness. Occupational therapists work with people of all ages who, because of physical, developmental, social, or emotional deficits, need specialized assistance in learning skills to enable them to lead independent, productive, and satisfying lives.

Most people tend to be familiar with the role physical therapy plays in the rehabilitation process. People seem to be less aware of the important role of occupational therapy in this process. A source of people's confusion may be that the two professions are not clearly differentiated and while there are significant differences, they are not easy to describe. Perhaps the best way to explain the differences between physical and occupational therapy is to offer an example of our approaches in the rehabilitation process.

Should an individual have a traumatic event, which has left them immobile, and were they fortunate enough to be able to work on the skills of walking, a physical therapist would focus on the process of getting them to walk. An occupational therapist would enter this process and would take it one step further. The occupational therapist would perform an assessment of what the individual's lifestyle had been before the traumatic event. The occupational therapist would determine what strategies need to be in place and what skills need to be developed in order for the individual to go home. Additionally, the occupational therapist would evaluate the strategies and skills that would be required for the individual to return to the roles that had been taken away from them or disrupted or diminished due to the traumatic event. Both physical therapists and occupational therapists work with a person to help restore independence. A physical therapist will focus on the person's physical abilities in regaining independence; an occupational therapist will work on strategies and skills to assist restoring the individual's independence in a more holistic sense. In other words, physical therapy teaches people how to walk, transfer, and move around. Occupational therapy helps people to regain their lives by teaching them how to take care of themselves, how to get dressed, how to cook, how to manage their homes, and how to return to their previous roles and lifestyles. To accomplish these goals, occupational therapy can teach someone compensatory skills to

complete an activity, they can assist in modifying the environment to support the individual's level of ability, or they may introduce adaptive equipment to complete a task.

Transverse Myelitis is a frightening and difficult condition, which can cause one to loose their ability to complete even the simplest tasks. Many of you experienced the sudden onset of TM and were offered little or no explanation as to the causes of this condition. Occupational therapy is an important resource for the TM population, because we can help you regain some control over your lives as your body is recovering from the disease. The ability to do for oneself is one of the most powerful tools to having control over a life-changing event that has placed you in a position of helplessness. Occupational therapy can help you begin the process of regaining back that control.

It is difficult to use a global example, which would apply to every person, because each of you is so different and possess different needs. In addition, the disease affects people at different levels, and the symptoms of TM demonstrate great variability.

Think to yourself, what is it that would help you feel better about yourself? To those of you who have limited use of your arms, would you want to be able to get dressed at your own pace and put on your makeup by yourself? Would you like to be able to cook your favorite meal by yourself? Would you want to be able to participate in leisure activities, such as gardening or fishing? To those of you who are fortunate enough to have use of your arms, but not be able to walk as you previously did, have you thought about wanting to be able to drive and being able to go wherever you want to go? Have you thought about wanting to go to the park with your children? Have you thought about wanting to return to work? For those of you who are adventurous, have you thought about wanting to snow ski or water ski, play basketball, or go rock climbing?

For most of you, the answers to these questions would be a resounding ***YES***; and, yes, there is a way to participate in all the above activities. We may need to alter the way you do it. For instance, we might need to show you tricks for tying your shoes without using your fingers. Or we might have to teach you how to modify the environment, for instance, by installing hand controls in your car. Or we might even provide you with adaptive equipment, such as adaptive ski equipment to race down the ski hill -- with lessons, of course! The important message is that there is a way to return to doing almost any task, if you have the will to do it. Occupational therapists can become your partners in achieving any goals you set before yourself.

Many of you are in a grieving process and may not think all of the above activities are important because your primary focus is on understanding what is going on with your body and on your recovery. I am suggesting that while your focus is vitally important, these other life-issues are critical, as well. Finding a balance in life is so important to all of us, and that is regardless of our life circumstances. Occupational therapy works from a premise that we should all have a healthy balance in our lives of work, rest, and play. When any of these important aspects of our lives has been disrupted, unhealthy habits may emerge.

Occupational therapy can help people regain some of the independence that is often lost when a person contracts TM. OT may also help you find ways to reestablish many of the important roles that defined your life before your illness. Finally, OT may be able to help you find the important balance, which all of us need in our lives and which provides us with meaning, happiness and fulfillment. Having an illness, such as TM, can create significant losses for a person. Life may be different after TM; but an OT can assist you so that different does not have to mean a diminished quality of life.

Progress Report of the Johns Hopkins Transverse Myelopathy Center

Douglas Kerr, MD, PhD

In July of 1999, Johns Hopkins opened the first transverse myelitis center in the entire world. Why was this started? There were several reasons, including the fact that my research dating back to 1988 focused on central nervous system infections and inflammation. Foremost among the reasons for starting the center, however, was the tenacity of my cousin, Gunny (a.k.a Richard Boyle). He and the Gilmurs were quite persuasive that a significant need existed for such a center. They impressed upon me (confirmed by my subsequent experience) that too

often patients received an erroneous diagnosis, or no diagnosis, or no follow-up treatment, or no understanding of what the future would hold for them. And I knew that to understand a disease, one has to see a lot of it and to have smart people think about it. With a rare disease like TM, this would never happen unless a 'center of excellence' was established.

So, Drs. Carlos Pardo, David Irani and myself dedicated ourselves to doing just that. We recruited physicians in other disciplines at Johns Hopkins, as well as other health care personnel, to see TM patients with us. The goal was clearly stated: to better diagnose and treat TM. Ultimately, we hope to devise restorative therapies for those who have had TM and preventative strategies for those at risk.

So, where are we now? We have seen over 120 patients with TM in under a year. Many of these patients were in the acute stages and received high dose steroids or a newer therapy, plasmapheresis. For those more removed from the acute event, we have attempted to focus on several issues: 1) to serve as an information resource about the disease itself, 2) to ensure that the medical evaluation was complete and to perform additional studies as needed, 3) to consult with local physicians as requested when new issues arose, 4) to suggest and implement aggressive health maintenance strategies, 5) to effectively and aggressively manage persistent symptoms, such as bladder dysfunction, pain or spasticity, and 6) to serve as a source of hope that we are working towards a day when we can better treat patients with TM.

We also have served as phone consultants for patients afflicted with TM and unable to come to Johns Hopkins. It is actually a rare day that I do not get called from somewhere in the world about a patient with a disease that sounds like TM (again, sometimes the diagnosis has been wrong). We will work with the family and local physicians, will have data sent to us for analysis, and will even analyze spinal fluid and blood in our laboratories.

We have had some problems along the way, however. My secretary, Philis Carbonell, is a wonderful and hard-working woman. But she and I have been truly swamped at times. (If anybody feels that she has done an excellent job for them, please write her a letter and let her know! It'll make her day). Some days we will get 75-100 calls or e-mails just relating to TM patients. (I also see patients with multiple sclerosis). So, we have failed some people in getting to them promptly. I apologize for that and hope that as we grow, we will improve in this regard.

We hope to begin some clinical trials within the next year. One of those would be the drug fampridine (4-AP) that many of you have heard about or even tried. Some patients have had marked success with this, while others have not. We hope to investigate this further and determine who would most benefit from this drug. We also hope to investigate the extent of and potential treatment for sexual dysfunction in TM, and to examine novel therapies for bladder dysfunction.

Every time I hear about someone getting TM, I become more resolved to better understand this disease. My hope is that the JHTMC will continue to grow both in size and in knowledge, and that our capacity to treat TM will likewise improve.

Dear Association Members:

Cody's Firststep Foundation: Education and Research
Shelley Unser

This letter is long overdue and I've been anxious to tell the story. Cody's story I'm not going to tell you, you can look that up on the Internet under ***www.codysfirststep.org***.

I am Shelley Unser, the proud mother of four great kids -- Al, 17; Cody, 13; Shannon, 11; and Joey, 3. It's been approximately 14 months since Cody came down with an acute case of Transverse Myelitis. I need to give a little background information before it all happened.

I married Al Unser, Jr. in 1982 when we were very young. We had a very public and sometimes stormy marriage that ended in November of 1998. I'll spare everyone the details.

I was going through my own grieving process and loss of identity. I had always traveled with Al and was heavily involved in the racing scene, its fundraisers and all it entails. I was also sports commentating part-time in a sport which was all consuming and is more of a way of life than most people can imagine.

Cody's Transverse Myelitis couldn't have happened at a worse time. Her father and I were barely speaking (after being inseparable for 17 years) and in the midst of a bitter divorce when Cody collapsed at her middle school basketball practice.

Cody was taken to the hospital in Albuquerque where, being still somewhat of a small town, it was decided she was probably just hysterical and trying to get attention due to her parent's situation.

If you know Cody, or once you meet her, this will truly make you angry. She is not that kind of child! The hysteria they saw was actually a severe needle phobia. The ambulance EMTs had made several attempts to put IVs in her on the way to the hospital. She was alone and frightened. I was out of town and, by the time I got there, Cody was paralyzed from the chest down. I was in shock, mortified and had three other siblings at home looking to me for answers I could not give them. Fortunately, with the help of my family and a few true great friends, we somehow lived through the beginning of the whole ordeal.

I knew from day one that Cody was going to make a difference; I just didn't know how.

With the last name Unser we were able to go outside Albuquerque for help. I didn't realize until later just how many people struggle with their insurance companies and never get this option.

I then found Dick and Deanne Gilmur through a friend on the Internet. Deanne also gave me the number of a woman named Gail Hirsch who was going through the same thing in California with her 13 year old son, Evan. She still has no idea how comforting it was to talk to her. She was a total stranger and yet I poured my heart out sometimes in the middle of the night during the initial stages of grieving and looking desperately for answers.

I remember, as a mother, lying there at night trying to pretend I couldn't move to help me feel more of what my daughter was going through! I would just cry and cry. Somewhere between denial and anger, Cody and I came to terms at the same time and took a different outlook. I suddenly realized Cody Unser was obligated to use the famous name and, despite the divorce, she and I had every right to capitalize on that name and do something good with it.

I somehow found some of my old confidence and realized just how much I knew about public relations, fundraising and awareness from my contributions to my marriage. I could do the same for Cody and, in turn, help her and others.

People Magazine started the snowball and before I knew it, Cody, like it or not, was becoming a poster child for Transverse Myelitis.

Her father and I had had numerous discussions on the subject because his life was spent in the limelight. He was worried Cody would be used up and tired out. Ultimately, as her mother, I decided the decision was neither Al's nor mine, but hers and I would support her all the way with whatever she decided.

The rest is history. Fourteen months and a few good mother/ daughter fights later, Cody has amazed me with 48 Hours (the television crew lived with us for two weeks), Inside Edition, Courage and numerous articles. We have pushed each other into TM mania. I no longer watch racing, but medical shows. I feel like a pre-med student and I have found new meaning in "life." I have become a better mother, held my daughter to her celebrity promises and, yes, at times worn her out.

I know with research there will be a cure for paralysis caused by TM. I know, through Cody's smile, she has certainly brought attention to TM. I wish every person with TM could have received the same amount of attention Cody is getting (and she would gladly share it, believe me) but more importantly, now that the word of TM is out, we need your help to focus on TM.

Cody has been sending out medical forms for Johns Hopkins to collect data. She has asked hospitals to contact Dr. Doug Kerr and share patient information during the acute phase. To make this work, every person reading this newsletter needs to take the initiative so her efforts are not in vain.

Please use your own contacts to tell your doctors and hospitals to find a way to share data. This horrible condition needs to be diagnosed quicker so more people don't end up in wheelchairs.

A very young couple in Indiana just lost their dad, Frank Meloy, to TM. At the funeral they decided, instead of flowers, to help Cody's Foundation. They had their late father's doctors contact Dr. Kerr and share their knowledge of his death.

Every single person with TM is a pioneer and, in my opinion, obligated to push the medical community to understand it. We also need hospitals that truly have a grip on how to treat it.

I am so proud of Cody and I am so touched by so many of you that I have met and talked to in just one year's time. This experience has restored my faith in humanity.

I cannot wait until the Symposium in 2001. Who knows, maybe they will be closer to a cure before we even get there. If nothing else, the world will think twice before sending someone away because they can't diagnose it. I can envision the day when they (the hospitals and doctors) might get on line, type in a few symptoms, a red flag will go up. Dr. Kerr will get a call and the proper drugs and procedures will be administered within hours and that fortunate person will walk out of the hospital within weeks never knowing that all of you and my daughter, Cody, made a difference! How cool would that be?

We Don't Want to Lose You

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

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

In Their Own Words

The In Their Own Words articles in this newsletter have been written by parents of children with TM. We are too frequently contacted by parents whose children have been recently diagnosed. Our goal is to provide them with as much information and to get them into a network of support as quickly as we are able. We know that the articles that appear in this newsletter about these very special children will offer invaluable information to parents of children with TM; and to parents who will contact us in the future. In writing these articles, we asked parents to provide the information they would have wanted to know when they were going through these very difficult experiences with their own children.

I am forever grateful to these parents for taking the time and energy to write about these experiences. Most of us can't know the emotional energy that was required for them to revisit these extremely difficult and personal issues. We greatly appreciate their willingness to share in their childrens' and their families' experiences.

You may submit your stories for the In Their Own Words column by sending them either by e-mail or through the postal service to Sandy Siegel.

Coline 9 Months
Chantepie, France

Hello Sandy and all TMA members! This is Roland et Pascale Erhel. We are French thus, first of all, we must ask your indulgence for the broken English we are writing in. We live in Chantepie, a little town near Rennes, in the west of France. We have two daughters: Aurélie, aged 9, and Coline, aged 3 ½. We live in a very beautiful area with the sea nearby and we could have been perfectly happy if Transverse Myelitis didn't come and turn this quiet stability upside down. *Myelitis*: we never even have heard about this disease before July 97.

July 97: Coline is a pretty little girl aged nine months. She just begins to stand up in her playpen but she still doesn't walk.
On the ***17th of July***, her mother picks her up from her nanny's home. Coline is very grouchy, she looks as if she has pain. The GP comes to our home and only finds that her ears are lightly red, nothing more.

When Coline woke up on the morning of the ***18th July***, she had a fever (39 °C) and we noticed she was a bit *limp*. The GP comes again and thinks she is weak because of the fever (he finds a double otitis plus a laryngitis). Coline sleeps all this day long. She sometimes has her eyes opened, but she doesn't cry. At the end of the afternoon we keep her out of her little bed and we discover at this time that she is completely limp, without any reaction. After a phone call to our GP, we go and take her to the pediatric emergencies at the Hospital.

She cannot move her legs, her hands, nor her arms. She only can move her head from right to left when lying on her back on the bed. In the space of a few hours, Coline has become almost totally vegetative!

From then on, the medical team performs the following procedures:

A **lumbar puncture** (*meningitis*?);
An **Electroencephalogram** (*convulsion* when she was asleep?

We were concerned about poisoning from medications that she might have gotten into at her nanny's home. This hypothesis was abandoned).
A **brain scanner** (normal);
A **MRI**, which finally confirmed the diagnosis of Myelitis made by the neuropediatric of the medical team. It's an ***acute cervical myelitis in C1 - C4***.
An **echography** of the bladder: the bladder is full and Coline is unable to empty it; this, again, confirms the diagnosis.

Coline stayed for three weeks in this vegetative state. She received different treatments:

An **IV** for rehydratation;
Antibiotics (CLAFORAN, NETROMYCINE);
Antipyretics (PRODAFFALGAN, ASPEGIC);
Morphine (SKENAN), because Myelitis is often painful;
A daily session of **Physical Therapy** (passive mobilization of the four limbs).

There is actually no real treatment for Myelitis. A medical protocol is usually used in this case to try to attenuate the inflammation of the spinal cord. Coline received this treatment during these three first weeks of hospitalisation:

A ***bolus* of Corticoids** (a great dose of corticoids given in a very short time -- in French we say a *dose de charge* -- during three days);
Immunoglobulines, one IV or perfusion, lasting two hours, over a three day period;
Corticoids (little doses) per os (oral -- by mouth) during 10 days.

On the ***11th of August 97***, Coline is transfered to Paris for a *super-consultation* with the French specialist of children's neurological diseases, Pr Pierre Landrieu. He gives us a great deal of information about a disease we didn't know until then, but he stayed very careful concerning the possibility of recovery for Coline, insisting upon the fact that there is an enormous individual variability in these neurological problems.

I can't describe the state we were in during this awful period. From one day to another, Coline was reduced to a vegetable state. We didn't know how it happened (perhaps a gastroenteritis she made at the end of June; they didn't succeed in finding out the virus responsible for this). And we also didn't know how she would recover. In fact, we didn't know the reason it came to be, and we didn't know where we were headed ….

At the end of the third week of hospitalisation, the recovery began very progressively: support of the head, movements of arms, folding the right arm, getting her right hand to her mouth .... Coline went back home on the ***14th of August***. After a few weeks at home, the improvements tended to slow and then apparently stopped.

From ***August 97*** until today, we haven't stopped trying to find anyone able to help her, to help us: the best and the worst, serious and honest people, but also charlatans (in desperation, we go and see anybody pretending to be helpful for us. Love makes blind, but sorrow too ...).

Coline today is a very pretty little girl aged 3 ½. Very happy to live, always smiling (which is a great help for us, her parents, her sister and relatives). Damages caused by TM are unfortunately visible and deeply disabling: Coline cannot normally maintain her chest, she stoops and has to lean on armrests or her thighs to support her back. She wears as often as possible, a surgical corset which extends from her hips to the armpits. Essential to prevent her spinal cord from any distortion, this corset limits to a certain extent the movements of her arms (when she plays, when she draws ...) and turns out definitely bothersome in certain situations (when it's warm, during our holidays in Corsica, for example ...).

Coline can use normally her right arm and right hand but her left hand has remained partially handicapped. In the beginning she could only use her two fingers, thumb and forefinger; she could use the *pliers* with the thumb and the forefinger, but the three other fingers remain more oftenly folded and inactive. She has yet to succeed in opening her hand, very slowly, for sease (for example, she can hold normally the handlebars of her scooter -- open, then close all her fingers on it -- I transformed it so that the accelerator could be activated by hand and she uses this little electric scooter to drive around the neighbourhood). Coline is recently able to open her hand, but not in a quick normal way.

Coline can't use her legs, even if those are sometimes animated by voluntary movements, mainly in the way of pushing. We have in our home a *verticalisator*, that we call *le debout* (the *stand up*), a mobile device in which we install her in order to fortify her legs (to avoid demineralization and weakening of her bones). Seeing our little girl strapped up tight in her corset and attached in her *debout* is a heartbreak. But we must get her in it. She, herself, feels quite good in it because of her unusual vertical

position which provides her a different perception of her own body and her environment.

To these already heavy handicaps go in addition, as if it was not enough, a whole trail of secondary problems (*secondary* but also hard to cope with). The dysfunction of her bladder which compels us to practise three urinary catheterizations per day (at her awakening, at midday and in the evening). We, of course, have learned to do ourselves this nursing act whose daily repetition for more than two years would seem unbearable for many, but it's now for us a part of our *routine.* Despite these catheterizations, or maybe because of them, Coline often develops urinary infections which need to be treated. Echographies of the bladder are regularly done, and soon, a scintigraphy of the kidneys will take place.

Each ORL (Oto-Rhino-Laryngologique -- ear, nose and throat problems) infection brings complications because Coline hasn't got a cough effective enough to clear the phlegms. Her daily session of physical therapy is then replaced by breathing physiotherapy, which occurs several times each winter.

Coline is being seen by Dr. Nicolas (Rehab) in Rennes. He deals with all the problems related to her handicap, especially all that concerns the corset, different orthesis and devices aimed to avoid distortions of her spinal cord, her hips and inferior limbs. Three times a week she has a visit from Yves, her physical therapist, and two times a week we go and see Marie-Claude, a PT too, but specialized in children with motor problems.

Coline has been precocious as regards language, she speaks very well and a lot (she is not a girl for nothing)! Perhaps her intellectual development has come and compensates for the motor insufficiency. She now goes to nursery-school three mornings a week. Annie, her teacher, is assisted by Delphine, who's job is exclusively to look after Coline at school. (These Youngs in France are called *auxiliaires d'intégration -- Integration auxilary*. I don't know if this exists elsewhere). A little non-mobile chair was created especially for Coline, for her activities in the classroom.

That was, until today, the story of Coline (which is also, of course, the story of us, her parents and all her relatives). The poor little story of a poor little girl that had badly begun with life. Sorry, we don't believe in God. It's certainly a pity, because if we believed, it would be, without any doubt, of some help for us. But you just can't obligate yourself to believe.

We do hope that life will be better for Coline in the future -- we believe in the progress of science; and a great deal of our time and energy will be devoted to her. Before TM, we had no particular aim in life, now we have one, and it is a magnificent challenge!

Roland et Pascale Erhel
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Roland and Pascale ERHEL

7, rue de Molène
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France

It has been four years since Danielle was diagnosed with tm. I will start from the beginning, the best that I can remember. Danielle was 9 months old when she was diagnosed in February 1996.

On February 14th, I picked her up from the baby-sitter's house. She looked a little flushed to me. She did not seem happy when she saw me. When I picked her up, I could tell that she had a fever, but thought it was maybe a cold or something. I only lived a few miles from the

Danielle 9 Months
Tennessee

sitter's house, so I waited to take her temperature until I got home.

When I did get home and took her temperature, it was about 100. She had a rash on her tummy. Again, I was thinking it was a virus or cold. Her temperature was going up and up for the next few hours. Tylenol was not helping with the fever. It had gotten to 102.5. So, I called her doctor, and was told to give her a little more Tylenol to see if the fever would come down a little. While I was talking to the doctor, Danielle started to have trouble breathing and could not swallow the Tylenol.

We met the doctor at the hospital. When we got to the hospital, Danielle's fever was 105. She was not crying or swallowing anything. She refused a bottle and the breast. At this time we had x-rays done and bloodwork. When the x-rays came back and were read, we were told that she had pneumonia. We were then sent to the local children's hospital. We were there for 21 days.

After being in the hospital for three days, Danielle went limp from her neck down. She cried all the time. We had been seen by so many

doctors. We were tired of them coming into the room and pocking and picking on my daughter. No one could tell me what was going on. I questioned whether a spinal tap should be done and was told that there was really no need to be doing a spinal tap. The doctors at the hospital were going to diagnose her with something that (I can't remember the name) was a temporary form of paralysis.

I talked to my doctor about it. The spinal tap was done the next day and they found out that she had spinal meningitis. So, antibiotics were started. Well, to say the least, Danielle got worse. Danielle was still not eating and was swelling up like a balloon with all of the meds that she was on. The doctors did an MRI and CT and found that there was fluid on the spine from c3--c7. At this time they thought that her ears had drained from an ear infection to her spine.

We had an intern assigned to her case. He came into our room about 3 am one morning and said that he knew what Danielle had. He said that it was so rare that he did not know how or where she may have come in contact with it. Then told me it was acute tm. He said that he had never seen or heard of a case before. Now that we were diagnosed, I asked, "now what?"

Physical therapy was started while we were in the hospital. The neurologist started her on an i.v.i.g.g drip that lasted two days and dripped for 12 hours at a time. Steroids and breathing treatments. There are so many meds that she currently takes and that she has taken, that I couldn't possibly begin to start listing them all.

After we were sent home from the hospital, we started seeing the neurologist and pulmonologist on a weekly basis. There was PT three times a week for the first three months. We then went for PT twice a week and currently it is once a week. Danielle has been in and out of the hospital several times with her lungs and not being able to breathe properly. Her lungs are getting stronger.

She is now only paralyzed from the waist down. She does have problems with being able to control going to the restroom, so we have her in pull ups. She started going to pre-kindergarten this past year and has made a lot of friends. Everyone says she is special. I believe them; she is special. She has proven all of the doctors wrong; they told me that she would not live two months after being diagnosed.

The out come of all of this is that Danielle is a typical five-year-old in a wheelchair. She loves her wheelchair; it gives her freedom! She also has braces and a walker that help her when she wants to go walking. She loves to swim and play with her babies and barbies.
She is still in PT and will be attending kindergarten this up coming school year.

Mary Troup
work7days@aol.com

February 28, 2000

My granddaughter, Kristen, has Transverse Myelitis. I would like to tell Kristen's story.

Kristen had her six months baby shots four weeks before her illness and the flu two weeks before her illness. The morning of January 21st 1998 at 7:30, Kristen's mother, Teresa, took her to the babysitter and went to work. Kristen appeared fine. Each day after my daughter, Heather,

Kristen 7 Months
Arkansas

got out of school, she would pick Kristen up from the sitter's. When Heather picked Kristen up that day at 3:30 p.m., she immediately noticed that Kristen did not raise her arms to greet her or move her body when she put her in the car seat. Heather called Teresa at work. Teresa immediately came home and took Kristen directly to a local hospital. Due to Kristen's age and condition she was immediately flown to Arkansas Children's Hospital in Little Rock. Kristen had no movement from her neck down.

Upon arrival at Arkansas Children's Hospital, Kristen was initially diagnosed with Guillian Barre Syndrome and treated with immunoglobulins. Three to four days later, after an MRI, this diagnosis was retracted and we were told that an unknown virus had attacked her spine destroying nerves on the inside and outside of her spinal cord. Her immune system had also become confused and attacked her body. Kristen had been on a ventilator since her arrival at the hospital and now was given large dosages of steroids. Kristen spent the winters of 1998 and 1999 at Arkansas Children's Hospital. Thankfully, this winter she has not been in the hospital at all. Kristen's diagnosis for the future - she can be functional.

Until this occurred in January of 1998 Kristen appeared healthy. She rolled

everywhere, sat up and had even begun to attempt to crawl. To date, Kristen has moved every part of her body except her left hand. She will roll over, although she doesn't do so without encouragement and it requires a lot of effort to accomplish. She will sit by herself if you place her in a sitting position, although she slumps forward (this is improving). Kristen does not crawl, stand or walk. She feeds herself fairly well using her right hand for grasping and her left hand for support. Kristen's right hand has loosened from a tight fist and she has fairly good control of it. Her left is very floppy. She is extremely active with her arms and can move her legs, although she does not do so with much frequency. She is very weak and can only lift light objects.

Kristen's mother has begun to try to potty train her. Kristen will use the potty, but we don't see a controlled function. Bowel movements are extremely painful for her.

Kristen is a delightful child. Last winter at Arkansas Children's Hospital, she learned all her nurses' names so she could get extra attention! She is very forgiving; even after painful medical procedures she is still affectionate with her doctors and nurses. And she is very loving. Because she is so young, we are hoping to see improvements in her condition as she grows. At age two she could recite her ABC's, count to 10 and sing several songs.

We feel blessed to have our Kristen and pray that a cure will be available for Kristen and everyone affected with Transverse Myelitis.

Sincerely,
Donna K. Hibbs

Maria 6 Months
Pennsylvania

Our daughter was 6 months old when she was diagnosed with TM. During the morning of the onset, she had been her usual self, happy, rolling on the floor, rocking back and forth in a crawling position, and sitting up by herself. After lunch, she became irritable and fussy; she nursed and fell asleep in her mother's arms. We continued to rock her and comfort her through the afternoon. We noticed something was not right while changing a diaper. Her arms and legs were limp and she was looking at us. She was able to move her head from side to side but there was no movement from her neck down. Our pediatrician did not understand what was going on when we spoke to him over the phone but he did agree that she needed to be seen. We were not aware of any previous illness such as cold, flu, or anything else. She did have a mild diaper rash a couple of days before that had healed. Our daughter had double hernia surgery at four months old with general anesthesia and a caudal block. She also had immunizations at four months of age.

At the hospital, the emergency doctor examined her. We were asked many times about how this happened to her. Making us feel very frustrated and guilty, like we had done something to her. We knew that our story was very vague. Finally, the emergency doctor consulted with a neurologist and a MRI was ordered and done. They had to intubate and sedate her for the MRI. Within six hours of entering the hospital, the neurologist was telling us that our daughter had TM, which was completely unknown to us. She was admitted to the Pediatric Intensive Care Unit for high doses of steroids and a dose of immunoglobulins. When we saw her, she was on a respirator, had two intravenous lines, and a foley. She stayed on the respirator for three days. The pediatric doctors and the neurologists ran many other tests trying to determine the cause of her illness, which ended up not telling us anything. We were told that the cause was autoimmune, something within her immune system attacked her spinal fluid. Initially, her MRI showed the area of swelling in the Cervical 4-6 and then continued down her entire spine. A week later there was a mild decrease in swelling when compared to the first MRI. We saw her first movement within the first 48 hours when she lifted her left arm up and down.

On the fourth day, she developed a urinary tract infection that required antibiotics. A spinal tap was done a week into the stay. The doctors expected to see signs of the infection but only found normal fluid. She remained hospitalized for 18 days in the pediatric intensive care unit. Two days before we came home, she had a cookie swallow done. She was able to chew and swallow normally so she started to eat some baby food and take her bottle again. We had to catheterize her two times a day, because her bladder did not empty completely. The medications prescribed on discharge were prelone (steroids), suprax (preventive), and oxygen. The equipment prescribed on discharge was an oxygen concentrator (nasal cannula), suction supplies (weak gag reflex), a pulse oximetry monitor, bladder catheters, and bilateral hand and feet/ankle splints.

She started outpatient rehabilitation three times per week for occupational and physical therapy. We saw very slow improvement. We tried to motivate any kind of movement through play and toys. At one point, we also had the Early Intervention Program come into our home for occupational and physical therapy. We felt that this was too many therapists with too many opinions. So we concentrated on the center for therapy. Our goal and hope is for her to have a complete recovery. Even though it's been two and a half years, we still believe this to be possible. She presently has great upper body strength. She can crawl dragging her lower body without difficulty. She can get into the proper crawling position with belly off the floor and knees under her hips, yet only rocks in that position. She feeds herself with either finger foods or feeding utensils. She sits on a bench with usually one hand down to stabilize herself. We do see muscle activity in her legs. Her legs were floppy up until two years of age (post one and a half years). Then we noticed she had her knees flexed in while sleeping and they were hard to relax. With the guidance of therapists, we made nighttime cloth leg splints to keep her legs extended. She can stand with minimal help at a bench for a brief period of time.

Presently, we use the following equipment for her daily routine; electric stimulation for her upper legs, air splints for her legs while she is standing, ankle/feet splints while she is standing or sleeping, night-time cloth leg splints, day-time hand splints to help keep her fingers extended, night-time resting hand splints for muscles/joints to relax, catheterize her three times per day, and a pony gait-trainer to get her upright several times per day. We are researching the type of wheelchair that would be best for her. And looking for out-door toys that are hand pedaled to give her the independence that she needs.

Her therapies consist of occupational therapy two times per week and physical therapy three times per week. She started hydro (water) therapy at 32 months old and equestrian (horseback riding) therapy at 35 months old. She loves them both and seems to be doing better in each activity.

Presently, she takes one dose of bactrim daily to prevent bladder infections. She also takes one dose of detrol daily to help her bladder to expand and hold urine. She sees a urologist one to two times per year. She sees a neurologist one time per year. She sees her pediatrician on a normal schedule, although our visits may be longer and we request extra time.

It has been tough as parents to see our child so ill with no definite reason why and so many unanswered questions. And not being sure what her future holds. Where will we be? Who will take care of her? In addition, trying to care and love siblings that are too young to understand why their sister does not walk or run. It's been a long two and a half years.

We are not sure how we got through the last two and a half years but we did. We talked a lot, cried a lot, and hugged a lot. We have had good days and bad days. We still hope and pray for complete healing to take place. Yet, we do want His will to be done. Our three-year-old is a very happy and loving child and we thank G-d that she has the mind of a three-year-old.

Pam and Morgan Hoge

Natasha 9 Years
Cheshire England UK

19th October 1998

Natasha got up for school as normal feeling fine. I dropped her off and went to work. At lunchtime (12.00 noon) I went for a sandwich. While I was out Natasha's school had telephoned and asked me to call back. I arrived back to the office at 12.30 PM. I telephoned the school immediately to find out what was wrong and their answering machine was on; half an hour later I managed to get through.

I was told that she had been running around in the playground with her friends when she suddenly felt a pain in her chest and felt sick. She was told to go and play and not to be silly. Five minutes later she felt very sick and went indoors. She was sick three times downstairs and twice upstairs. At that point the school decided to telephone me. Whilst they were ringing me, Tash was left alone. She started to get a funny feeling in her body and the pain in her chest was still there. She stood up and immediately fell to the floor and banged her head on the corner of a table. When the dinner ladies got back to her, they realised what had happened.

I arrived at school thinking that Tash had a stomach virus and would be fine. When I saw her lying on the

bench, I called to her so I could pick her up and give her a hug. She told me she couldn't move. I had no idea. The school had told me none of this. Then I saw a huge lump and bruise on her head.

I thought the loss of use in her legs was a symptom of concussion due to her bang on her head. I decided to take her to our local hospital to check her out. We arrived at 2.15 PM. On the way and when we arrived at Casualty, Tash was complaining of excruciating pain in her back. She was extremely distressed, as was I.

The nurses and doctors in A&E were appalling. They had no idea what was going on and thought that Natasha was having them on. One nurse said, "Oh don't worry, we've had loads of children in this week with the same symptoms, wanting time off from school. They all got sent home with the same answer – go to bed, you will be fine in the morning."

In Tasha's case, they were sadly wrong.

We were left alone in A&E for five hours not knowing what was going to happen. She had not been sick since I had picked her up, but from her chest down, she was getting strange feelings. One minute she could feel everything and the next she felt nothing. It was ever so strange.

They decided they would admit her to the Children's Ward (5.30 PM) and monitor her. When we arrived, a Doctor examined her. He had no idea what was wrong, so he called the Consultant. At this point Natasha's breathing was quite quick. She was getting very breathless. They thought they knew what it was but they were not sure. They mentioned performing a lumbar puncture.

They decided to contact the specialised Children's Hospital (9.30 PM) about 10 miles away to see if they could admit her. Their main worry was whether her breathing would deteriorate further while she was being transported from one hospital to another.

We managed to get there OK (midnight). She was checked by a House Doctor, who again thought she knew what it was but was not completely sure. A lumbar puncture was performed and she beeped the Consultant for further diagnosis. We were then taken to the High Dependency Unit for monitoring (2.00 AM).

At 2.30 AM I tried to put my head down for a while. Natasha had gone to sleep. At 2.45 AM I was told that the Consultant had arrived and she needed to speak to me. She had immediately requested a MR Scan and told me she would know further after seeing the scan.

4.00 AM in the scanner. I could see the reaction on the Consultant's face. It was starting to dawn on me that something was seriously wrong.

5.00 AM. I was told what was wrong; it was TM. Natasha had contracted a stomach virus that had convinced her immune system that the virus was in her spinal cord. The immune system destroyed part of the cord. We did not completely understand the total severity of the situation until the Doctors drummed it into our heads the next day. We were told that if she didn't start to regain anything within the next few days that she would be like this for the rest of her life; not being able to be touched because the slightest movement causes more pain than you could possibly imagine; not being able to move from the chest down; not being able to give your mum a hug.

We are now 18 months down the line. She can sit up with a straight spine for a short period. She can stand, although not for very long. And she can walk with a frame for about ten steps before she gets too tired. She can feel from the chest down although it does not feel right. The base of her feet are still incredibly sensitive and she would rather you didn't touch them but they are much better than 18 months ago. She has private physio three times a week and NHS physio once a week, and she works incredibly hard. She set a goal last year to walk a step and she did it. This year her goal is to replace the walking frame with crutches. She has such a strong will. I know she will do it.

Natasha is a remarkable child. She is brave and extremely strong willed. She always has a smile on her face and whenever I find that I can't cope and it gets to be too much, she gives me a huge hug and tells me everything will be OK.

I will never forget those first few days. I will never forget the traumatic three months in the hospital. I have been scared for life. It still brings tears to my eyes every time I think about it. Writing this has been extremely hard.

It was difficult not being able to talk to parents who have had children with TM that were attacked so quickly. It only took 20 minutes for Natasha to go from a fully abled child to becoming a child paralysed from the chest down. It hits you like

a ton of bricks and your life is turned upside down. It's only time that heals and life does get better; even though the future is uncertain. Natasha will walk again on her own; she has me to make sure of that and her determination.

Andrea Allen
giu22@dial.pipex.com

Rachel 6 ½ Months
Ohio

It was Saturday, October 9, 1999, a day our family will never forget. It was on that day that our daughter, Rachel, woke up and could only move her neck. She had exhibited cold symptoms for two days prior and we felt she was probably coming down with an ear infection (she had two previously) so we had planned on taking her to the Pediatrician on Saturday morning anyway. Rachel looked very sick, and had a high fever and very weak cry when she woke up, although she was alert and responsive. We were obviously very concerned and called her Pediatrician right away. When we took her there about three hours after she woke up, he did find a double ear infection and gave her two shots of antibiotics, one in each leg. She didn't cry when she got the shots (which, of course, concerned us) but the doctor felt that her muscles shut down due to the flu. After all, you don't go to bed with a cold and wake up with a neurological disorder, right?? Anyway, that was the beginning of such sadness and mourning for our daughter who had been developing so normally up until that day. She was just beginning to lift up a little on her knees and could pretty much sit up without falling over when all of that changed literally overnight last October.

We took her back to the Pediatrician's office the next two days and they continued with the shots of antibiotics. She didn't cry for any of them. Rachel did improve and began to look better and during these three days, she began to move her arms, first the right one and then the left in large sweeping movements. When she showed no signs of leg movement by Tuesday, the doctor arranged for us to go to Rainbow, Babies and Children's Hospital in Cleveland so the large staff of pediatric specialists could adequately access Rachel's condition. We entered through the emergency room and left 18 days later. We were asked a lot of questions about Rachel's immunization history and she did, in fact, have immunizations for Diphtheria, Acellular Pertussis, Tetanus (DtaP3) and Haemophilis Influenza B (HIB) on September 23, 1999, a little more than two weeks prior to her onset of TM. Even today, her Neurologist cannot completely rule out some connection. At the hospital, they performed a Cat Scan, a lumbar probe and then an MRI of the brain and spine. During this time, they transferred Rachel to the Pediatric Intensive Care Unit as a precautionary measure since her respiration was weak and they wanted to watch her more closely. They wanted to make sure whatever she had would not eventually affect her ability to breathe on her own. Thankfully, we were only in the Intensive Care Unit for two days. On Saturday, one week after the onset of her TM, we were definitively told of Rachel's diagnosis and she began intravenous steroid treatment. We were told of her diagnosis on this day only because Rachel's MRI showed a couple of other things that they had to rule out as having any contributory affect. They found swelling at C3-C7, a small thoracic syrinx (fluid filled cyst) and they also said there was a decreased amount of white matter in her brain for her age. This was all so scary!

During Rachel's hospitalization, she had therapy everyday and she showed rapid improvement in her upper extremities, showing increased purposeful movement and strength. Also at the hospital, she periodically wore custom-made hand braces (to help her fingers straighten out) and custom-made foot braces (to prevent her toes from pointing downward all the time). Her trunk was weak and she was not able to sit unassisted or roll over. It was also determined she was retaining urine and so she had to be catheterized every six hours and this ultimately resulted in a urinary tract infection. This condition did reverse itself while in the hospital and we were able to go home with her urinating on her own. The Pediatric Urologist indicated her bladder was now considered overactive and she dribbled urine frequently. Thankfully, Rachel only needed an enema once and we continue to watch her bowels and monitor them through diet.

We were very happy to go home, having spent a lot of time away from our two sons, Matthew (who turned six while Rachel was in the hospital) and Kevin, age four. We arranged to have Occupational Therapy two times per week and Physical Therapy one time per week on an outpatient basis. On November 1st we started our outpatient therapy and continued to see improvements at every visit.

This was very encouraging, but by early December, the progress had slowed, although it was still there. At first we were told by her Neurologist that she would be seriously concerned if Rachel was not moving her legs in three months and this made us extremely anxious. We watched her constantly for any sign of new movement. While in the hospital, Rachel could move her legs stiffly from the hips, however, after we got home, we would notice very slight changes or frequency of movement. We would notice this more when her upper body was stimulated or when she was sitting on a hard surface. It was nothing regular or predictable, but it was wonderful to see, just the same.

Rachel is now a little more than 13 months old and she has had Transverse Myelitis longer than she hasn't had it. It really is hard for us to remember her any other way and we really don't have much memory of her being mobile at all since she was just beginning this stage of development when she got sick. She now goes to Physical Therapy two times per week and Occupational Therapy one time per week since she has shown some increased leg movement and considerable upper body improvement. Her trunk is still weak although it has improved with therapy. Her arms are at 100% strength and she can get around the house pretty quickly by doing the commando crawl. We have noticed irregular movements in her hip flexors and quads and we are working hard at trying to capitalize on that. We do a lot of sit to stand exercises and have recently begun to do electrical stimulation on her back and lower extremities. Rachel cannot roll from her back to her stomach without assistance so we are working on developing the muscles to help her do that so she doesn't feel so trapped. She gets very frustrated being on her back unless she is very tired. Rachel stands in her standing frame for approximately one hour each day in 15 - 20 minute increments which should provide her some additional weight bearing which will help in her structural development. We also periodically do warm water pool therapy and she will be fitted for dynamic AFO's in a couple of weeks. At this point, Rachel spends a lot of time at therapy and at home we work on a large therapy ball and do a lot of stretching exercises to keep her tone good so that if the signals do get through, her muscles are loose and ready to move.

Thankfully, throughout this, Rachel is not in any pain which many people experience with TM. She is a very happy baby and does not know that anything is amiss. It is difficult to assess everything about her condition because she is non-verbal, but we do know that she has some feeling in her legs. She had an ear infection just a month ago and they gave her a shot of antibiotics in her leg and this time she wailed! Rachel has recently begun to scratch her legs quite a bit and we feel this is in response to increased sensation she is getting in her legs.

We don't know exactly where this uncertain road will take us, but we do know it will take a very long time for Rachel to recover whatever function she will eventually have. The waiting and the uncertainty is so very difficult, but we continue to be hopeful for Rachel's future. We have to be. We know at this point that she would be able to live independently and we are so grateful for that. As we wait, we surround her with a lot of love and encouragement and, hopefully, someday our prayers, that one day Rachel will walk, will be answered.

Cathy and Dan Dorocak

Carpenter With a Dream

Hal Ketchum is a country western singer and songwriter who contracted Transverse Myelitis. One of his fans, Suzanna Eckchum, has written and recorded a song about Mr. Ketchum to honor him and to celebrate her appreciation of his music and career. Ms. Eckchum has graciously pledged to donate all of the proceeds from the sale of this song to The Transverse Myelitis Association. "I hope my song will help The Transverse Myelitis Association find the cure." We are most appreciative of Suzanna Eckchum's kindness and generosity.

If you are interested in ordering the *Carpenter With A Dream* song, please send a $10 check or money order to:

FeatherMoon Publishing
902 CO Rd 345
Marble Falls, TX 78654

In 1989, I was a fit and happy-go-lucky type of person. I was married to a smashing girl, Annie. We were living in a flat in a small town called

Life After TM: Triumphs of the Spirit

Mel and Darlene are members of The Transverse Myelitis Association and both have TM. Coincidentally, Mel and Darlene recently communicated their experiences to me. I was so moved by their spirit and courage, that I requested permission to share their experiences with all of you. Both Mel and Darlene have suffered from depression. What I found so inspiring about their experiences was that they found relief from their depression not from a recovery from TM, but in spite of it. I do not mean in any way to imply that there is an easy fix for depression or a simple formula that a person may apply to treat their depression. In fact, I believe that just the opposite is the case; that the treatment of depression is extremely complex. With tremendous tenacity, Mel and Darlene have created some wonderful and positive changes in their lives. If their stories inspire one person to seek that light at the end of the tunnel, they will be gratified for having shared their experiences.

Life After TM: An Olympic Effort
Melvyn Corley

Redbourn, which was in Herfordshire, England. I was working for a major clothing company called Next. I took this job after leaving the Armed Forces in 1989. I left the service because my new wife did not like me going back and forth to Northern Ireland.

On the subject of the 23rd March 1989, I was at work until the usual time. But I felt unwell. I had previously had a massive chest infection for which the doctors gave me some antibiotics. I had completed the course of antibiotics and then went back to work thinking that all was well again with my body. That week I was working nights. We had a rush job on and I volunteered to stay on and get the job done. We finished around 10:00 PM. I had started work at 6:00 PM on the previous evening. After I got home, I told the wife that I had a massive headache. I took some paracetamol thinking that the headache was punishment for having worked so late and so many hours without rest. Anyway, during what I called my sleeping shift, a sudden sharp pain in my back woke me up. I got up or I tried to get up but I could not. My legs would not move and they felt weak and heavy. I remember trying to lift my arm to grab the phone in order to call the wife who was at work, but I found that the left arm was in the same state as the legs. By now I was completely frightened. I was completely paralysed down the left side of my body. I had a massive headache, and there was a pain just below the rib cage. I phoned my neighbour with the good arm, who contacted the wife. She came home from work, and immediately phoned for the doctor. The doctor said that he had never come across these symptoms. He decided that it would be in my interest and his to get me admitted to the hospital to get it checked out. He was the first visitor that I had, and he kept on visiting me until they established what was going on inside my body.

I was first taken to the local hospital A&E, but I was then transferred to a specialist hospital in London, where they had all the testing equipment. Here they carried out many tests, such as MRI, CAT scans and spinal taps. The last test that the neurologists asked for was a myelogramme; this was the worst of all the tests that they put me through. However, it did show elevated CSF levels. The medical maestros ruled out MS, because this was the only attack that I'd had so far.

After many days of uncertainty, the senior neurologists decided that I was suffering from a condition called Transverse Myelitis. This was a complete shock to my system; I did not want anyone to get involved with me. I went into the deepest black holes. The neurologists were going to call the clinical shrink, but this was deemed unnecessary by the rest of the medical staff. I felt like I was the only person that had this terrible virus. I could not even call the illness by its proper name.

My dearest wife, Anne, then went and found all that she could on TM. We were lucky that she found a medical student that was looking into TM. He was brought onto the ward and was questioned for hours on the disease. At the same time, the doctors were pumping me full of steroids. I believe that it was predisalone. All that they did was blow me up in the face. They also fitted a fulltime catheter, which was later to change to a superpubic catheter. However, I kept on getting urinary tract infections. So by the time I was discharged, I was on the intermittent self-catheter, along with a condom catheter and leg bag to catch the drips, so to speak.

My bowels were eventually brought back, but nowadays it is controlled by diet. There are some days that I have to take matters into my own hands, but I have been doing this for so long, I have now got it down to fine art. I was given loads of PT

while I was on the wards, however, they were never able to get me up and walking again. I took my last walk on the 22 March 1989. The only thing that the TM now causes me problems with is pain, paralysis, and the bladder.

When the hospitals had completely finished with me, I went home. We were moved to a more suitable house in St. Albans Herts. After the diagnosis I became a sort of slough spud; I sat in the front room watching TV all day, yelled at the kids because the pain was so bad, and basically made everyone have a bad day along with me. In fact, I often told the wife to leave me and give me a divorce. Then one day, we had a massive argument and once again we went round the same track. Me moaning that I could not do anything for myself. We had no where to go, and my life was a complete bore, so to speak. I told the wife that I wanted to die. She then turned up and said, "fine, if you want to die then go ahead," and then gave me the morphine pills. Annie then went out and left the wheelchair outside. So, I got myself off the Loo (John) and went outside and dragged the chair in, with me lying on the floor. It took ages, but I did it. When the wife got in she was astounded that I had not taken the overdose. Annie said, "you did not finish what you planned to do; did you not have the bottle?" I responded to her that there was something worth living for. I have never been a religious-type person, but on that day, I'm sure that G-d had a purpose for me. Ever since that day, things have never got me down. I get depressed, but that is because of the pain and all of the other problems we have to put up with. That day I said, "I got this problem, and I can work round it." Also, from that day on, Annie has always let me ask her if I wanted help.

Much of my depression was rectified by a visit to a spinal hospital. My local occupational therapist showed me an article in a disability magazine; it was outlining the benefits of taking part in sport. Being an ex-service person, sport played a big part in my life. Therefore, I was able to channel all my energy and pain into rebuilding some sort of life for my family and myself.

Before my diagnosis I was a very sporty type person, who went for some running, and a little bit of swimming when I could find the time, but I was not the Olympic champion at anything. Perhaps I have started things rolling within my family now.

BEWSA stands for the British Ex-Service Wheelchair Sports Association. It is a national association and is part of the Royal British Legion that helps to fund the Association. It is quite similar to your PVA, with which BEWSA has grown great links. We quite often send a team to the PVA games each year.

I then went on to take part in the Leonard Cheshire Foundation Project that was called "Workability." The foundation was kind enough to give me a computer linked up to the internet, and I passed the course and graduated with a RSACLAIT which stands for the Royal Society of the Arts Computer Literacy and Information Technology. This is how I discovered the TMA. I also found out more about BEWSA and other wheelchair sports associations.

So, I went along to the spinal hospital, namely the famous Stoke Mandevale in Aylesbury. There I meet a chap named Wally Kelly. Now, this chap opened my eyes, and brought a little bit of light into my dullest days. He pointed out different types of sports that were available to disabled men and women. He also said that if I was to train regularly, there might be an opening to get me into national and international events. At the time I thought that he was full of hot air, but as the day progressed, I saw different disabled people all taking part in different sports. It was then that I realized there was something there to replace what I'd lost through my disability.

Then Wally showed me all types of equipment that are used by the disabled. There were throwing chairs, basketball chairs, and chairs for throwing the Javelin, which I thought in the hands of disabled chaps was a bit dangerous. I was then introduced to a chap named Geof. Now, I thought that I had problems. But Geof had more than anyone else did. He was away on exercise with the Royal Marines, and he was involved in a road accident. Because he had his legs on the dashboard of the landrover, he had both of his legs chopped off; one above the knee and one below. He also had massive internal injuries.

His sport was wheelchair racing. He had a chair that made my normal NHS wheelchair look like it was something out of the dark ages. He then went on about all of these major events in which he had taken part. He then mentioned how much BEWSA had helped him get over the bad days in his life. There was one thing that shocked me. Not once did he mention his disability. I thought I had problems, mine were nothing compared to Geof's.

Anyway, I signed up there, and paid my membership subs, which was

only £10.00. I thought that this was a good value. I then started to go away on training weekends. Here I was taught not only sporty trades, but I was shown how to transfer from a wheelchair to say a car seat. I was never taught this in the hospital. I then met up with Geof, and we got talking about wheelchair racing. Then the Association was kind enough to lend me a Bob Hall Racing wheelchair, along with a Bromakin Roller. The purpose of the roller was if the weather was on the British type, wet and windy, I would be able to stay inside a wheel whilst watching my neighbours. Then the team manager informed me about this race that was held in Germany, in a town called Bruggen. He thought that this would be a good start for my racing career.

Training Weekends and Race Preparations

Training weekends were held on a RAF base in the UK. For security reasons I cannot tell you where; I hope you understand. Here we were put through our paces by an ex-PTI who had broken his neck in a game of Rugby. And they say the game is safe. We were placed in groups where we completed different disabled sports, such as discus, shot-putting and javelin. We then had periods of intensive physical torture; it was like being back in the Army. Then once that was all completed, we decided what sport we wanted to continue and specialise in; this is when I chose wheelchair racing. We also did campaigning for better services for war veterans, like war pensions, etc. Then, in 1993, we had the Challenge 93. This was where many countries, including the USA, came across to the UK and took part in the first-ever disabled ex-servicemen games. These were held at the famous Stoke Mandevale Spinal Unit in Aylesbury UK. Of course, the team from BEWSA came in second to the USA. Unfortunately, I did not take part in these games because of a shoulder injury that had occurred during training weekends.

Before I competed in the Bruggen, it took many months of hard work, both at the RAF base and at home. I had to be self-motivated to get outdoors and face the fact that I had to do at least 8-10 miles each day. Then I had to go to the local gym, and take part in a rigorous training schedule that had been set up for me by the team manager. The biggest problems that I had were pain and my bladder. The pain played up when the weather was really cold and wet, but I had to get out and do something. The other problem was with the "water works" in that it would continue to empty. The doctors said the only thing I could do was split the condom catheter into two so I ended up having a leg bag strapped to each leg. This was necessary because I had to take on a lot of fluids during the race. I was also lucky, because my son also came out with me during the training periods. This then meant I had someone to talk to, which helped pass the hours that I was out. I also had problems with my legs. They would keep on spasming as I was pushing along. The spasms never threw me out of the chair, but it was another problem that I had to deal with.

As each week passed, I began to feel different in some way. I cannot explain what it felt like, but I do know that it made me think how lucky I was that I did not take the dreaded pills that day. I now knew that I had passed my darkest days. I still get depressed, but this is only because I cannot get out and do my training.

My Sport Career

Now things started to progress. Like I said, I had been given the chair and roller, and it was now my turn to change my life like my old mate Geof. Geof was kind enough to be my training coach for the Bruggen. Every time that I had a problem, he was there. I first got started by getting the chair to a dealer, who checked to make sure the chair was in a roadworthy state. Basically, I did not want the wheels falling off as I was going along. I was lucky, all I needed was some new tires.

Then I joined a local gym where I was able to pump some iron, and work on the cardiovascular part of the body. I used weight training to increase my upper body strength; the cardiovascular exercise was designed to make my heart work faster. This part of my training played up with the TM, because of the fatigue. However, the more times that I did the workouts, the easier it became to handle. It was nice to be taken as a normal person and be treated like one by other members at the gym. They started by asking if I needed help opening doors and moving equipment, but as the time went on, they saw that I wanted to be treated like the rest of them and they started treating me like they treated each other. In their words, I had to ask them for help. It was nice knowing that all I had to do was ask. After a couple of months, there was a new instructor who joined the gym. He was ex-service so he was able to give me some more valuable assistance. He even worked out with me. Then I started to take the chair with me to a local running track where I learned how to handle the chair under a type of protective curtain. I did not want to start my endurance training by taking the chair on the road, and I did

not know how to handle the chair and avoid going under the first car that I came up against. The way that Geof used to move in his chair, he made it look so easy. But when I got in mine, believe you me, it was not easy. You have to make sure that the chair is always running straight, and that you are pushing the wheels to get the best out of the chair. I had problems getting into mine, because my legs would not bend. This caused me some severe pain and discomfort. Even today, they play up. But like everything else, you learn to take the bad with the good.

After going on the running track, I ventured out onto the roads, and then I hit a snag in my preparations. Nobody told me that I needed public liability until a policeman stopped me. But this did not cause too much of a headache. I then carried on pushing with this new piece of paper in my pocket. I then increased the amount of miles that I did in each push. Some days it would be eight; some other days, it would be about 10 or 15 miles. This roadwork was incorporated with my gym work. After a couple of months, I was really keen to get outside and get the wheels moving. It was like it was taking over my life. The wife also mentioned that I was a different chap to live with and the kids backed her up.

I then started a new venture; I went flying. There is an association called the British Flying Club for the Disabled. Their aim is to get as many disabled people flying as they are able. I went one day in August 1999. Although I found it great fun, it did not give me the same buzz as the racing, though it was nice to see the wheelchair on the ground as we took off into the Oxfordshire skies. I was sent a form to apply to go to either South Africa or California to learn to fly solo. For now, the wheelchair racing is my priority.

After the flying, I had completed the Workability Project. I had taken the word-processing, spreadsheet, and online communications examinations. I was then awarded the RSA certificate. I then started a new course called the European Computer Driving License. This was a computer course run by the British Computer Society (BCS). I continue to plod my way through this course; it is longer than the Workability Project.

So, from then on, I was always busy either sitting behind a computer with my head stuck in a book, or I was stuck into pushing a wheelchair around the streets of St. Albans. It is nice because people often remark at the difference in me.

Anyway, the training for the Bruggen continued for many months. There was a combination of swimming, weight-training or pushing the chair. Then in March 2000, it was time for the last push. Geof had told me, that one month before the race, I should only train 3 days per week. Now, this was a big culture shock. My body had started to get used to going everyday. But I had to listen to Geof; he was more experienced than me.

So, on the 11 April, I took off for Germany. The race was planned for a Saturday morning, and it was being held on a RAF base in Germany. There were loads of able-bodied runners and there were just as many wheelies. The race started at 11:00 AM. Because I was a novice and I was not the only one, we were allowed to start at least 30 minutes before the rest of the pack. It helped a little, but not a lot. I was going fine. The legs were causing a few problems, but not as bad as I thought that they were going to be. I settled myself in behind another chap, who I had been drinking with in the mess the Friday night before the race. He had lost both of his legs in the Falklands War. I got to the centre of the town and was going to approach the last corner when I heard this sudden "hissing." I had four miles to go and I had picked up a puncture. What bad luck I heard the crowd say. I would not let this get the better of me. So I put all my weight on the bad wheel. This made the air in the good one inflate slightly; this would help me to get to the end. It did but in a longer time than I had hoped for. I went home on Monday, completely satisfied. I had completed something that the medical people thought that I would never accomplish. Even my own Doc did not think I would finish. I was not in the first group, but I was not in the last.

My next race is the New York City Marathon in November. But first me and the wife are going on Holiday for a week. On my return, it all starts again. Watch this space; I'll keep you posted on my progress.

Mel
mel@mcorley.freeserve.co.uk
St. Albans Herts England UK
April 26, 2000
This letter has been a long time coming. Please be patient with this long drawn out story! A year ago I was trying to decide if I should continue my education after earning an Associates Degree from our local junior college. The university I would attend was difficult to navigate and the major I wanted to go into was one that I was sure I would be discouraged from trying to earn. Fortunately, Social Workers are the kind of people who like to

Life After TM: Finding the Light and a New Career at the End of the Tunnel
Darlene Maynard

help people. The head of the department surprised me by telling me that I was perfect for the department within five minutes of meeting me! As we discussed the courses I would take, I brought up my concerns about navigating the campus and before I realized what had happened, she had a former student on the phone and I was talking to her and making an appointment for that very same week. Before the week was over I would be registered for fall classes, I would have a peer counselor, and I would reapply for Vocational Rehabilitation Services. As I said, Social Workers like to help people and they do not fool around when they are able to help someone!

First, my peer counselor. I hope that you and everyone with transverse myelitis have heard of The Centers for Independent Living! I had not until that day and I really could have used these people long before now! The first time I talked to Beth, I knew she was special. She was bright and bubbly and so easy to talk to. When I met Beth for the first time, well, she looked like her voice. Beth has a rare form of muscular dystrophy and uses a wheelchair but that is not the first thing you notice about Beth. Her face reflects everything you hear in her voice. She has very short, gray hair, and she just shines. I don't know how else to explain it. Our first meeting lasted at least two hours. Did I mention that Beth likes to talk? We talked, we laughed, and we cried, and we talked some more. I was exhausted by the intensity and range of the emotions I went through in that two-hour period. We made an appointment for the following week and again a two-hour session with the same results. Now, here I have to mention that I have suffered from depression a few times over the years but the last time was the first time I had been on medication. I truly believe that if I had had someone like Beth from the beginning, I would have had less trouble with depression over the years. Beth had already been through **everything** that I was going through and I believe it was difficult for her to relive it all, but she did for my sake. Well, maybe for both our sakes. As others that have had a disabling disease, we endured the stares, and rude comments, thoughts unlike "normal" people ever have cross their minds, the struggles just to keep up, and finally, being yelled at for using handicapped parking spaces because we look too young to have a disability! But that was not all Beth did. She helped me realize that by using a wheelchair or scooter, I would become more independent. There were trade-offs to be sure. And then she accompanied me to the wheelchair clinic at my request to be sure I was given the best recommendations possible because I was too emotional to think very clearly.

Beth was also my advocate and encouraged me to reapply to the state's Vocational Rehabilitation Office for assistance in earning my degree. My previous attempt was not what it was supposed to be, but this time I had someone who knew what I was entitled to and counseled me on how to handle unanswered phone calls and one delay after another. As a result, I am now attending the University of West Florida, I am using a scooter, I am getting my tuition and books paid for, and they helped pay for the lift in the van I use and the balance that my insurance did not cover on my scooter. My life compared to a year ago is completely different. For the first time in years, I look up as I "walk" (on my scooter). I don't have to worry about falling anymore! I get from one place to another so fast, it still amazes me. I love my scooter and the freedom it gives me. My grades are great. I love the people. Social Workers are great people but their only fault is that they try to help too much sometimes. I have yet to open a door by myself at school! It's either the automated doors or a fellow student. I have never enjoyed life as much as I do now. I am much more active than I ever thought I would be at this stage of my life. I had thought about the time I would be in this condition. I knew it would happen. I just did not expect it to happen this soon. But, now that it has, I am surprised to find myself enjoying life so much. My daughter, who is nineteen, cannot believe how much I do. I volunteer at The Center for Independent Living of Northwest Florida. I'm also a Board Member. I just finished my junior practicum working 120 hours this semester at Sacred Heart Hospital. I mentor a first grader. Oh, and I go to school full time. This is the time I thought I'd be spending reading, watching TV, just enduring the last few years of my life; and I am so glad it doesn't have to be that way.

The most important part of this whole story though is that Beth knew someone with transverse myelitis and she had your website address. Why is this so important? March 2, 1962, this nine-year-old little girl woke up one morning paralyzed from the waist down. As well as I had recovered and had kept my spirits up, there was always something missing. I thought it was

because we were an army family and there was no extended family around for support, but that was only part of it. I did have uncles that came to check on us, even in Germany. We were transferred to Fort Sam Houston, Brooke Hospital in San Antonio, Texas after a couple months and it was there that I found two other people who had transverse myelitis. One person was a woman who had a three-month-old baby and by then they knew she would be paralyzed for the rest of her life. The other person was a young GI. He was just beginning to get some feeling and movement back but I don't know how successful he was. I was lucky. I was able to walk again and I do not have the pain that I've read so much about. I do have the usual bladder dysfunction so many of us have though. Now my deterioration is due to age and the length of time my muscles have worked so hard to help me keep up with the "normal" people. But, last year around this time, I found out that I was not alone. I was shocked by my reaction to finding out that there are so many other people like me. I was so overwhelmed that I could not reach out to anyone or really share how I felt with anyone. I tend to keep my feelings to myself probably because I've felt like I didn't belong, even with my own family (mother, brothers, and sister); I never felt they really understood. They didn't, how could they? Now, a year later, it was all topped off by the most recent newsletter with your editorial and, again, I could not get over the feelings of having someone who knows how it feels to feel so useless. During my last depression, the only reason I could not contemplate suicide was my children. I simply could not do that to them. Even more than that, though, I have never put into words or read anyone else's words describing how it felt to worry about going out in public and having to worry about gas, because my sphincter does not work properly, or having an accident, which happened all too often as a child in elementary school before all the wonderful products they have now! How many people know what it's like to worry about falling? I don't need a crack in the sidewalk to cause a fall, my own feet will do that! Depression, I don't even want to think about how bad it was, I want to enjoy how good I feel now. Although I am always on guard for those awful symptoms! Your points about needing to talk about all these things are exactly why I want to be a Social Worker. They are exactly why I want to work with children with disabilities so they don't have to go through all this alone. There is a better life out there for people with disabilities. There is happiness to be had and a life to enjoy.

A couple years ago, I took a class in communication and the instructor had us play a game where we would name a person to match the color she named. I took this little test home and did it with my own children. My daughter chose me for the color yellow which really surprised me. When I asked her why she thought I was yellow, she said because I was so sunny and cheerful. Well, my depression had gotten much better, but I felt anything but sunny and cheerful. The way my daughter saw me touched me so much that when I choose the color of my scooter, I chose a bright yellow! It's a reminder to me now not only of how she sees me, but it reminds me to be cheerful. A really nice side affect of the bright yellow is that it makes people feel more comfortable about approaching me. I cannot tell you how many comments I overhear from people who think it's great. I even had a security guard at the hospital stick his thumb out as if hitchhiking.

I hope this hasn't been too long or too boring. What I hope is that people can see that even with a disability, life can be very satisfying. Our attitude makes such a difference. I know it is a struggle to stay UP but it can be done. It may have to begin with medication, but counseling is vital so when you can get off medication, you can stay UP by yourself. Sometimes you have to stay on medication and that's okay too. I can't say that traditional counseling doesn't work, because it does. But at some point, a peer counselor, someone who really knows what you are going through, helps so much more than a regular counselor ever can. I will graduate in a year and I hope I will not have trouble finding a job like most people with disabilities do, but I will not regret any of this time I have spent earning this degree. I truly hope I can repay all the people that have helped me get to where I am today. And I especially want to thank you all for being there and letting me know that I AM NOT ALONE!!

Sincerely,
Darlene Maynard, Pace, FL
Darlene.m@mindspring.com
Netta's paintings are shown with Sam's poem. The cloud, El Nino, was painted in February 1998 (acrylic on canvas; original size 25 cm x 20 cm). The birds were painted in June 1998 (acrylic on canvas; original size: 25 cm x 15 cm). The paintings are wonderful – Netta is wonderful! To see these paintings in color and to see her other paintings, please go to Netta's web site: ***http://go.to/netta***

My name is Netta Ganor and I am 20

Thief In The Night

I never asked you in, thief in the night
Slowly, silently you came
Stealing each day a bit more of me
Fingertips then fingers
Hands, wrists, forearms
Like a giant "What`s this" game for a child,
You named
And claimed
Parts of me.

Hands which once held a pencil to capture another`s image
Held a pen to share a thought
Hands which threw a lightning bolt to start a dying heart
Or stroked the cheek of one I loved
You named
And claimed
Parts of me.

Feet and legs which danced on air
One with music, became the music
Feet and legs which danced with a mountain
Pine and snow and sky unending
Feet and legs which ran with my children
Laughing, racing, catching, cuddling,
You named
And claimed
Parts of me.

Energy and motion
Whirling here and there
Checklists conquered
Activities deftly balanced and moving
Like a juggler tap-dancing in the street
Even this you took, uninvited guest
Leaving only bone-drenched fatigue
Where to cross a room is a victory
You named
And claimed
Parts of me

I never asked you in, thief in the night
Or asked for the gifts you brought and left me with
Claiming the stillness of my arms and hands:
Leaving a thrum
Constant buzz,
Rippling like a stone-thrown lake
At any tender touch or gentle breeze.
Freezing burning evening gloves of pain
Sunburn from no friendly sun
And dancing now only with the Earth, as I fall to greet her.

And yet
Unwelcome guest, thief in the night,
You have not claimed my self, the heart of me
There is a room you cannot enter
A claim you cannot make.
I draw
Though it be shakily
I write
Though it be with my voice
I dance
Though it be in my heart
I touch
Though it be with my cheek.
And I live, and laugh, and love
Though it be with the pain.

I have you, uninvited guest, thief in the night
But you do not have me.

Sandra Sam Melville
Boston

The Painter: Netta Ganor
Israel

years old. I am a c-4/5 quad from Israel. I was struck down with Acute TM on November 25th, 1994, at the age of 15. It all started one Friday afternoon, after I came back from school. After lunch, I suddenly started to feel a terrible sharp pain in my upper back (behind the shoulders). Gradually, but quite fast, in less than one hour, I lost sensation and the ability to move my hands and finally my legs. My mother immediately called an ambulance, which took me to the hospital. I was taken to the IC department and was diagnosed after 10 days with Acute TM at c-3. Of course, I was ventilated. After three months, more or less, I saw the first improvement; my left arm started to move. Gradually, in the next one and a half years, I got rid of the vent due to hard work in exercising my breathing muscles. After spending more than two and a half years in the rehab hospital, we all had to move to a new house, and that included leaving our city, Jerusalem, in order to be geographically closer to our family.

Today, I still have no sensation from the shoulders down, including my arms. I move the left arm without feeling it. I'm driving a motorized wheelchair, paint and write with my mouth, swim(!) with my head and shoulder movements and do things that people are not supposed to be able to do in my physical condition. I'm very optimistic as for my condition in the future. I don't know what will happen with me or when. I do know that others with TM have had improvements that are measured in years. I've never lost hope and I'm sure that someday in the near future the medicine will find the right cure to our syndrome.

In the meantime, I'm trying to do the maximum I can to make my life as normal as possible. I just don't see any point in sitting around the whole day and mourning. Currently, I'm a second year student for Computer Science at the College of Management in Rishon Letzion. I'm still a fan of sports (especially basketball) and stayed an athlete in my soul :-) I was a tennis player and an athlete in high school.

After one year of being disabled (back in 1994-5), and after watching some other quadriplegic people painting with their mouths, I decided to give it a try myself. It was very hard at first, but as the time went by and with a lot of practice, I learned how to paint this way.
I was the busy mother of two young sons; den mother, soccer and T-ball coach, wife of a physician, and nurse practitioner providing primary care to over 100 elders in ten nursing homes when I began to notice numbness in the fingertips of one hand. Over a period of several months, I noticed the odd numbness and tingling spreading up my arm. Then I noticed the same thing happening on my other arm. Electric shock sensations shot down my arms, if I flexed my neck or coughed. One neurologist I consulted brushed me off, ordering no tests and insisting this would go away

The Poet: Sandra Sam Melville
Boston

without treatment. My handwriting deteriorating, unable to type because of the numbness in my hands, unable to feel the skin of my patients, I knew this could not be right. When I tried to play catch with my son and couldn't move or feel my arm, I knew something had to be done. With the support of a neurologist friend, Dr. Christopher Martino, and my primary care physician, Dr. Leonard Finn, I was referred for evaluation at St. Elizabeth's Medical Center by neurologist Michael Hayes, and on May 23, 1997, my diagnosis was confirmed as acute transverse myelitis. On that day, my life changed forever.

I responded well to IV and oral steroids, but was unable to come off of the steroids. I was one of those with ongoing, smoldering TM. With every effort at weaning me off of the steroids, my symptoms worsened, and by December of 1997 I could barely walk. I fell frequently, once cutting my mouth so badly that stitches were needed. I had severe spasms, if I extended my arm, or tried to open a twist jar, and I didn't have enough strength to open a pop-top can of soda. Cytoxan helped tremendously, stopping the progression of symptoms, and I began to reclaim a little of my life.

There have been many ups and downs, as other autoimmune disorders struck. I developed severe low blood pressure, and inflammation of the eyes. I was found to have an unstable cervical spine, with the bones putting pressure on the spinal cord. I required surgery, with placement of delicate screws and plates to prevent further spinal cord damage. Multiple medication adjustments have been required to maintain function at a livable degree. In order to live a "normal life," I take 30 some pills daily, and intravenous immunoglobin every four weeks. Today, I have some degree of function of my hands and arms, and can maintain my home and family with outside help doing

housework and laundry. I plan my activities carefully, with rest as needed. I can walk well for short distances, but use a cane or stick for long distances. I have tremendous support from my husband and sons, and other family members. I count myself fortunate in my abilities. My life is changed, but it is good. And TM does not have me.

The Transverse Myelitis Support Group is a group that developed in Australia, based in Brisbane Queensland to provide information and support to individuals with Transverse Myelitis, their caregivers and families. The Second TM Awareness Day meeting was held at the Paraplegic and Quadriplegic Association, Kangaroo Point, Brisbane, Queensland.

The Paraplegic and Quadriplegic Association of Queensland is an organisation that provides services and support to people with spinal disabilities including quadriplegia, paraplegia, post polio and transverse

AUSTRALIA
Transverse Myelitis Awareness Day: 17 May 2000
Penny Beeston
pbeeston@pqaq.com.au

myelitis. I am manager of community services in the organisation and my major role is to develop support groups and member networks across Queensland in response to our member needs. These groups are all convened by people with spinal disabilities. The Transverse Myelitis Support Group commenced about two years ago at the request of Ian Hawkins, a member with transverse myelitis. Ian is the convenor of this group. We do not have a large number of people on our database with TM, however, those members with TM are keen to see the group develop.

Through its post polio membership this organisation is used to dealing with the problem of raising awareness of a little understood condition. In Queensland the medical profession is sadly lacking in knowledge and understanding of post polio. TM is another such condition.

This year the group invited Dr. Tim Geraghty, the new Director of the Spinal Injuries Unit, at the Princess Alexandra Hospital in Brisbane, to give the Second TM Awareness Day lecture to our members and staff. Dr. Geraghty informed those present that he was not an expert on transverse myelitis and that his specialty is rehabilitation. Dr. Geraghty gave an address on TM and the impact of the disease. We are pleased that he is prepared to take transverse myelitis on board and pursue an interest in the condition.

We had an audience of about 25 individuals. Twelve of the people had transverse myelitis. Some had traveled from regional Queensland and one had traveled nearly 1,000 kilometres to attend. We had a bar-be-que after the address and people came together in an informal group to share experiences. Queensland is a very large state and many of those on our database are spread across enormous distances. The woman who traveled up from New South Wales to attend has a child with Transverse Myelitis and she had attended the Seattle Symposium in 1999. After lunch she spoke to members about her experience.

Our Community relations Manager at the Association did a large media release for TM Day. We also developed posters for TM Day and had them distributed in various General Practitioner's rooms, Community Health buildings and hospitals.

People who could not attend the awareness day meeting will receive copies of Dr. Geraghty's address in our newsletter and videotapes will be available from our library. We recently forwarded copies of the TMA newsletters to all those in Australia who are on our database. Errol White, a member of the TM support group, provided us with the originals.

In 1999 the Association registered the name Transverse Myelitis Australia and all mail we send out goes to members across Australia who we have on a separate database. The Association has Member Networks and there are local and regional forums throughout Queensland where all members (including members with TM) come together around issues that are impacting on their lives as a result of living with a disability. This includes issues of access to services and the environment (built and natural), health issues, and equipment issues. These are very dynamic gatherings and provide great linkages with all members across a large state. As an organisation of 40 years we take a long-term view to raising awareness and build on each awareness campaign the following year.

National Radio Interview (RTE) with Pat Kenny

Hello to everyone and greetings from Ireland. On Monday May 8th, RTE Radio Telefis Eireann, which is our National Radio and Television Service, came to my hometown,

Westport, to stage a public awareness meeting on "the Future of Broadcasting in Ireland." These meetings, which are being held at various venues around the country, are part of a strategy by RTE to promote their station and to get public opinion on the programs

IRELAND
Creating TM Awareness
Ann Moran
annmoran@gofree.indigo.ie

being shown and listened to on RTE. I went along to the meeting because, since returning from the TMA Symposium in Seattle, I have wanted to get some awareness out there into the public in Ireland. But I had not done anything about it and had become annoyed with myself. So, when I discovered that RTE was coming to Westport, and that Pat Kenny was also coming, I just knew I had to go to the meeting. I must explain now about the RTE people who were at the meeting. There was a panel of six people who were producers and/or presenters of programs, both on TV and radio. Other reporters and presenters from the west of Ireland were also in attendance. But the most important person was Pat Kenny. Pat is one of RTE's, most popular presenters. He hosts a weekly TV program of chat and entertainment called "The Late Late Show." He also does a radio program called "Kenny Live." Pat is such a pleasant person, and I found him easy to talk with. He is well liked here.

I am not so great about speaking out and was just going to see one of the producers after the question and answer session. But then I got to thinking; that was the wrong way to go about it. So I got up the courage to raise my hand to put a question to the panel of producers. I explained about how I had acquired this disability and I described TM. There was great interest. By talking out at the meeting, I made all of the people there, around two to three hundred, aware of TM. Pat was actually sitting in the audience, just two rows from me. And when I told about my disability and a request for an awareness program interview, Pat turned around straight away and said that he would certainly do it and that I was to talk with his producer after the meeting. Pat did come and talk to me himself afterwards, as well. He was very interested. He asked me, "so this could happen to anyone, even me?" I told him that TM knows no age or class differences. It can happen to anyone.

An interview was to be set up for the following week. We uncovered another 'awareness' problem. The studios, which are about eleven miles from me, were found to have three flights of concrete steps up to it. I guess that no one volunteered to carry me up as they put the interview off until the next week, and I was asked to travel to Galway, which is 52 miles from me!
Since then I have also done an interview with one local radio station, a lot of which was about disability and I did get a plug in about TM.

Well, I had my "few minutes of fame." I did the interview on the morning of Wednesday, May 24th. All went very well, and I found that I didn't have enough airtime to tell all of what I had planned! I only had about twenty minutes. I had a whole pile of notes on the table in front of me, and I didn't get to use any of them. I had butterflies on the journey to Galway studios, which is about 50 miles from my town. Anyway, I kept quiet calm. My daughter taped the interview for me, and when I listened, I couldn't believe how confident I sounded. My other daughter, who is a reflexologist, was working on a local bank manager (doing reflex) when the interview came on the air, so she asked if he would mind if she listened to it while working. He was interested in hearing it also. Afterwards, he said how articulate I sounded. Okay, Okay, I'll stop being big-headed!

There were a few calls into the studio before I left, so I was able to take them. I got home around 3 PM and spent almost all of the rest of the day, until 10 PM, on the telephone answering calls about TM. I had the same feelings with some of these people, just how we all felt in Seattle when we met; the sheer relief of having some other person to talk to who knows and understands how and what you feel like. I even had a call from the Rehabilitation Centre from a lady who had been recently diagnosed. We spoke for almost an hour. I think it was also a relief for her. They had not told her much at the hospital where she was diagnosed, and had sent her on to rehabilitation. Thursday was full of many calls also. It feels so good to be able to help others, and particularly thinking back on my own experiences. I also spent a lot of time on the telephone on Friday. I have been contacted by 28 people. I have given all of these people the address for the TMA and also the tmic. For those who do not have access to the Internet, I will be sending them information about the TMA. I will be keeping in touch with all of these people.

Center for Independent Living

In 1991/1992 a Center for Independent Living was started up in

our capital city, Dublin, with the help of a lady from, Berkeley, California. She had been in Ireland on a holiday and could not believe how people with disabilities had to cope with everything. She went home and was thinking about Dublin all the time, so eventually she returned the next year, gave up what she was doing in Berkeley, and helped to set up the first Center for Independent Living. The Dublin Center was working very well. She then decided to open two more Centers across the country, one here in Mayo, the other in Clare.

Mayo Center started up in May of 1995 and I joined them in June of that year, as a Leader Coordinator (name given to the person with a disability). My duties were to visit with all the people who wanted to be part of a Center for Independent Living (CIL). Becoming a participant in a CIL offered a person the opportunity to work with a Personal Assistant who would assist them in living a more independent life, and also help to take some pressure off of their families. We were able to get Personal Assistants into the Cheshire Foundations (Institutions). This caused a few problems at first with the staff in the homes, but now it is acceptable. The Personal Assistants have helped to provide a new lease on life to a lot of people; people who have often not had a say about their lives, or never been outside an institution, or had always been told what they could and could not do. We have two Personal Assistants in Mayo.

There were also people who lived at home, and were cared for by their families. Many of these people also lost a great deal of their independence, becoming very dependent on their families. As a result of the Centers for Independent Living, many of these people have had a chance to become part of society. Some have found part-time work. Having the opportunity to leave their home environments, get out into their communities, and see how other people live their lives, has made such a difference to many.

There was a 22-year-old man who had always lived at home and rarely went anywhere. When I first started to visit him, I could barely hear him speak, because he was so shy. I would have to coax him and keep asking him questions just to be able to get him to talk. Two years later he really surprised me by giving a thank you speech to our Program Manager. It was short but it was such a joy to hear. He now works three days a week and lives in an Independent Living Unit on the grounds of a Cheshire Home. He has complete control over how he lives his life.

Things are still going very well with Centers for Independent Living. We have an on-going battle with the Government to make permanent funds available for this very necessary service, one which is considered a norm in other European Countries. At the moment it is run on a Community Employment Scheme, which means that people who want to become a Personal Assistant have to be unemployed for a year before they can take this job. Also, when they have completed a year working, if they are less than 35 years of age, they again have to relinquish their roles as a Personal Assistant until they are unemployed for another year. The Leaders (PWD) then have to find another PA. This can be very distressing for some people, as they have gained trust in this person, and they now have to start over with a new PA. I, myself, had to leave the scheme after three years. I have just started back with the group about five weeks ago. I do a lot of my work from home. I am able to work out my own time schedule and try to visit everyone at least twice a month. The rest of the time we keep in touch by telephone. As Mayo is a large county, and the roads are not good, it can take an hour and a half to travel fifty miles. I sometimes have to do more than one hundred miles in a single visit. We are currently working, along with other disability organizations, under the flag of Disability Federation of Ireland (DFI). I had a meeting Tuesday with my Program Manager, who has asked me to apply to DFI to form a Support Group for TM. This was wonderful news, as I may be able to get a little funding to help with phone calls and postage. It will give us an opportunity to appeal for funding for TMA and will also create more awareness about TM.

Stars For A Brighter Future: Raising Funds for TMA

I am making a quilt in order to raise funds for the TMA. I announced this project on the TMIC by requesting that people make blocks of 12 and a half-inch square depicting stars. Any star pattern will be acceptable. The colours I have chosen are predominantly blues and creams. I have chosen to name the quilt "Stars For A Brighter Future."

It was suggested on the TMIC that the Quilt be auctioned over the Internet. This is a good idea, but if I am going to pursue this approach, I will need assistance from someone who has had previous experience in doing this type of auctioning. Another option would be to hold a raffle for the quilt. We will have plenty of time to think about this, as it will take a while to get it together.

Members of my quilting group have offered to help me to sandwich it and get it ready for quilting. I will takes pictures of the quilt when it is completed and will send them to Jim to post on our web site for everyone to see. If you would like to contribute a block for the quilt, please contact me via email. I would encourage as many people as possible to participate in this project. I would really like for this to be a truly international quilt by having it composed of blocks from our TMA members from all over the world!

My best to everyone,
Love, Ann, in a rainy Westport
annmoran@gofree.indigo.ie

On Saturday, May 27, 2000 the third meeting of the New York Transverse Myelitis Awareness Group was held at Ben's Delicatessen and Restaurant in Bayside, Queens. The luncheon, support-group meeting marked the first anniversary of the New York State Resolution and Proclamation of Transverse Myelitis Awareness Day. On this special occasion, fifty persons attended the meeting, including TM members and their families and friends from all over the New York region. Some of the attendees traveled from as far as Newark, New Jersey and Madison, Connecticut.

Dr. Douglas A. Kerr, a co-director

NEW YORK
NY Transverse Myelitis Awareness Group Meeting
Pam Schechter
(718)762-8463

and distinguished neurologist at Johns Hopkins Transverse Myelopathy Center at Johns Hopkins Hospital in Baltimore, MD had kindly consented to be our guest speaker. Fortunately for us, he was able to attend the meeting because he had a previous engagement in the area.

The meeting began with introductions; I wanted Dr. Kerr to meet our NY TMA members, and some of the attendees were meeting each other for the first time, as well. After the luncheon, Dr. Kerr began his formal presentation. He opened his remarks with a description and anatomy of the spinal cord and the definition of TM and how it effects the spinal cord. He discussed the four major symptoms associated with TM, which include weakness, numbness, bladder and bowel dysfunction and pain. His comments were a general overview of the disease before getting to the more specific aspects he wished to discuss.

He remarked that most patients with TM have spasticity while a fair number of them also have pain due to the illness. He further commented that both symptoms may interfere with recovery and with quality of life. He explained that spasticity often makes it harder to move about or to use one's extremities in a coordinated way. Many medicines are prescribed for these conditions, but unfortunately, he said the doses may be inadequate or in suboptimal combinations and have troubling side effects, such as fatigue. He went on to say that at Johns Hopkins, a novel approach is employed and may be appropriate. A small catheter from a subcutaneous pump is inserted directly into the fluid space which bathes the spinal cord. This method can administer medicines directly into this fluid either for pain control or for relief of spasticity. The medicines do not travel throughout the body and so there are fewer side effects. Patients frequently report good to excellent results and wish they had started using the pump sooner as a means of pain/spasticity management. Dr. Kerr also emphasized that this procedure should be done only by experienced doctors or at large hospitals and/ or a major university.

Dr. Kerr explained that TM is mostly a one-time occurring illness unless there is an underlying condition, such as Lupus or Multiple Sclerosis and then TM can become a relapsing or reoccurring condition. He categorized TM as an auto-immune disorder which occurs when the anti-bodies produced by the immune system to fight foreign substances or viruses, instead attack the cells they were produced to protect causing focal inflammation at one level of the spinal cord. Dr. Kerr said that TM can happen at any age and nor is it gender or racially specific.

Dr. Kerr then posed a question for the group. He asked, "how many patients were diagnosed with TM at the onset of the illness versus how many were diagnosed much later?" At least half responded to a later diagnosis. He explained how we can better educate our doctors to TM by providing them, for example, with information from the Johns Hopkins Transverse Myelopathy Center website or the TMA website. Dr. Kerr feels very strongly that you should not remain with a doctor who does not take an ongoing concern and interest in providing you with the best and latest treatments for TM. At this point in the discussion, many members who had come especially prepared to ask Dr. Kerr general or personal questions about TM proceeded to do so. Some questions concerned the use of the subcutaneous pump and who might

benefit from it. Dr. Kerr replied that the pump would only help those where the inflammation effected the lower extremities. He said it would not benefit those with shoulder and hand involvement. Another member wanted to know if new treatments or drugs would help those with a long-standing TM condition. Dr. Kerr replied that, yes, it would also help and benefit those who have had TM a number of years. One of the members told of taking a prescription drug to lower her cholesterol, but instead worsened her TM condition. Dr. Kerr explained that you have to be very careful about the prescription or over-the-counter drugs you take because some of the side effects may cause muscle weakness. Other questions were about whether vaccinations or flu shots can cause TM. Dr. Kerr said it was possible although he didn't know of any studies being done to support this. An unusual question asked by a concerned parent of a seventeen-year-old daughter who had TM for two years was if there was a possibility that, as happened in her daughter's case, temperature sensitivity could be lost on one side of the body. Dr. Kerr replied that this was possible but quite rare, because temperature sensitivity loss usually effects both sides of the body. Another interesting question was posed, "Is there a difference between the lesion of TM and that of MS as seen on an MRI?" His answer was, "No, under a microscope, the lesions would look the same." Another member asked whether after six months or longer, would scar tissue show up on an MRI to indicate the presence of TM. He replied that, yes, it can depending on the damage done to the site. Generally, Dr. Kerr stated that, for example, a somato-sensory evoked potential test, urodynamic testing for impaired bladder function, spinal taps done to show any inflammatory response, will come up positive for TM. He also suggested seeing a neurologist who specializes in MS or demyelinating disorders. In order to follow Dr. Kerr's presentation, each member received comprehensive literature obtained from the Johns Hopkins Transverse Myelopathy Center Website. There was literature thoughtfully supplied by Debbie Capen, a TMA Officer, which included a guide to disability rights laws, TMA brochures, and a news release about the TMA celebration of five years of service.

The consensus of the members was that this meeting was a great success. Our special thanks to Debbie Capen, Secretary of the TMA, for coming all the way from California to attend our modest luncheon and especially for bringing her delightful friend and companion, Lori Biehler with her. We wish particularly to thank Jude Dudow for the tremendous job she did in helping us organize the meeting and performing all of the tasks necessary for a successful meeting. Our thanks to all of the TM members who came to the meeting and asked such thoughtful and pertinent questions of Dr. Kerr. And most of all, our heartfelt thanks to Dr. Douglas Kerr for his generosity, kindness and incredible knowledge that he so willingly shared with all of us. Participants in the TMIC had been expressing a need to follow on Pam Schechter's lead in New York and request our state legislatures to designate a TM awareness day in states around the country. In deciding the appropriate date, we, again, followed Pam's efforts and attempted to have June 6th be identified as TM awareness day. I approached my state representative with this request. By Concurrent Resolution No. 74, the Ohio General Assembly has recognized June 6, 2000 as Transverse Myelitis Day in the State of Ohio. The Resolution was sponsored by Representative

OHIO
June 6, 2000, Transverse Myelitis Day in Ohio
Richard J. Boyle

Ron Gerberry from the 65th House District. The purpose of the resolution is to heighten the public's awareness of TM. It recognizes the serious need we have to educate the public and the medical profession about Transverse Myelitis. The resolution also recognizes Rachel Dorocak. Rachel contracted TM when she was six months old. Rachel celebrated her first birthday this past March. Her brothers, Kevin and Matthew, initiated the Reading for Rachel Program to honor their sister. The resolution recognizes the wonderful efforts of the Dorocak family in raising money for TM research.

When Rachel first got sick last October, we were in such a state of shock and sadness for our baby girl. She was only six and a half months old when TM struck, right when she was just beginning to become mobile. Life had been so good, and overnight all that changed. At the beginning we saw improvements come very quickly and so we were very hopeful for a recovery. But Rachel's progress slowed and we really had to face the reality of our situation and as a family we wanted to do something positive for Rachel and for others who have Transverse Myelitis. More than anything, we

THE GENERAL ASSEMBLY OF

THE STATE OF OHIO

H. Con. R. No. 74

REPRESENTATIVE GERBERRY

Recognizing Transverse Myelitis Day, June 6, 2000.

WHEREAS, The members of the 123rd General Assembly of Ohio are pleased to recognize Transverse Myelitis Day in Ohio, June 6, 2000; and

WHEREAS, Transverse Myelitis is a neurological syndrome caused by inflammation of the spinal cord, and it may occur in isolation or in the presence of another illness. Symptoms include back pain, numbness of the lower extremities, and headache, with the eventual outcome of paralysis, sensory loss, and bowel and bladder dysfunction, and recovery may take months with no guarantee of improvement. TM is extremely rare, yet it is estimated that 34,000 people in the United States currently suffer from this debilitating condition; and

WHEREAS, While spinal cord injuries have been well-publicized lately, Transverse Myelitis is often overlooked since many medical professionals are unaware of this condition and of the needs of patients with TM. If the condition were more widely recognized, diagnosis and further scientific research would benefit those who suffer from TM; and

WHEREAS, On October 9, 1999, at the age of six and a half months, Rachel Dorocak awoke paralyzed after a couple of days of cold-like symptoms, and, after extensive testing, doctors determined that she had Transverse Myelitis. Although she can now move her upper body, Rachel remains paralyzed from the waist down, and her prognosis is uncertain. With the help of the Transverse Myelitis Association, a non-profit organization that is seeking ways of increasing awareness of TM, Cathy Dorocak, Rachel's mother, and her young sons, Matthew and Kevin, launched the Reading for Rachel program in March of 2000, an initiative in which schoolchildren get sponsors to donate money to the TMA for each book they read or that is read to them by their parents, in honor of Rachel's first birthday; therefore be it

RESOLVED, That we, the members of the 123rd General Assembly of Ohio, in adopting this Resolution, recognize June 6, 2000, as Transverse Myelitis Day in Ohio and urge all citizens to learn about this condition in order to aid and support those who are affected by it; and be it further

RESOLVED, That the Clerk of the House of Representatives transmit duly authenticated copies of this Resolution to the Transverse Myelitis Association, to the family of Rachel Dorocak, and to the news media of Ohio.

ADOPTED

May 30, 2000

ATTEST:

OHIO HOUSE OF REPRESENTATIVES OFFICIAL

SPEAKER OF THE HOUSE OF REPRESENTATIVES
JO ANN DAVIDSON

PRESIDENT OF THE SENATE
RICHARD H. FINAN

CLERK OF THE HOUSE OF REPRESENTATIVES
LAURA P. CLEMENS

Reading for Rachel
Cathy Dorocak

wanted a cure for TM so that other families would not feel the same pain and suffering that our family had to endure.

Our sons, Matthew (age six) and Kevin (age four) thought of the actual fund-raising event, called "Reading for Rachel," where all funds collected would go towards research to find a cure. We all needed to channel our energies in a positive manner and the boys wanted this to be the best 1st birthday present they could ever give Rachel! … And it was.

The first thing we did was come up with a letter that the boys helped write. It talked about what happened to their sister, Transverse Myelitis and how families could help. We asked kids in the community to read as many books as they could during the month of March 2000, the month Rachel would celebrate her 1st birthday. We also requested that they ask friends and family to sponsor them for a certain amount per book they read. At the end of the month, we asked them to collect from their sponsors and send the money they collected to the Transverse Myelitis Association, referencing "Reading for Rachel." At first, we emailed our own personal friends and family but also asked them to pass the email to as many people as they could. In addition, we got support from the local school system, by having information about the "Reading for Rachel" program included in all the school newspapers. The preschool PTA, an organization we are very involved in, as well as Matthew's school, put all the materials (letter, reading list, sponsor form) either in its newsletter or in the student's book bags to take home. Matthew's school was very supportive; allowing us to talk to the students on a live TV broadcast that featured Rachel, Matthew and Kevin. They even simultaneously sponsored another program called "Reach for the Stars for Rachel" where kids could buy stars for 25 cents each and decorate them with their name or other designs. These stars were hung all over Matthew's school showing support for Rachel.

In addition to promoting the program in the local school system, we contacted the local newspaper to do a story about Rachel and take her picture so the kids in the community could see whom they were helping. We made the front page with a very large story and even larger picture! Rachel was also on the local CBS news following the airing of Cody Unser's story on 48 Hours on March 2nd. The timing was perfect since the local newscast made reference to the fund-raiser and also gave out the TMA website address where the "Reading for Rachel" materials were available. Our church was also supportive, providing information about our fund-raiser in the church bulletin.

We have received so many wonderful notes and words of encouragement from so many people around the country during this process and above all, we are so very proud of our two sons. The fund-raiser has raised over $6,000 for TM research and this is just the beginning! We will be planning for another "Reading for Rachel" campaign for March 2001 and hope to get the support of many more school systems throughout the country. Not only did we raise funds; we have also raised awareness of Transverse Myelitis in our community - something we have been thanked many times for doing. In addition, this whole project has taught a valuable lesson about helping others in need to so many young people. Together, we can make a difference!

As you read earlier in this newsletter, the Reading for Rachel Program was a tremendous success! Considering that we initiated the program with about one month of preparation and were somewhat limited in the geographic scope of our communications, we were able to raise significant dollars for The Transverse Myelitis Association. All of the money raised by the Reading for Rachel Program is designated exclusively for the purpose of funding TM research. And as you are aware from Dr. Irani's article, TM research is already being performed at the Johns Hopkins Transverse Myelopathy Center. It is imperative that we raise significant dollars in order to further this research and to attract other researchers into the specific study of the causes of, and treatments and cures for Transverse Myelitis.

The Reading for Rachel Program: Help Us Fund TM Research
Cathy Dorocak, National and International Chair of the Reading for Rachel Program

The Reading for Rachel Program represents the first significant activity of the TMA designed for the purpose of raising research funds. We have been so delighted by the positive response to Matthew and Kevin's efforts that we have decided to roll out the Reading for Rachel

Program nationally and internationally.

We need your help! We are looking for ***Ambassadors*** for the Reading for Rachel Program. Ambassadors play a critical role since they will be the local contacts for this very important fund-raising effort. There is significant competition for good cause dollars. When individuals are deciding what causes and organizations they wish to support, they have many from which to choose. People support organizations that they know and they support causes in which they have a personal understanding and an emotional tie. As an Ambassador, ***you*** are the ***person*** in the personal with which individuals will identify. Rachel's story has definitely motivated a great deal of empathy in people and her experiences have touched many in the TMA as well. But people who have no knowledge of TM will more easily relate to a person they know of or who lives in their own community. It brings TM that much closer to home.

As an Ambassador, we are asking you to promote the Reading for Rachel Program in the schools in your community. In order to effectively promote the Program, we need to organize our efforts this summer and very early in the school year. School districts and classroom teachers do much of their planning and scheduling in advance of the school calendar year. The Reading for Rachel Program will be competing for classroom time with many different activities, from science fairs to other fundraising efforts. If teachers are going to consider our Program, you are going to need to reach them early.

If you are a school administrator or work for a school district, if you are a classroom teacher, if you are active in a parent teacher organization or association, if you have children in school, if you are a retired school employee, we need you to become an Ambassador for the Reading for Rachel Program. Working with and through people in the schools with whom you have existing relationships is the most effective way to promote the Program. But please do not hesitate to appear at district offices where you do not know anyone; you may find sympathetic and supportive people even where there are no personal relationships.

Gunny is serving as the Reading for Rachel Program Administrative Coordinator. Should you wish to become a Program Ambassador, please contact Gunny as soon as possible.

Richard J. Boyle
4843 Westchester DR 207
Youngstown OH 44515
Phone number: (330)797-9465
GUNNY0011@AOL.COM

Gunny will provide you with the instructions you will need to promote and initiate the Reading for Rachel Program in the schools in your community. We are grateful for your participation in the Reading for Rachel Program. It is our great hope that this research will result in more effective treatments and a cure for Rachel and for all of you!

One of the most interesting and exciting developments of the TMA has been our growing international membership. Along with this excitement has come a concern for the costs that are associated with the international mailings. As some of you are aware, Pauline and I made an attempt to solicit support from Sarah Ferguson when we met her last year. We have not heard back from her; we will only be relying on Sarah for weight loss. My next attempt at soliciting

A Growing International Membership; And Thank You, Errol

assistance was a letter I wrote to the executive director of the World Health Organization. I did not ask for money; I requested any assistance they might offer me in finding organizations that could assist us in this area. They never answered me.

I sent an email message to Errol White seeking assistance. Errol answered.

Errol is a TMA member from Australia. If you are a member of the TMIC, you already know Errol very well. We have a relatively large membership from Australia and New Zealand. Errol very graciously offered to take the responsibility for reproducing all of the TMA newsletters and directories for our members in Australia and New Zealand and for mailing them. As printing and postage remains the most costly expenses for the Association, he has saved the TMA a substantial amount of our operating budget. We wanted to take this opportunity to thank Errol for his kindness and to recognize his contribution of time, energy and money to the TMA. Actually, Errol offered to handle the mailings for TMA members in Australia and I asked him if he would also take on New Zealand. He was kind enough to accept my request. Errol, I know Australia and New Zealand are different countries; from Ohio they look like the same neighborhood.

Thank you, Errol!

We are seeking other volunteers to assist the TMA with these important mailings of newsletters and directories. The savings for the Association would be substantial since the postage costs for our international mailings are quite high. Our largest concentrations of members for the international mailings are from Canada and the United Kingdom. We also have an increasing membership in India. If you are interested in assisting the TMA by volunteering to help with these mailings, please let me know. We would be very grateful for your help. In order to facilitate this work, you will need to have Internet access so that we can communicate via email. Please contact me at srulyosef@aol.com.

Our latest international member is from Mauritius Island in the Indian Ocean. Thank you, Jim Lubin; it is your web site that has made this international membership possible.

The TMA international membership:

Argentina
Australia
Bangladesh
Belgium
Brazil
Canada
China
Denmark
France
Germany
Greece
Holland
Hong Kong
India
Ireland
Israel
Italy
Japan
Korea
Malaysia
Mauritius Island
Mexico
Netherlands
New Zealand
Norway
Pakistan
Panama
Peru
Portugal
Romania
Russia
Saudi Arabia
Scotland
Singapore
South Africa
Spain
Sweden
Switzerland
Turkey
UK
Uruguay
USA
Venezuela

You can send us information, submit stories and articles for the newsletter, contribute your articles for the *In Their Own Words* column, send us your questions and refer new members to TMA by using our Internet addresses. You can also use the Internet to submit your surveys and to send questions for the Dr. Lynn and Dr. Uretsky Question and Answer columns for the newsletter. Please send your e-mail to:

The TMA on the Internet

srulyosef@aol.com or
ssiegel@myelitis.org

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

The following are some of the TMA web pages:

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

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

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

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

The Transverse Myelitis Association 1999 Statement of Financial Activities (in US Dollars)

Paula Lazzeri

The following tables present The Transverse Myelitis Association Annual Report for 1999. 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 1999. 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.

	TMA General Fund	**Total Donations and Expenses to Benefit TMA**
Revenues		
General Charitable Donations	15,398	15,398
iGive.com Donations	610	610
amazon.com Donations	35	35
Symposium Fees & T-shirt sales	14,285	14,285
Symposium Donations	2,900	2,900
Donations made by Board of Directors		11,556
Total Revenues	**33,228**	**44,784**
Expenses		
Checks	31	31
Computer Software & Virus Protection	-	158
Domain Address Subscription (myelitis.org) and Website	234	429
Internet Access	-	790
Mileage & Parking	-	123
Office Supplies	-	1,213
Postage and shipping	1,789	4,869
Printing/Copying	2,538	2,717
Secretary of State Fees	10	10
Telephone & Fax	-	1,471
TMA PR (Bellingham & Baltimore)	-	1,740
Symposium & Board Meeting	-	-
Advertisement in Neurology publication	114	114
Board of Directors Fees, hotel, etc.	-	2,260
Cake	64	64
Doctor/Presenter reimbursement for travel, hotel/meals	2,764	2,764
Hotel - meeting rooms, coffee, and event meals	11,167	11,167
Name tags/notepads	-	307
Printing/Copying	2,193	2,231
Refunds	125	125
Transportation	400	400
T-shirts	631	631
Video tapes	100	100
Total Expenses	**22,159**	**33,715**
Net Income	**$11,069**	**$11,069**

Transverse Myelitis Association 1999 Statement of TMA General Fund Account Balances

1998 End Balance	9,668
Add 1999 Deposits	33,228
Less 1999 Expenses	22,159
1999 End Balance	**$20,737**

We would like to express our deepest gratitude to the persons and the organizations that support the work of The Transverse Myelitis Association. It is through their generosity that we are able to offer services to our membership; they also make possible the expansion of services to our existing and future members. The following persons and organizations made donations to The Transverse Myelitis Association in 1999. The donations made by members of the Board of Directors include non-reimbursed expenses.

Transverse Myelitis Association 1999 Donor Recognition
Paula Lazzeri

$5-25
Susan Artiga
Pamela Ashcom
Virginia Barnitz
Donna Baumgartner
Frederick Beiner
Richard Chassee
Congregation Beth Tikvah Rabbi Fund
Cox Motor Co., Inc.
Sandra Deming
Edward Eaton
Terry Gregory
Phyllis Haney
Patrick James
James Martin
Diane Mayer
Phyllis McGairk
Elizabeth Morris
Mary & Benjamin Morris
Jacque Moster
Doris Phinney
O.L. Puccini
Richard Renner
Thelma Rollins
Joseph Romagnano
Barbara Rozul
Susan Shalda
Sherman & Barbara Siegel
Deborah Stephens
Phyllis Stevens
Eileen Sutherland
Barbara Synhorst Libby
Y. Trapp
Margherita Wang
Janice Yoder
Evon Young

$25-50
Charles Appley
Daniel & Barbara Cole
Scarlet Cox
Ruth Dreyer
Monica Duebner
Judith Filler
Margaret Ingman
Roland Johnson
Jackie Landry
Audre Nicholas*
D.J. Pendall
Nellie Reyna
Stan Riddle
Charlene Schapker
Maria Scott
Norman Shafran
Mildred Vaughan

$50-100
Robert Alex
Bruce & Janet Andrews
Charles Burress
Carmen Cottrell
Raymond Farr
Sian Foulkes
Jill Hammond
Wendy Henderson
Roger Livingston
Judy Mayo
Dorothy Monahan*
Marie Walker

$100-200
Lisa Andrews
Lawrence Dubow
Hargrove Construction, Inc.
Omnitronix, Inc.
J. Vincent O'Reilly
Buddy and Shauna Peltier
United Way (King County, WA)
United Way (Wyoming Valley, PA)

$200-300
Gail Buch*
Maureen Wroblewski*

$300-400
Debbie Capen
Frank & Janet Hargrove
Hart Crowser, Inc.
Paula & Myk Lazzeri

$500-700
Attachmate Corporation
Cyril Mansperger
Joseph Kopistecki
Esther Stone

$700-800
Anchor Enviromental, L.L.C.
Johnson International, Inc.*

$1,500-2,000
Medtronic*
Wal-Mart Foundation

$4,000-5,000
Dick & Deanne Gilmur

$5,000-6,200
Claddagh Foundation, Inc.
Sandy Siegel & Pauline Habib

Contributions through MA United Way (Exact amount unknown)
Carla Lecompte
Pauline Moran

***Those who made specific donations to the First International TMA Symposium**

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.

The TMA Children's and Family Network Directory

The Transverse Myelitis Association is developing a Children's and Family Network Directory that will only be provided to parents of children with TM. The purpose of the Children's and Family Network Directory is to provide a safe means for parents to support other parents and for parents to find other children for their children to communicate with and build friendships/supports with peers. Please note that the Children's and Family Network Directory is still under development and has not yet been published. Our goal is to also publish annual updates to this directory. ***This directory will only be sent to those TMA members who have registered for and are included in this directory.*** We know there is a need for this information, because it is frequently requested from both parents and children. Please take the time to send us the following directory information:

Parents' Names
Street Address
City, State/Province
Country, Zip or Postal Code
Home & Work Phone & Fax
Parents' Email Address
Child's Name
Child's Email Address
Child's Age at Onset of TM
Year of Onset of TM
Spinal Cord Level of Effect

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

The Transverse Myelitis Association Medical Advisory Board

James Bowen, MD
Assistant Professor of Neurology and Assistant Professor of Rehabilitation (adjunct), Director of Neurology Services for the Multiple Sclerosis Center, Director of the Multiple Sclerosis Research Center, University of Washington

Douglas A. Kerr, MD PhD
Assistant Professor, Departments of Neurology and Molecular Microbiology and Immunology, The Johns Hopkins Hospital; Co-Director, Johns Hopkins Hospital Transverse Myelopathy Center

Charles E. Levy, MD
System Chief, Physical Medicine and Rehabilitation Service, North Florida/South Georgia Veterans Health Service; Assistant Professor, Department of Orthopaedics and Rehabilitation, University of Florida

Joanne Lynn, MD
Assistant Professor of Neurology, Multiple Sclerosis Center, The Ohio State University

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The Transverse Myelitis Association

The Transverse Myelitis Association announces the Second International Symposium in Baltimore, July 12-15, 2001